

**Exploring perceptions of and experiences with diabetes care in
the Sioux Lookout Area by patients, community stakeholders
and service providers**

Diabetes Environmental Scan for the Sioux Lookout Area



Sioux Lookout
First Nations
Health Authority



DIGNITAS

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EXECUTIVE SUMMARY

The diabetes environmental scan was developed as a response to Chief's Resolution #13-07, Community-Based Diabetes Strategy and Programming. The resolution, passed by the Chiefs in Assembly at Sioux Lookout First Nations Health Authority Annual General Meeting in 2013, recognized the endemic nature of diabetes in First Nations in the Sioux Lookout Area. Thus, the resolution directed the Sioux Lookout First Nations Health Authority to conduct a comprehensive review of current diabetes research and knowledge and its relevance to First Nations, and of existing programs and resources that provide diabetes education, treatment, support and preventative health services.

The purpose of the diabetes environmental scan was to explore perceptions and experiences of patients, community stakeholders and service providers, highlighting facilitators and barriers to optimizing diabetes care. The methodology of the environmental scan included a document and literature review, key informant interviews, direct observation, and patient surveys.

Results of the diabetes environmental scan showed that, in general, health services were perceived as good once they had been accessed by patients. However, diabetes care was perceived as fragmented; all participants - patients, community stakeholders and even service providers themselves - expressed much confusion regarding which services were available where and when, and how to access specific services. There was a strong desire from all participants for increased support at the community level, such as increasing the scope and frequency of home visits, and facilitating self-management of diabetes with behaviour change, diet and lifestyle counselling. Participants from all levels reported inconsistent support for people living with Type 2 diabetes in the community: patients often did not have a personal copy of their diabetes treatment plan from their physician to help with adherence, many communities lacked support groups or forums for people with diabetes to share their experiences, and health providers irregularly follow-up with their diabetic patients regarding health habits and lifestyle issues.

There was a strong emphasis from all participants to orient more health services to the preventative aspects of diabetes care, and to strengthen community education, participation and engagement. Support for mental health issues was identified as a major need toward addressing diabetes care and meeting diabetes management objectives and targets. Patients, community leaders and service providers all emphasized their desire for expansion of mental health support for patients in the communities, closer to where people reside. Universally, CHWs were regarded as the most appropriate service providers to bridge the gap between the health clinic and the community.

In addition to reporting to Chiefs in Assembly, results from this diabetes environmental scan will inform the development, implementation and evaluation of a CHW Pilot Program, currently being undertaken in the Sioux Lookout Area through the partnership of Sioux Lookout First Nations Health Authority and Dignitas International.

LIST OF ABBREVIATIONS USED

AHP	Anishinabe Health Plan
ADI	Aboriginal Diabetes Initiative
ADP	Assistive Devices Program
CCDC	Centre for Complex Diabetes Care
CHR	Community Health Representatives
CHW	Community Health Worker
CIRCLE Study	Canadian First Nations Diabetes Clinical Management Evaluation Study
EMR	Electronic Medical Records
FNIHB	First Nations and Inuit Health Branch
LHIN	Local Health Integration Network
NAN	Nishnawbe Aski Nation
NIHB	Non-Insured Health Benefits Program
NWLHIN	North West Local Health Integrated Network
ODB	Ontario Drug Benefits Program
ODSP	Ontario Disability Support Program
OHIP	Ontario Health Insurance Program
OSCAR	Open Source Clinical Application and Resource
RN	Registered Nurse
RPN	Registered Practical Nurse
SLA	Sioux Lookout Area
SLDP	Sioux Lookout Diabetes Program
SLFNHA	Sioux Lookout First Nations Health Authority
SLRPSI	Sioux Lookout Regional Physician Services Incorporated
UTI	Urinary Tract Infection

