Fatalistic attitudes by patients and providers	Create positive messages and celebrate role models who live with diabetes
Language and culture is at times a barrier	Focus on implementing culturally competent care and consistent messages about the role of traditional medicine in diabetes care
Barriers exist at the community level to support healthy lifestyles for children and adults	Address barriers in collaboration with community leaders

Next steps for the development of a comprehensive diabetes strategy

The consultation provided very concrete information for research as well as for enhancing the existing services. A research plan and a strategic plan for diabetes care and prevention should work in a complementary fashion.

In order to address the research priorities it will be necessary for community organizations and university based researcher to work closely together on the development of proposals.

1. Working committee

Develop a small working group to implement the research plan. Membership should include community representation such as health directors or manager and university-based researcher(s).

2. Explore funding opportunities and resources

Funding possibilities and resources should be explored by the working group from the following:

- research councils: particularly SSHERC and CIHR

- provincial and federal health agencies

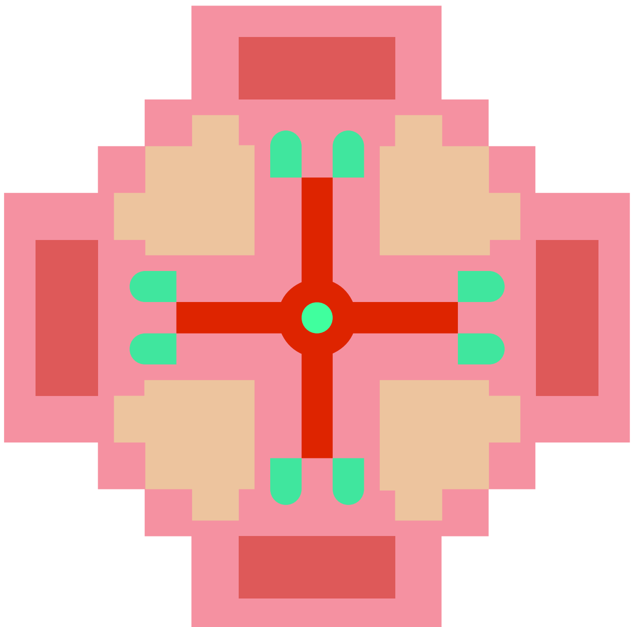
- partnerships with health and academic organizations

3. Update community organizations and leadership

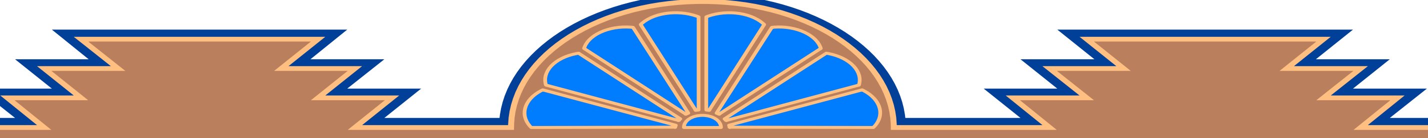
Regular updates of the results of the current consultation and resulting initiatives should be communicated to health boards/committees and community leadership on an ongoing basis.

Diabetes Care and Prevention Research Project

Results and Recommendations of the Community Consultation



May 2007



Prepared by:

Marion Maar, PhD, Northern Ontario School of Medicine
Lorrilee McGregor B.Sc., MA, Community Based Research
Mariette Sutherland B.Sc. Community Based Research

In collaboration with:

Diabetes Consultation Steering Committee
M'Chigeeng Health Services
Mnaamodzawin Health Services Inc.
Noojmowin Teg Health Access Centre
First Nation of the United Chiefs and Councils of Manitoulin Tribal Council

- Effects of the education – how much are they learning, how much does it change their behavior?
- Relationship between exercise and mental health
- Health profile and history linked to renal failure and other secondary complications
- Effect of alternative therapies
- Relationship between trauma, mental health and diabetes

7. **Diabetes Care**
   - Level of knowledge among health care providers of CDA guidelines and adherence
   - How can service integration/collaboration among health care professionals be enhanced?

8. **Traditional health and diabetes**
   - What are Traditional perspective and traditional healing perspectives related to diabetes?
   - Are there cultural aspects that prevent or contribute to diabetes? Investigate how our people used to take care of themselves using traditional diet and historical practices
   - What is the link between the types of foods eaten locally (in particular traditional foods), nutritional needs of Aboriginal people and diabetes?
   - How can diabetes be treated with traditional medicines?

Program Development Priority: Enhanced Service Integration

While the consultation was specifically geared towards collecting information on research priorities, care providers and community members who participated in focus groups consistently identified the need for improved service integration.

Participants suggested that there are many existing services that are locally accessible for patients with diabetes and many collaborative relationship between service providers are established, however this is not true for all services and significant variation seems to exist.

Diabetes Care and Prevention Service: Integration Priority Issues

A strategic plan focused to improve the coordination of services for diabetes care and prevention could be used as a tool to ensure that service integration becomes a priority for the coming years.

Issue	Suggested strategy
Level of service integration and collaboration between providers varies significantly	Develop best practices based for service integration related to diabetes care and prevention using this consultation as a starting point
Patients with chronic health issues have difficulties coping and managing their illness	Improve coordination of diabetes care between health and mental health providers
For many patients diabetes takes a backseat compared to social or economic difficulties	Improve coordination of services between health sector and social service
Only some collaborative relationship exist, care is still often fragmented	Improve coordination of care between all on reserve and off reserve care providers
Patients are receiving conflicting messages, providers do not always agree if a person even has diabetes or not	Improve the level of consistency of health messages for diabetes clients, for example by providing CDA guidelines training for all providers
Client concerns about confidentiality is a barrier to service integration	Address client concerns about confidentiality
Health information is fragmented in various systems	Address fragmentation of patients' health information in various systems

Recommendations

The intent of this consultation was to collect information from service providers as well as community members regarding research priorities related to diabetes care and prevention in the UCCM communities.