1.0 INTRODUCTION

1.1 BACKGROUND AND RATIONALE

Access to high-quality health care by remote Canadian First Nation populations remains impeded by a number of important challenges, including: geographic isolation, limited human and financial resources, high medical staff turnover, and lack of culturally safe care. It is well known that Indigenous people, globally, experience significant health-related disparities, such as higher rates of chronic and infectious disease, and lower life expectancy. In Canada, rates of Type 2 diabetes are 2.5 to 4 times higher among First Nations compared to among the general population.¹ It has also been documented that First Nations in Canada experience elevated prevalence of diabetes-associated risk factors, diabetes-related complications, and mortality.^{2,3} The estimated average prevalence of diabetes among First Nations is 17%.^{4,5} In the Sioux Lookout Area (SLA) of Northwestern Ontario, the estimated prevalence of Type 2 diabetes is 30%, with some communities reaching prevalence rates as high as 45%.⁶ First Nations women generally have higher rates of Type 2 diabetes than First Nations men, and women are diagnosed, on average, at a younger age.¹

The SLA encompasses 385,000 km² and has a population of approximately 30,000.⁷ The SLA is composed of 33 Ojibwe, Cree and Oji-Cree communities. The communities range in size from approximately 100 to over 3,000 people. Eighty-five percent of the population is geographically isolated, with more than 100 kilometers between communities and the nearest hospital, the Sioux Lookout Meno Ya Win Health Centre. Remote communities are only accessible by plane year-round, and sometimes by ice roads in winter, weather permitting.⁷

There have been diabetes studies specific to communities within the SLA, in particular, those conducted in Sandy Lake between 1995 and 2005 as part of the Sandy Lake Health and Diabetes Project. The project published several studies relating to the prevalence of diabetes and the hormonal, metabolic, nutritional and lifestyle characteristics associated with diabetes, and ultimately implemented several community-based interventions.⁸⁻¹⁰ Findings from these studies have contributed to the knowledge base of the clinical and social determinants of health and diabetes among First Nations people, especially among those residing in Northwestern Ontario.¹¹⁻¹⁷ For instance, one cross-sectional survey within the Sandy Lake Health and Diabetes Project cohort examined serum levels of vitamin D concentration. Using a multivariate analysis, the study identified a significant positive correlation between consumption of traditional foods and serum vitamin D levels, and a significant inverse correlation between Western diet-market foods pattern and serum vitamin D levels.¹⁷ (Suboptimal vitamin D status negatively impacts bone health and may be a risk factor for chronic diseases such as cancer and diabetes.)¹⁸

In 2011, the CIRCLE study (Canadian First Nations Diabetes Clinical Management Evaluation Study) reported major gaps in diabetes clinical care among Canada's First Nations populations based on chart reviews from a randomly selected sample of 19 First Nations communities across Canada.¹⁹ The study reported that most patients in the sample did not achieve glycemic, lipid or blood pressure targets. In addition, a national survey from 2008 of health care providers

working in First Nations communities across Canada explored their perceived challenges to the provision of optimal diabetes care.²⁰ Both this national survey and a similar study conducted in the SLA in 2010 examined providers' perceptions of barriers to the management of Type 2 diabetes in remote First Nations communities.²¹ Both studies found that among patient, provider, and systemic factors, providers perceived patient factors as having the greatest impact on diabetes care. With regard to perceived patient-related barriers, providers "were divided between those advocating for greater patient-provider partnership and those arguing for greater patient responsibility".²¹ While providers' "general sense of frustration" could potentially be perceived as "patient blaming", the results of the study supported development of programs to bolster patient self-management through the work of community health workers (CHWs).²⁰ To our knowledge, there are no previous studies addressing the perspectives of patients or community stakeholders in relation to their experiences with diabetes service provision in the SLA.

Sioux Lookout First Nations Health Authority (SLFNHA) is recognized as the self-governed regional health authority in the Sioux Lookout region and provides health services and advocacy to its communities.²² SLFNA is guided by the Anishinabe Health Plan (AHP), which identifies a model of holistic, integrated primary health care service delivery for the region. There is a SLA Chiefs Resolution committing all communities and their respective tribal organizations to work together on implementing the AHP for the SLA. The AHP identifies diabetes as a key priority area for action by the communities, tribal organizations and SLFNHA.²³

In 2014, SLFNHA and Dignitas International, a non-governmental health and research organization, partnered to launch a CHW project in the SLA's remote First Nations for improved care and management of Type 2 diabetes²⁴. Dignitas International has worked in Malawi, in Southern Africa, since 2004, to improve health care for people facing a high burden of disease and unequal access to services, primarily through supporting the scale up of HIV/AIDS services. By partnering with SLFNHA, the team at Dignitas International wanted to explore the opportunity to take lessons learned in scaling up high-quality health services in remote and rural areas of sub-Saharan Africa to remote and rural areas of Canada.²⁵

The diabetes environmental scan was developed as a response to Chief's Resolution #13-07, Community-Based Diabetes Strategy and Programming. The resolution, passed by the Chiefs in Assembly at SLFNHA Annual General Meeting in 2013, recognized the endemic nature of diabetes in First Nations in the SLA. Consequently, the resolution directed SLFNHA to conduct a comprehensive review of current diabetes research and knowledge and its relevance to First Nations, and of existing programs and resources that provide diabetes education, treatment, support and preventative health services.²⁶

SLFNHA is committed to improving diabetes prevention, management and care for the 33 communities within its jurisdiction. Dignitas International and SLFNHA are collaborating to improve community-based health provision for diabetes. This study will provide key information to inform development of future initiatives that aim to facilitate a coordinated and integrated approach to addressing diabetes as a high priority health issue in SLA.

1.2 AIM OF ENVIRONMENTAL SCAN

The aim of the diabetes environmental scan was to gain an in-depth understanding of diabetes service provision in the SLA from the perspective of patients, community stakeholders and service providers, and to identify facilitators and barriers to optimizing diabetes care in the region. Our study team employed a number of different approaches: we examined existing policies and program documentation, interviewed individuals, conducted patient surveys, observed health clinics in action, and participated in community meetings. By using a multi-faceted approach to our environmental scan, and by embedding a research study within it, we feel that we were able to gain a better understanding of the factors that might improve diabetes care in First Nations in Northwestern Ontario. This environmental scan was not intended to provide a comprehensive assessment or evaluation of individual initiatives or organizations; rather it was intended to give a broader perspective on the state of diabetes care in the SLA.

Primary Objectives

1. To gain an in-depth understanding of diabetes service provision in the SLA through the perspective of patients, community stakeholders and service providers.
2. Identify facilitators and barriers to optimizing diabetes care at patient, community stakeholder and service provider levels.

Secondary Objectives

3. To contribute to developing an evidence-based foundation for developing future initiatives addressing diabetes services in the Sioux Lookout Area, including quality improvement initiatives and new pilot programs.
4. To provide a baseline assessment for evaluating future initiatives.
5. To contribute to strengthening collaboration, coordination and information sharing amongst the different parties who have a stake in diabetes programs and services in the SLA.

1.3 COMPLEX JURISDICTION FOR DIABETES SERVICES IN SLA

Diabetes service provision exists within this paradigm. Availability of services can vary depending on many factors, including a person's status under the Indian Act, whether one lives on- or off-reserve, funding mechanism of the health service required, an individual's health status and medical needs, and their socioeconomic status.²⁷

Health service management and delivery has a complex framework for First Nations in Canada, with several levels of jurisdiction involved in funding, governance and provision of services. In the SLA First Nations, the federal government has fiduciary responsibility for health care, through direct provision of services via Health Canada's First Nations and Inuit Health Branch (FNIHB) or through funding transfer agreements with the community's Band, or some combination of the two (i.e. some health programs are funded and available to all communities,

regardless of transfer agreement status, such as Home and Community Care). Transfer agreements, which involve transfer of funds from the federal government to a First Nation, are individually and uniquely negotiated between the federal government and a Band or Tribal Council in a given community, so that the community can make its own primary health care service decisions.^{28,29} Despite best intentions, an individual trying to access care can still often experience gaps in services on a case-by-case basis, due to factors related to the complexity of the health system for First Nations, and their sociocultural determinants of health.³⁰

The provincial government operates the Ontario Health Insurance Program (OHIP) through the Ministry of Health and Long Term Care. OHIP pays for a wide range of medically necessary services for all residents of Ontario, and it primarily covers physician and other outpatient health provider services. Additional Province of Ontario benefits include: the Ontario Drug Benefits Program (ODB), Ontario Assistive Devices Program (ADP), Ontario Works, Ontario Disability Support Program (ODSP), Trillium Drug Program and Northern Health Travel Grant Program.³¹ ODB, Ontario Works, ADP and ODSP are available to Status Indians living on reserve in Ontario, although there are some nuances in understanding the funding and delivery of the services.^{32,33} For example, on reserves, Ontario Works is administered by First Nations under the terms of the 1965 Canada-Ontario Indian Welfare Services Agreement, which provides for Ontario Works and some other social services to be delivered by First Nations but financed about 95% by the federal government.³⁴