The consultation provided rich information for research priorities as well as suggestions for diabetes program development. These findings are provided in this section.

Research Priorities

Research priorities can be grouped into several research topics, in random order.

1. **Literature Review**
   - Prevention programs geared towards the youth
   - Effectiveness of programs
   - Relationship between mental health and diabetes

2. **Baseline research**
   While statistics for the prevalence of diabetes are relatively well accessible in UCCM communities, statistics for other related conditions are not. Data should be established for the following:
   - Childhood obesity on Manitoulin
   - Incidence of diabetes (i.e. new cases diagnosed each year)
   - How many diabetic patients (a) control by insulin (b) control by pills, (c) control by diet and exercise
   - Prevalence and incidence of secondary complications
   - Incidence and prevalence of gestational diabetes
   - Mental health statistics of clients with diabetes
   - Client care profiles of people living with diabetes and comparisons to CDA guidelines
   - Lifestyle especially of children, including eating and exercise habits, leisure activities

3. **Prevention**
   - Explore how information is best communicated amongst children; investigate hands on, interactive, visual and culturally appropriate mechanisms to inform and teach
   - Explore the implications of difficult home situation which may have an impact on health/wellbeing
   - Barriers and supports for healthy lifestyles in local communities

4. **Local attitudes, knowledge and behavior**
   - Is there a stigma related to chronic disease, particularly diabetes?
   - What is the local belief systems related to diabetes?
   - How can we change the "marketing" or message related to diabetes to make it more positive?
   - Can positive role models with diabetes help to curb fatalism?
   - Knowledge and behavior - determine how much people know and whether they follow CDA guidelines – "we know there are programs but are they getting through to people?"

5. **Coping with diabetes**
   - Why are many patients unable to cope with diabetes and adhere to diabetes treatment plans?
   - What factors contribute to patient self care and adherence?
   - Identify local coping strategies, including culture, spirituality and stress as factors
   - Explore underlying issues related to eating habits, including economic and mental emotional issues. Is there a common occurrence of undiagnosed mental health issues/depression/anger/denial/addictions that prevent people from doing things that have a positive impact on their health?
   - What tools are required for people to deal with their diabetes?

6. **Long-term diabetes management research**
   - Longitudinal study of client outcomes tracking the following:
     - What programs are having a positive impact

Table of Contents

Introduction 4
First Nations community involvement in this project 4
Purpose of the Diabetes Research Consultation 4
Limitations 6
Research Methodology 7
Phase 1: Framework Development 7
Phase 2: Consultations with Health Care and Service Providers 7
Phase 3: Consultations with other interest groups 7
Phase 4: Patient and Community Perspectives 7
Phase 5: Summaries and Analysis 8
Phase 6: Final Report and Suggestions for Research Directions 9
Results Part 1 - Consultations with Health Care and Service Providers 9
1. Summary of consultation with specialized care providers 9
Issues related to diabetes care and management: 9
Issues related to health service provision 9
Issues related to prevention 10
Suggestions for Research Directions 10
Research related to clients: 10
Research related to client care: 10
Research on local barriers to care: 10
1. Summary of consultation with mental health care providers 10
Issues related to diabetes care and mental health service 11
Health service provision 11
Suggestions for Research Directions 11
2. Summary of consultation with physicians 12
Issues related to prevention 13
Physicians suggested that a paradigm shift was necessary to change the way people think about diabetes: 13
4. Summary of consultation with recreation workers 14
5. Summary of consultation with education professionals 15
Education professionals included teachers and principals from Lakeview School in M'Chigeeng, Shawanosowe School in Whitefish River and St. Joseph's School in Sheshegwaning. 15
Results Part 2 - Consultations with community members 17
6. Summary of consultations with Elders 17
7. Summary of consultations with youth 18
8. Summary of consultations with patients living with diabetes and community members interested in diabetes prevention 19

Recommendations *21*
Research Priorities **21**
Program Development Priority: Enhanced Service Integration **22**
Diabetes Care and Prevention Service: Integration Priority Issues 22
Next steps for the development of a comprehensive diabetes strategy **23**

- Providing information on diabetes in youth and gestational diabetes.
- Providing mental health services specifically for diabetics.
- Early and clear diagnosis of diabetes. People should not be told they are "border-line" diabetic.

> *It is hard to accept this diabetes, it makes me feel depressed to have it. I never wanted to have this. – Community member quote*

Attitudes and Impact of diabetes

Community members discussed their concerns about diabetes and how it had affected them.

> *If I get a cut in my foot I get scared of infections. I had a toenail removed so I'm scared for my feet. – Community member quote*

- Diabetes affects the entire family.
- Having diabetes alerted several people to diabetes in their children or grandchildren.
- Coping with diabetes is difficult.
- Fears about secondary complications of diabetes such as eye problems or infections which could potentially lead to amputations.
- Concern that if medications weren't taken that it would lead to insulin use through needles.
- Concerns that family members would develop diabetes. Young adults and children were of particular concern
- Community members without diabetes were concerned that they will develop it no matter what.

> *So many people in my family have it – am I destined to get it no matter what I do? Is there a guarantee that I won't get it? – Community member quote*

Suggestions for research directions

Community members provided some interesting suggestions for research directions.