In addition, Ontario has 14 Local Health Integration Networks (LHINs) that are responsible for health care administration and services in their catchment areas, including: hospitals, long-term care homes, Community Care Access Centres, Community Support Services, Community Health Centres and Addictions & Mental Health Agencies.³⁵ The SLA falls under the North West LHIN's (NWLHIN) catchment area.³⁶

Finally, the federal government, through the First Nations Inuit Health Branch (FNIHB) of Health Canada, operates the Non-Insured Health Benefits Program (NIHB), which provides additional health benefits coverage for eligible First Nations people in Canada.³⁷ Service providers must be recognized and registered with NIHB for clients not to be billed directly.³⁷ NIHB includes: dental, drugs, medical supplies and equipment, medical transportation, vision care, short-term crisis intervention mental health counselling, benefits outside of Canada, and chiropractic care.³¹

For medical transportation, individuals who have access to OHIP (usually those living off-reserve), generally have easier access to Ontario's Northern Health Travel Grant than they do to FNIHB-funded medical travel.³⁸ The access to the Northern Health Travel Grant is easier because this program directly accepts physician referrals and reimburses travel based on a standard funding formula, whereas FNIHB-funded travel must pass through an administrative approval process so that travel adheres to NIHB policies regarding allowable travel distances and service providers.

Diabetes Services Available at the Community Level

At the community level, the majority of the residents live on reserve and are Status Indians. Primary care is the mainstay of diabetes services for screening, diagnosis and management in SLA. On reserve, primary care is provided by nurses in nursing stations, who are employed by Health Canada unless the Band has negotiated a transfer agreement. In this case, the Band is responsible for primary care in their community, which includes hiring nurses. Some Bands have agreements with their Tribal Councils whereby the Tribal Council provides support for nursing services.

Physician services in the communities are provided by family doctors contracted to the Sioux Lookout Regional Physician Services Incorporated group (SLRPSI). Physicians are usually assigned to serve a specific community, and are present in the community for a few days per month. Physicians do not reside in the community. There is a shortage of physicians, so communities that do not have a physician contracted to regularly provide services are assigned locum (temporary) physicians. Many communities will have more than one physician providing services throughout the year (i.e. multiple locum physicians), which can sometimes interrupt continuity of care.

Diabetes services in the community are also provided by community health workers (CHW) of various titles including Community Health Representatives (CHRs) and Aboriginal Diabetes Initiative (ADI) workers. CHRs are hired to work in the clinic and provide clinical support, often they are called upon to provide language translation for elderly patients, dispensing medication and other administrative tasks. ADI workers are hired to provide health promotion and community education and are specifically funded to work on diabetes, and are federally funded.

The Home and Community Care program, also a federally funded program, is implemented nationally in all First Nations. The funding structure is the same as the ADI program in that funds are transferred directly to the Band, and the community decides how to allocate the monies. This program is intended to support in-home clinical care coordinated or provided by a registered professional health care provider, often a nurse.³⁹ Additionally, some non-clinical community support services in the SLA are funded by the NWLHIN may include: home maintenance, home making, transportation and other non-clinical supports, often provided by a Personal Support Worker.⁴⁰

Some communities are visited by diabetes providers, such as foot care nurses, nutritionists, and dieticians. Diabetes providers from the Sioux Lookout Diabetes Program at Sioux Lookout Meno Ya Win Health Centre are available to travel to provide services to clients on reserve. However, funding for travel to and from fly-in communities has to be approved by NIHB prior to departure. There is no regular roster or rotation schedule for specialist visits. Again, funding models dictate whether an individual community may or may not engage its own diabetes providers, but these are usually limited to foot care nurses or chiropodists. Sometimes other organizations (NAN, Tribal Councils) have received funding to run programs to provide specialist

care to communities (such as foot care nurses), but these funding tracts are impermanent and not integrated into the larger primary care system.