- Effective diabetes education and prevention that focuses on children.
- The development of an early screening program that reaches all adults.
- How many women with gestational diabetes will develop Type II diabetes later on?
- What is the link between the types of foods eaten and diabetes (in particular traditional foods)?
- Can early diagnosis and treatment reduce complications?
- How can diabetes be treated through traditional medicines?
- What is the mentality of someone who is at risk for developing diabetes?

> *I manage stress through smudging, praying, talking to someone like mental health workers, sit in the bush and be alone. – Community member quote*

- Lack of recreational facilities or equipment such as outdoor rinks, gymnasiums, ball fields, and playground equipment.
- Lack of programs or someone to organize activities
- Safety concerns such as traffic, dogs, broken glass, bacteria and weeds in swimming areas, and bears.
- Financial barriers (no money for registration, equipment, and transportation)
- Long distances to travel to play on a team.
- Not enough participants within some communities for some games or team sports.
- Personal issues such as allergies, obesity, laziness, and lack of motivation
- Lack of time due to part-time work and homework.

Suggestions for research directions

In addition to suggestions for finding a cure for diabetes, the youth provided some excellent suggestions for research:

- Personalizing the diabetes awareness by having someone with diabetes educate children and youth about the disease.
- Research on the specific nutrition needs of Aboriginal people particularly as they relate to traditional foods.

8. Summary of consultations with patients living with diabetes and community members interested in diabetes prevention

Community member focus groups in the six First Nations were held in conjunction with "Lunch and Learn" information sessions hosted by diabetes educators. A summary of these focus groups, which involved 33 community members, is summarized below.

Issues related to diabetes care and management

Community members are actively involved in diabetes self-care through eating healthily, exercising, reducing stress, engaging in spiritual practices, and reducing or quitting alcohol consumption. They also mentioned having family support and getting emotional support as being helpful in managing diabetes. Community members listed numerous health care providers and programs that they accessed for diabetes care including physicians, nurses, dietitians, diabetes educators, community health representatives, chiropodists, as well as eye, heart and kidney specialists. Traditional medicine people were also included as providing diabetes care.

Despite the range of health care providers and services there are some challenges facing community members:

- Some specialist services are not available within the communities or on Manitoulin Island and must be accessed in Sudbury.
- Concerns about confidentiality or competence cause some community members to utilize health care providers outside of their community.
- Accessibility to and affordability of healthy food.
- Lack of fitness facilities in 4 of the communities.
- Mental aspect to changing their lifestyle and keeping motivated to eat healthily and exercise.
- Understanding medical terminology and self-monitoring using the glucometer.

> *For some people who are on a fixed income and have no transportation it is hard to get healthy foods. – Community member quote*

Issues related to health service provision

Community members provided some clear suggestions to improving diabetes care:

- Reduce wait times to see specialists and provide local access rather than going to Sudbury.

Introduction

During the summer and fall of 2006, a regional consultation was conducted in the Manitoulin District to determine the appropriate direction for a collaborative research project in Aboriginal Diabetes Care and Prevention. This consultation, funded by the Canadian Institutes for Health Research - Indigenous Health Research Development Program is a partnership that involved First Nations health organizations and a researcher from the Northern Ontario School of Medicine (NOSM) including:

- Mnaamodzawin Health Services Inc;
- Noojmowin Teg Health Access Centre;
- M'Chigeeng Health Services;
- First Nations communities of the UCCM Tribal Council and;
- Dr. Marion Maar, Faculty of Medicine, NOSM, Laurentian Campus

First Nations community involvement in this project

The consultation was initiated by the health directors/ manager and health boards/committees of Mnaamodzawin Health Services Inc., M' Chigeeng Health Services, Noojmowin Teg Health Access Centre. It was undertaken as a partnership between First Nations communities, First Nations organizations and the university-based researcher. Health directors/manager provided advice and support throughout the project. Approval for this project was provided by local First Nation communities and health boards during the early planning stage. The consultation plan and methodology was reviewed and approved by the Manitoulin First Nations Ethics Review Committee before the start of the project. The research team included research consultants Lorrilee McGregor and Mariette Sutherland from Community Based Research in Whitefish River First Nation and Marion Maar from the Northern Ontario School of Medicine. In order to ensure community involvement throughout the project, the project received guidance from a local steering committee.

Table 1: Community involvement in the project

Role	Participants
Advising health directors/ managers	Douglas Graham, Mnaamodzawin Health Services Inc. Roger Beaudin, M' Chigeeng Health Services Pamela Williamson, Noojmowin Teg Health Access Centre
Steering committee	Cheri Corbiere, CHR Sheshegwaning Val Beaudin, Diabetes Educator, M'Chigeeng Eleanor Debassige, Diabetes Educator, Mnaamodzawin Mary Danseuse & Bernice Pleta, Brenda Beaudry, Nurse Practitioners, Noojmowin Teg Maryanne Nardi, Diabetes Nurse Specialist, Mnaamodzawin Zsolt Toth, Dietitian, Noojmowin Teg Leah Migwans, CHR, M'Chigeeng Gordon Waindubence, Elder, Sheguiandah
Aboriginal Ethics Review	Members of the Manitoulin Aboriginal Ethics Review Committee
Research Consultants	Lorrilee McGregor Mariette Sutherland

Purpose of the Diabetes Research Consultation

The prevention of diabetes and appropriate care for people living with diabetes is an important concern for the First Nations of the UCCM and many improvements have been made by local leaders and health care workers. Over the past decade, local access to culturally appropriate prevention programs and diabetes care has much improved in UCCM communities. However health care workers say they have not seen a decrease in diabetes rates at this point.

The objective of this consultation was to determine local information needs and research priorities to improve diabetes care and prevention. The short term goal was to gather information for the development of a collaborative research project that involves local First Nations and addresses issues of local importance. The long-term goal of this project is to improve the effectiveness of prevention programs as well as the level of care received by patients with diabetes. Over the coming years, this consultation also has the potential to provide the basis for the development of a large research project focused on improvements in prevention of diabetes and secondary complications and community-based and culturally specific approaches to diabetes programs.

Groups consulted over the course of this consultation included health care providers both on and off reserve, patients, community leaders, youth, elders and concerned community members. Discussions centered on current services, and patient and provider issues which influence diabetes care and prevention. Twenty-two (22) focus group sessions were completed and included the groups outlined in table 2.

Table 2: Overview of focus groups

Group	Month
Nurse Practitioners and Registered Dietitians	June 2006
Elders	August 2006
Youth	August 2006
Recreation coordinators	August 2006
Teachers, principals	September 2006
Patients and community members	September through November 2006
Diabetes Network	October 2006
Long Term Care workers	October 2006
Mental Health professionals	October 2006

Specific findings and recommendations arising from these discussions are documented in this report.

While the primary aim was to determine an appropriate direction for a larger research project, there were additional benefits related to this project, including:

- The process of consulting with health and service providers and community members on diabetes had a noticeable team building effect: Health care providers learn more about the work of other members of the local diabetes team. In addition, better ways to coordinate and access care have emerged as gaps and inconsistencies in care were identified.
- Raising awareness of diabetes within communities and groups, and
- Increasing collaboration and networking amongst all stakeholders based on current information and concerns shared by all participants.

Many fear for their grandchildren who are eating poorly (junk food, sugary foods, pop) and spending all their time with toys and games that keep them indoors and sitting down. They recall a time when communities were busy with kids playing outdoors, swimming, climbing trees, playing Indian ball, red rover and running around and adults walking about and socializing.

Other specific concerns

Elders expressed their fear that modern diets are unsafe: they perceive that everything that is grown in greenhouses has been sprayed with chemicals to make them grow fast; canned food is suspect as is food that is frozen or been cooked in a microwave. They even worry that the fish have become poisonous.

Research directions

- Elders expressed the view that emphasis should be placed on children and ways to teach them about diabetes which are visual and tangible
- Research should explore underlying issues around food and eating habits
- Research should explore the link between spirituality and diabetes and stress as a risk factor

7. Summary of consultations with youth

"Diabetes does cross my mind, because it is in the family, but I don't do anything about it." – Youth quote

Youth focus groups were conducted in the six First Nation communities and involved 49 youth, both male and female, with ages ranging from 11 years old to youth in their early twenties. Their discussions are summarized below.

Attitudes and issues related to diabetes prevention

Diabetes is not as worrisome as a health risk as AIDS, for example. – Youth quote

Youth have been the target of educational campaigns about diabetes and healthy lifestyles in school, from health care providers, and from family members; as a result most have a rudimentary understanding of the disease. Many youth believe they may be genetically predisposed to acquiring diabetes, but know that eating healthily and exercising is important in preventing its onset. Some of the challenges in providing diabetes care to youth are:

- Awareness of diabetes does not seem to change attitudes among the younger youth.
- Older youth were more conscious of it and experienced feelings of fear, horror and sadness.
- Perceptions that eating healthily "ruins the fun in eating"
- Sense of inevitability due to genetic predisposition.

"If it is genetic, I am pretty much screwed". – Youth quote

Youth are involved in a wide range of physical activities that can take place either within their community or in neighboring towns. However they identified significant barriers to participating in physical or recreational activities. These barriers include:

Results Part 2 - Consultations with community members

6. Summary of consultations with Elders

The Elders who participated are part of the OCF Elders Council and included individuals from Sheshegwaning, Aundeck Omni Kaning, Whitefish River and M'Chigeeng.

Families and communities in the past enjoyed healthy active lifestyles

Elders spoke about how daily living kept people healthier. In particular:

Daily chores such as working in the garden, tending to animals, haying, hauling water, chopping wood, washing clothes, housework, gathering food, berries, sweet grass and other medicines incorporated physical activity into everyone's day. In addition there were few vehicles so it was normal for people to walk several miles in the course of their week.

Processed food was not part of their diets. Most ate locally grown or available foods including lean game such as deer, rabbit and moose, fresh, salted and smoked fish, fresh vegetables and those canned at home. Preparation methods included boiling and baking more so than frying. Portion sizes were much smaller and sweets such as candy and pop were very rare treats. Sugar, salt, coffee and alcohol were used in moderation.

Daily schedules were arranged around daylight hours so that families typically retired as the sun went down and rose at sunrise. Breakfast was an important part of their day as were sit down meals together. Lunch would have been the main meal with dinner a smaller meal such as soup.

Recreation included music, dancing, swimming, outdoor games, visiting and socializing. Elders don't recall a lot of stress within families and communities as there was very little time to dwell on problems when daily living was very busy.

Herbal medicines and other traditional medicine and approaches were the norm within communities before residential schools and other influences discouraged their use.

Spirituality was emphasized as individuals and families lived by their traditional teachings including daily prayer & meditation in the woods, giving thanks, respect for nature and all living creatures, and an understanding of your place in the clan system, stages of life and creation. There were even strong teachings about caring for your body and health which seem to be missing today.

Diabetes has affected their families and communities

Some elders spoke of how diabetes has affected them personally either as individuals being diagnosed with diabetes or having family members affected by diabetes.