Medical specialist appointments are sometimes available by Telehealth, which involves a visit through live, interactive videoconference. This is often used for physician specialist consultations and follow up appointments for endocrinology, nephrology and cardiology.

Diabetes Services Available in the Town of Sioux Lookout

Both primary care and tertiary care services are available in the Town of Sioux Lookout. Primary care is available through outpatient health clinics such as the Meno Ya Win Health Centre, or the Hugh Allen Clinic. Tertiary care services are available at the Sioux Lookout Meno Ya Win Health Centre, which is a fully accredited 60-bed hospital and 20-bed extended care facility, and includes a hemodialysis unit.

The Sioux Lookout Diabetes Program (SLDP) is based at Meno Ya Win Health Centre and aims to provide comprehensive diabetes services foot care, client support groups, community screening, cooking classes, exercise programs, grocery tours, presentations in community and school visits.⁴¹ The multidisciplinary SLDP team includes a foot care nurse, dietician and kinesiologist. Some members of the team travel regularly into the communities on a rotating schedule, dependent on funding approvals from NIHB.

Meno Ya Win Health Centre also hosts a satellite site for the Centre for Complex Diabetes Care (CCDC) based in Thunder Bay. The CCDC has an interdisciplinary team that utilizes a case management model to provide coordinated, advanced care to patients over the age of 18 with complex diabetes needs, including: vascular disease, renal failure, impaired vision, mental illness or recurring diabetic emergencies.⁴² The CCDC program provides support to all 33 communities via physician referral, and often refers complex patients to the Thunder Bay site. Specialists from CCDC do not travel to communities.

Diabetes Services Available Outside SLA

Community members also access diabetes and related services, including renal services and dialysis, through the Thunder Bay Regional Health Sciences Centre North West Regional Renal Program. Additionally, all pediatric cases of diabetes are treated in Winnipeg through the Department of Pediatric Endocrinology at Children's Hospital.⁴³ However, it should be noted again that the travel approval for these trips is under the control and discretion of NIHB, and refusal of travel funding is not uncommon.⁴⁴

2.0 METHODOLOGICAL APPROACHES TO THE ENVIRONMENTAL SCAN

2.1 PURPOSE AND RESEARCH QUESTION OF THE ENVIRONMENTAL SCAN

The purpose of the environmental scan was to explore perceptions and experiences of patients and community stakeholders, as well as service providers, highlighting facilitators and barriers to optimizing diabetes care through an embedded research study. Additionally, the purpose of the study was to contribute to an evidence-base for developing future initiative addressing diabetes in SLA. The research question that guided the study was:

“What are the perceptions of and experiences with diabetes care in the Sioux Lookout Area by patients, community stakeholders and service providers?”

2.2 METHODS

Study Design

This study employed a mixed methods design with the following components:

1. Document and literature review to map existing strategies, programs, services, guidelines and program evaluations/assessments/reports.
2. Semi-structured interviews with key informants from the different sub-groups: patients, community leaders, and health service providers.
3. Direct observation of community and health-facility service sites.
4. Descriptive analysis of patient surveys on overall health care experience as well as experiences living with diabetes and chronic care conditions.
5. Additional case study informant Community Health Worker (CHW) program interviews in SLA.

Component 1: Document and Literature Review

Structured searches of the published and grey literature on diabetes services in Northwestern Ontario were conducted. Literature searches followed an interpretive scoping review methodology, as described by Arksey and O’Malley.⁴⁵ We reviewed existing strategies, programs, services guidelines and program evaluations, assessment and reports. This document and literature review form the basis for the Background section of this document and is also the subject of a stand-alone report entitled “A desk review of diabetes services and programs in Sioux Lookout Zone”, prepared by Mina Kazemi for Dignitas International in September 2015. This report is available upon request from Dignitas International.