Many cannot recall their elders, parents or uncles and aunts having had diabetes. Rather, they speak of their elders who were quite strong and enjoyed good health well into their later years.

Individuals who had been diagnosed with diabetes spoke of the necessary changes they have made and the difficulty in acknowledging it at first.

Amongst their adult children, they see that they are being beset by diabetes at younger ages and cannot seem to manage or control this disease.

Figure 1 and 2: Community based research consultants Lorrilee McGregor and Mariette Sutherland conducted many of the discussion groups

Limitations

Participation by communities, groups and individuals was generally excellent given the inherent difficulties in scheduling and coordinating discussion groups. However, not all groups were equally strongly represented due to time and scheduling limitations. In particular, youth participation in M'Chigeeng was lower than we had planned given the size of the community; in addition, physicians' participation was mainly at a single clinic. The views and perspectives of the First Nation community leadership (e.g.: Chiefs and Councils) were only informally collected during this round of consultations, however we anticipate to gain their feedback during the presentation of our findings.

Participants provided rich information during the course of this consultation. The information was documented in three ways: via digital audio recording, flipchart notes, and typed notes on a laptop. Unfortunately, we were not able to include all of the detailed information in this report due to the large volume of information that participants were willing to share. However the information was analyzed and summarized by the project team into major themes that participants focused on and discussed in detail.

Research Methodology

In order to accomplish the goals of the project, the research team undertook this consultation in six steps:

- Phase 1: Framework Development
- Phase 2: Consultation sessions with health care and service providers
- Phase 3: Consultations with other interest groups
- Phase 4: Patient and Community Perspectives
- Phase 5: Summaries and Analysis
- Phase 6: Final Report and Suggestions for Research Directions

Phase 1: Framework Development

This phase focused on conducting a review of the health literature related to diabetes care and prevention as well as local documentation and previous research related to diabetes. A Steering Committee comprised of health care professionals from the First Nation health organizations and an Elder was also formed during this phase. The Steering Committee provided advice on which groups of health professionals needed to be consulted and how to recruit community members for discussion groups. The steering committee also provided guidance to the research team to determine which questions needed to be discussed with participants in the various groups.

Phase 2: Consultations with Health Care and Service Providers

A total of 9 focus groups were conducted with specialized health care providers, mental health care providers, and physicians who serve the First Nation communities on Manitoulin Island. The total number of participating health care and service providers were 55. See table 3 for details.

Phase 3: Consultations with other interest groups

Thirteen focus groups were conducted with Elders, youth, educators, and recreation workers. The Elders met at the Ojibway Cultural Foundation in M'Chigeeng First Nation in conjunction with its Elders Advisory Committee meeting. Six focus groups were held with youth in the First Nation communities. A total of 49 youth, both male and female, participated in these focus groups with participant ages ranging from 11 years old to youth in their early 20's. Educators from Lakeview, Shawanosowe and St. Joseph's were consulted. Recreation workers were also consulted. A total of 95 people participated in these focus groups. See table 3 for details.

Phase 4: Patient and Community Perspectives

Community member focus groups were held in conjunction with "Lunch and Learn" information sessions hosted by the diabetes educators. Thus, people in attendance were community members who had an interest in learning more about diabetes. A total of 33 community members from 6 different communities participated in these focus groups. See table 3 for details.

Healthy eating and physical activity is encouraged in the school setting

To the extent they can, educators are trying to encourage and reinforce healthy behaviors within the school setting:

- Some schools have enacted policies to restrict pop and junk food.
- Breakfast and snack programs have been established.
- One school is implementing a "balanced day" program which is structured to allow for two nutrition breaks instead of one lunch.
- Parents and children are encouraged to pack healthy lunches and snacks.
- Nutrition workshops for parents have been offered by the dietitian to demonstrate how to prepare quick, easy, and healthy lunches and snacks.
- Teachers are modeling healthy behaviors by making healthy food choices, participating in walking clubs etc.
- Sports and other intramural activities are encouraged.
- As part of the curriculum, music and dance is incorporated in the class room.

Students face many barriers to a healthy lifestyle

Nonetheless, there are numerous challenges and barriers for students in maintaining a healthy lifestyle including:

- Economic circumstances: poverty impacts on lifestyle choices. There is a perception that healthy food is expensive and not easily accessible.
- There is a lack of education about healthy foods and lifestyles. Within the limited time, educators must teach a rigorous curriculum which leaves little time for information and education about health and healthy lifestyles.
- Educators perceive that for many students there is limited role modeling of healthy behaviors at home. Many also lack quality family time, including sitting down as a family for meals etc.
- Organized sport emphasizes competition, is costly and involves frequent travel. Parents spend a lot of time and effort getting kids to hockey, for example, versus the actual time the child spends in the activity or exercise.
- Distance between communities, lack of people willing to volunteer and organize activities, lack of funding for a physical education teacher limits the range of physical activities that students can become involved in.

How information about diabetes is shared in schools

Educators explained that information about diabetes is not emphasized but rather information is conveyed about health and healthy lifestyles in general. For example, healthy eating is in the curriculum all the way through but none of the provincial curriculum is geared specifically concerning diabetes. Nonetheless, efforts are made in the following areas to teach students about diabetes:

- Some schools have used the lesson plans from the Kanawake Diabetes Program.
- Health centre staff has come into the schools to talk about diabetes.
- Some schools participate in the diabetes walk and other awareness week activities.

Research directions

- Investigate the feasibility of mandating diabetes prevention as part of the provincial curriculum
- Prevention/awareness amongst primary levels - explore how information is best communicated amongst children; investigate hands on, interactive, visual and culturally appropriate mechanisms to inform and teach
- Explore the implications of difficult home situation which may have an impact on health/wellbeing
- Investigate how our people used to take care of themselves using traditional diet and historical practices

It is recognized nonetheless, that there are barriers which can hinder participation in physical activity:

- **Safety** - walking is unsafe due to animals and/or highway traffic
- **Accessibility** - daily activities are not within walking distance; west end communities, have a 2 hour drive to get to activities/facilities
- **Transportation** - community recreation vans experience a lot of wear and tear; there are no late buses for kids in some communities
- **Money** - equipment, registration, transportation, tournaments are all very costly; communities have limited resources to purchase equipment and build and maintain facilities
- **Time**- community members have work, families, elderly parents and many other commitments which take priority
- **Information** - difficult to ensure all community members are aware and informed of activities and recreation programs
- **Structure** – not all community members respond to structured competitive activities
- **Attitude or lack of motivation**
- **Disability or injuries**

Research directions

- Incidence/prevalence - determine baseline data which can be used for a measurement of success e.g. decrease in number of new cases of diabetes
- Effectiveness of strategies - Investigate how many diabetic patients (a) control by insulin (b) control by pills, (c) control by diet and exercise
- Which strategies are the most effective to prevent or control diabetes (e.g. organized diabetes support network)
- Longitudinal study - of a group over a 10 year period – who recovers; what programs are having a positive impact; evaluate at a certain point in time and then again later
- Knowledge and behavior - determine how much people know and whether they follow CDA guidelines – "we know there are programs but are they getting through to people?"
- Alternative therapies – explore links between diabetes care and alternative health practices such as massage therapy

> *"One of the biggest barrier is the sense of* 'territorialism' *which results in a lack of continuum of care, for example the recreation worker cannot overstep his or her bounds and must refer to the health centre staff for care. We need a forum where everyone can see common ground and work together to share expertise" (rec worker quote)*

5. Summary of consultation with education professionals

Education professionals included teachers and principals from Lakeview School in M'Chigeeng, Shawanosowe School in Whitefish River and St. Joseph's School in Sheshegwaning.

Health and lifestyle trends observed

Education professionals explained that students in their schools experience many challenges in maintaining a healthy lifestyle within their family, school and community settings including:

- Poor nutrition choices coupled with too much "screen time" like television, internet and computer games and little daily exercise and physical activity are contributing to an increase in children who are overweight and or obese.
- A lack of role models amongst families and peers results in a general acceptance of inactive lifestyles and obesity. "this is the way I've been, and this is the way I'll always be"
- Students are exposed to increased use of alcohol and other substances.
- Teachers report poor respiratory health amongst students as evidenced by an increased use of puffers
- Teachers perceive that students are sexually active at a younger age and are sexually aware and informed as young as in kindergarten

Table 3: Focus group details

Group	Representation From	# of participants
Health Care Providers	NPs, RDs, LTC Mental Health Nurse	4
	Diabetes Network (CHRs and CHNs, Diabetes Educators)	5
	Physicians group	4
	Long-term Care (PSW, nurses, coordinators)	8
	Mental Health	7
Elders	Aundeck Omni Kaning, M'Chigeeng, Whitefish River, Sheshegwaning, Sagamok	10
Youth	Sheguiandah	9
	Sheshegwaning	9
	Aundeck Omni Kaning	7
	Whitefish River	13
	Zhiibaahaasing	6
	M'Chigeeng	7
Recreation Leaders	Aundeck Omni Kaning, M'Chigeeng, and UCCM	4
Educators	Lakeview School (M'Chigeeng)	15
	Shawanosowe School (Whitefish River)	5
	St. Joseph's School (Sheshegwaning)	3
Community Members	Aundeck Omni Kaning	6
	Sheshegwaning	2
	Zhiibaahaasing	6
	Sheguiandah	6
	M'Chigeeng	8
	Whitefish River	6
	Total number of groups: 22	**Total number of Participants: 150**

Phase 5: Summaries and Analysis

Responses to the focus group questions were summarized by sector and are provided in the results sections of this report. An overall analysis of the key issues on diabetes care and management, health service provision diabetes prevention and suggestions for research are included.

Phase 6: Final Report and Suggestions for Research Directions

The writing of this report and presentation of findings was the last step in this consultation. In this report, we provide a summary of observations and recommendations provided by participants during the consultation and we make suggestions for (a) research directions for diabetes care and prevention; (b) service priorities, as well as; (c) suggested next steps to move this project forward.

Results Part 1 - Consultations with Health Care and Service Providers

1. Summary of consultation with specialized care providers

Specialized care providers in this section include nurse practitioners (NPs), dietitians, the long-term care team and the Aboriginal Diabetes Initiative team members. These providers participated in three different sessions which are summarized here.

Issues related to diabetes care and management:

Providers explained that ensuring that patients receive care according to Canadian Diabetes Association guidelines is a priority. There are many positive aspects about local education and prevention programs as well as the specialized care that clients receive locally, such as nutrition counseling. However, significant challenges prevail that have an impact on the care and management of diabetes. They include:

- Different charting and health information systems exist, there is no single place where comprehensive patient information is found
- Client concerns about sharing of information and confidentiality
- Level of integration and collaboration between health care providers varies greatly
- Clients require ongoing education and support once they are diagnosed
- Many clients have issues in their lives that are very consuming and diabetes takes a backseat
- Many clients do not have the necessary tools or skills to manage their diabetes
- Some clients have a fatalistic attitude towards diabetes
- Fear is an issue – many clients are afraid of getting diagnosed; denial is the way some cope

Issues related to health service provision

Providers believed that re-orientation of some service including improvements in service integration[1] might improve diabetes care and patient outcomes. For example in some communities, NPs focus on treating walk-in patients. This eliminates the focus on prevention and diabetes management and does not make use of all dimensions of NP practice. Provider suggestions included:

- There are long wait times for clients to access physicians. It would be beneficial for clients if NPs scope of practice could be extended in the treatment of diabetes.
- Prescriptions for glucometers and supplies are time consuming and may be improved to take less of NP time
- Access to mental health for all chronic illness clients
- Quality of consulting with physicians varies among health care providers and communities, some need improvement

[1] Service integration refers to the coordination of care between various service providers

4. Summary of consultation with recreation workers

This group included the recreation advisor/planner, a community recreation program coordinator and a private personal trainer/massage therapist who has worked in First Nation programming.