Component 2: Semi-structured interviews with patients, community stakeholders and service providers

We examined how key diabetes stakeholders (patients, community leaders, and service providers) interacted with and experienced service provision in the SLA, including facilitators and barriers to optimizing diabetes health care services. This included a discussion of contextual, cultural and social determinants of health relevant to the SLA as highlighted by informants. A culturally competent translator and interpreter was available for those who felt

unable to speak directly with the research team due to limited fluency in English. The study team developed a list of contacts to be included as key informants based on, but not limited to, anticipated participating organizations and their clients. Key informant interviews took place in-person and by phone.

Component 3: Process observation with case-based review

We captured and analyzed observations on the system and processes of delivery of diabetes care in SLA. This included observation of processes and procedures related to:

- Early identification of diabetic patients, initiation on and adherence to recommended drug regimens/treatment plans, routine monitoring and follow-up of patients including abnormal results/warning signs, appointments and tests
- Support for patient self-management, condition and treatment literacy and motivation
- Information flow between different providers, sites and care settings, and between providers and the patient
- Collection of key data on diabetes care (e.g. populating diabetes flow sheets) and feedback process to clinicians and managers
- Information systems' (MediTech, OSCAR) support of care delivery (prescription of drugs, follow up on lab tests, referrals to specialists and communication with other members of the care team)
- Documented and/or recognized standard operating procedures understood by the relevant providers and managers, and targets and desired results

Component 4: Descriptive analysis of survey data

Baseline data was collected from 4 participating communities as part of a pilot diabetes CHW program. Details regarding participating communities and measurement tools are located in subsequent sections. The following survey tools were utilized for data collection:

- Diabetes distress scale
- Assessment of care for chronic conditions
- Health care experience survey for general population

Component 5: Case study CHW program interviews for SLA

Data from program interviews of CHWs in SLA with cross-sectional data collection was incorporated into the environmental scan. Program interview questions inquired about program structures, features, systems and processes including tools, manuals and guidelines. The 20 semi-structured interviews were with the original program designers, current managers and leaders, CHWs, physicians and other clinicians who work with CHWs.

2.3 STUDY POPULATION

The study population consisted of adults involved in diabetes care in the catchment area of SLA, including patients diagnosed with type 2 diabetes and their caregivers, community leaders and health service providers.

Diabetes care was considered to be any health related activity involving prevention or management of diabetes. Patients were considered those 18 years old and over who were either accessing diabetes services for themselves or as the primary caregiver for an adult diabetes patient (e.g. elderly family member). Community leaders included adults aged 18 years and over involved in implementation of, policy-making for and/or decision-making for diabetes care in the target communities. Health service providers included medical, paramedical and non-medical staff involved in direct patient/client interactions for diabetes care in the target communities.

2.4 SITE DESCRIPTION

Sites included 4 communities within SLA; Kingfisher Lake, Slate Falls, Kasabonika and Kitchenuhmaykoosib Inninuwug (Big Trout Lake); as well as the town of Sioux Lookout and Thunder Bay. We utilized mixed purposeful sampling while seeking input from community leaders in the SLA to identify health facilities and key informants for data collection. We attempted to include average, high and low functioning communities in terms of optimal diabetes care. We anticipated 15-20 key informant interviews from each of the three sub-groups (patients, community leaders and service providers), with a total sample size of 45-60 individuals required to reach saturation. Field observations were conducted at health facilities (nursing station) in participating communities.

2.5 ETHICS

Ethical clearance to conduct the study was obtained from University Health Network Research Ethics Board, from the joint Sioux Lookout Meno Ya Win Health Centre and SFLNHA Research Review and Ethics Committee, and from participating communities. During the data collection process, all participants provided written informed consent. All data was recorded using unique numeric codes. A numeric code list and corresponding key informant identities were maintained in a separate secure location accessible only to the study team. Interviews were audio recorded and transcribed verbatim, with a quality check performed by a second study team member on 20% of interviews. All paper documents were stored in locked cabinets within locked rooms. All electronic study records, including digital audio recordings, were password protected and stored on a secure server with access to study data limited to study team members. The study data will be kept by SLFNHA on behalf of the SLA communities for a minimum of 10 years. The research study team gave SLFNHA the anonymized study data at the end of the study. Data collection was conducted from June 2015 to June 2016.