There was numerous recreation activities are taking place within communities. Some were described as being organized or structured. These activities take place in the context of a community's recreation programming such as walking groups or dance classes or as part of organized sport such as hockey or baseball. There are also unstructured activities that occur informally within the communities as part of an individual or family initiative such as running, sliding or hunting. There are many ways for an individual to become active within their community.

Recreation workers may interact with some clients who have diabetes and may provide general information on exercise programs; however they generally leave specific care issues and questions to the health care professionals. Their client groups include:

- Children and youth – ages 7 or 8 on up to teens
- Adults – young parents, baby boomers (45 and up)
- Those focused on weight loss – older teens to mid 50's and 60's, predominantly female

Key factors which tend to encourage physical activity:

- fun
- involves friends
- competition
- team oriented
- organized and structured
- parental involvement and recognition
- rewards – prizes, trophies, recognition

> *"Younger kids will get involved in whatever you organize for them – it almost doesn't matter what the activity is because it is really about socialization" (recreation worker quote)*

Existing support systems and structures

Within the First Nation communities a number of supports are in place to encourage healthy active lifestyles including:

- **Facilities**: gym, youth centres, community centres, arenas, playgrounds, outdoor rink, equipment, ball fields, skateboard parks, beaches, hiking and walking trails
- **Health and recreation workers** – health workers who promote healthy lifestyles/healthy living, community recreation workers
- **Some financial supports** – transportation to tournaments, subsidized registrations, community fundraising and support, equipment
- **Community Policy** – school policies aimed at healthy lifestyle choices, no smoking policies in band facilities, walk/bike to work days
- **Role models and peers** - peer groups help encourage one another along with the community; lots of people cycling or walking, people engage in gardening/lawn care or simply daily housework/chores

Barriers to physical activities

> *"A visiting health professional said to me he can tell he is on reserve by the number of wheel chair ramps he sees when driving through the community." (Physician quote)*

> *"One of the attitudes we encounter is*: 'I don't want to go on insulin – My aunt went on insulin and two years later she died' *" (physician quote)*

Health service provision

Physicians believed that further service integration[4] is necessary to improve diabetes care. It might be difficult to ensure care according to Canadian Diabetes Association (CDA) guidelines[5] without improvements of service integration:

- More integration necessary with on-reserve service providers, particularly nurse practitioners to share care of diabetic patients
- One barrier to integration is that some patients do not consent to information sharing between their doctor and their community service providers.
- Confidentiality needs to be addressed on an individual basis

> *"Patients often chose traditional [Aboriginal] medicine when it is too late" (physician's quote)*

Issues related to prevention

Physicians suggested that a paradigm shift was necessary to change the way people think about diabetes:

- Role models for good health and physical fitness need to be promoted
- Role models who are successful at managing their diabetes and have good health outcomes need to be promoted
- Local attitudes toward food and food choices may be a barrier
- Lots of education going on, but there are still many misconceptions about diabetes (e.g.: unspoken belief systems that diabetes is transient or a death sentence)
- Traditional medicine is often chosen as a last resort when the patient is experiencing severe complications

Suggestions for Research Directions

Important research questions which came out of our discussion with physicians are listed below:

- Why are many patients unable to adhere to diabetes treatment plans?
- Why are some patients unable to cope with diabetes?
- What is the local belief systems related to diabetes?
- How can we change the "marketing" or message related to diabetes to make it more positive?
- Can positive role models with diabetes help to curb fatalism?

[4] Service integration refers to the coordination of care between various service providers

[5] Canadian Diabetes Association published clinical practice guidelines in 2003, which are the standards of care for the management of diabetes. The CDA guidelines were developed to help health care professionals and patients make decisions about screening, prevention, or treatment related to diabetes.

Issues related to prevention

Providers discussed the following community issues and circumstances of clients that make prevention difficult.

- Community environment not conducive to exercise – no sidewalks, no facilities, dogs running loose, weather
- Activities focus primarily on good athletes <u>not healthy exercise for all</u>
- Need for healthy role models like teachers, health care workers, community members
- Lack of access to healthy foods and/or lack of healthy cooking skills
- Financial barriers, many clients are on a fixed income

Suggestions for Research Directions

Providers explained that research in Aboriginal communities is often difficult, however in the Manitoulin First Nations; there are many positive things to build on, including the Aboriginal ethics committee and a good number of people who have experience in health research and a partnership with the Northern Ontario School of Medicine. Providers identified many research needs that were directly relevant to improve the care they provide to their patients.

Research related to clients:

- Why are so many patients not adhering to medical advice? What factors contribute to patient self care and adherence?
- Is there a common occurrence of undiagnosed mental health issues/depression/anger/denial/addictions that prevent people from doing things that have a positive impact on their health?
- Cultural aspects that prevent or contribute to diabetes
- What tools are required for people to deal with their diabetes
- What are Traditional perspective and traditional healing perspectives related to diabetes?
- Childhood obesity on Manitoulin
- Research prevalence of onset of various secondary complications
- Research health profile and history of patients with renal failure

Research related to client care:

- Develop a full picture of client care and services they receive. Determine percentage of diabetic patients who receive care according to CDA guidelines. Follow care of clients over a long period of time and compare outcomes
- Review literature on effectiveness. Measure on outcomes and effectiveness on Manitoulin

Research on local barriers to care:

- Level of knowledge among health care providers of CDA guidelines
- How can we improve service integration/collaboration among health care professionals?
- Is there a stigma related to chronic disease, particularly diabetes?

1. Summary of consultation with mental health care providers

Mental health care providers in this section include the Mnaamodzawin, Noojmowin Teg and M'Chigeeng members of the Island mental health networking group.

> *"People don't come to us for mental health problems related to diabetes – they are coming to us for trauma, family issues – but because they have diabetes they are carrying a heavier load and it complicates how they can respond to and manage their diabetes" - mental health care worker quote*

Issues related to diabetes care and mental health service

Mental health providers explained that clients are not normally seen for mental health issues related to diabetes; however those that do have diabetes are encouraged to seek care. As a team mental health providers participate in diabetes workshops as well as traditional service providers. The team members had additional insights to share:

- There is a language barrier for care for some of the elders which prevents them to deal with physical, emotional and other aspects of the disease, as well as to ask the questions of the doctor
- The traditional health services are an important strength related to diabetes care
- Mental health issues related to diabetes can be serious. Many clients believe it is a death sentence
- Many clients have severe financial limitations which impact on their choices
- Addictions can be a barrier to diabetes care

> *The approach has been to address the physical side of diabetes – the focus has always been to manage your diet and your activity – the emotional side never gets identified or prioritized – that in itself is a barrier. The first response in a client is usually the trauma – but in general, the overall approach is just to manage as if the physical is the only side of it. (Mental health service provider quote)*

Health service provision

Mental health providers suggested that further improvements in service integration would benefit clients and provide a more holistic approach to diabetes care. Greater integration between providers and programs is seen as essential in order to provide better care for patients with diabetes, however resources are limited. Some more specific issues are listed below:

- A closer working relationship between diabetes program and mental health programs is desirable to reflect how closely chronic illnesses and mental health impact on one another
- A behavioral health service provider is needed – someone who has background in managing chronic illness – this service is missing on the island.

Suggestions for Research Directions

> *"Some people are able to manage diabetes as if they had an ingrown toenail and for other people it is just devastating – some give up; some people fall apart – maybe they don't have good coping skills anyhow. Where it wouldn't matter what happened whereas others have high functioning in coping and can manage around it?" (Mental health provider quote)*

Research related to clients:

- Research lifestyle especially of children, including eating and exercise habits, hours per day in front of computers, TV, etc.
- Using a health psychology approach to research why some people have such a difficult time managing their illnesses.
- What is linked to good coping skills? Is there a link to spirituality? Why is denial often a component? Research project on qualitative basis – speak to people who are good "copers" and those who are struggling. What is their support system and the history of that support system? How did they learn to cope?
- Long-term or longitudinal study of client outcomes
- Effects of the education – how much are they learning, how much does it change their behavior?

- Relationship between exercise and mental health – there is strong evidence – the interaction between exercise, mental health and diabetes – if they can exercise they can reduce their stress and impact on their diabetes
- Study patients who are exercising and research if they are doing better mentally and physically in terms of their diabetes
- Interview people firsthand as to how they are managing depression and what their support systems are
- For patients who have difficulties with their diet find out what thoughts or events precede their eating

Research related to client care:

- How is mental health and emotions related to diabetes?
- Is trauma in adults and children linked to diabetes?
- Literature review on the relationship between mental health and diabetes, using psychology, medical, nursing, social work databases
- Gestational diabetes
- Research positive approaches that might be used in diabetes care

Research related to barriers:

- Barriers and supports to exercise in local communities

> *"Having diabetes – it is un-curable – you have it for the rest of your life – that depresses you – managing all of that is the challenge" (mental health provider quote)*

2. Summary of consultation with physicians

Issues related to diabetes care and management

Physicians were in agreement that on average they see poorer outcomes for Aboriginal patients with diabetes then they would see in their non-Aboriginal patients. While they acknowledged that some of their Aboriginal patients are doing very well managing their illness, there is a very high percentage of Aboriginal patients who are struggling very much. Below is a list of issues related to diabetes care and management that physicians encounter frequently with their Aboriginal patients.

- Social and family issues often take priority over focus on diabetes care
- High rates of non-adherence to treatment plan
- High rates of non-adherence to recommended lifestyle changes
- High rates of poor glycemic control[2]
- The secondary complications[3] tend to be extreme and of early onset
- Some patients have internalized a self-destructive attitude towards their care and are unable to make chronic illness management a priority
- Some patients are fatalistic about diabetes

[2] Glycemic control is a medical term referring to the typical levels of blood sugar (glucose) in a person with diabetes mellitus. Much evidence suggests that many of the long-term complications of diabetes, especially the microvascular complications, result from many years of hyperglycemia (elevated levels of glucose in the blood). Good glycemic control, in the sense of a "target" for treatment, has become an important goal of diabetes care. Poor glycemic control refers to persistently elevated blood glucose and glycosylated hemoglobin levels. (Source: wikipedia)

[3] Secondary complications are a result of the long-term damage that can arise from these high glucose levels - complications include blindness, heart disease, kidney problems, nerve damage and amputations.