3.0 RESULTS FROM KEY INFORMANT INTERVIEWS AND SURVEYS

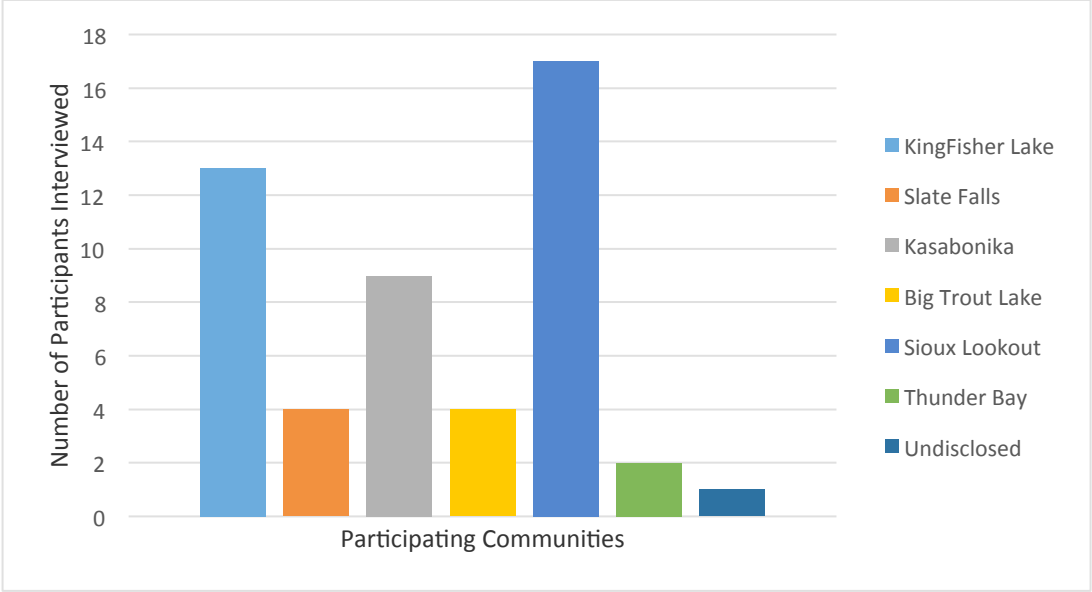
3.1 DEMOGRAPHIC CHARACTERISTICS

There were a total of 110 participants included in the study, with 70 people interviewed and 40 people completing surveys. Fifty interviews were conducted among the sub-groups of patients, community leaders and service providers, and an additional 20 interviews were conducted from the CHW program interviews (Table 1). Most of the CHW program interviews were conducted in Sioux Lookout town, and this is the reason that the largest group of participants appears to be from that area (Figure 1). Due to the small sample size, further demographic breakdown is not possible, in order to respect participant confidentiality.

Table 1: Participant Demographics

	Community Leader	Service Provider Key Informant	Patient	Service provider CHW Program Interview	Health Care Experience Survey	Surveys: Diabetes Distress Scale & Assessment of Care for Chronic Conditions
Total	N= 10 (7%)	N= 18 (12.6%)	N=22 (15.4%)	N= 20 (14%)	N=30	N=19
Male	6	2	5	9	13	4
Female	4	16	17	11	15	15
Gender not disclosed	0	0	0	0	2	0

Figure 1: Origin site of included participants for the diabetes scan



3.2 KEY INFORMANT INTERVIEW RESULTS

Key informant interview results were qualitatively coded into three main categories, using a macro, meso and micro frame analysis. In this framework, the macro level is the Health System, the meso level is the Health Service and the micro level is the Community. Through an iterative process of qualitative data analysis, each level was further sub-categorized as follows:

1. Health System (Macro)
 - a. governance,
 - b. human resources,
 - c. funding,
 - d. use of CHWs,
 - e. services utilized,
 - f. isolated fly-in communities,
 - g. research, and
 - h. data and information sharing

2. Health Services (Meso)
 - a. clinical care,
 - b. provider collaboration,
 - c. diabetes flowchart, and
 - d. patient engagement and support

3. Community (Micro)
 - a. role of culture and history,
 - b. location,
 - c. food insecurity, and
 - d. mental health

3.2.1 HEALTH SYSTEMS

Governance

Currently, diabetes services in the SLA are provided by a mix of different providers including federal, provincial, Band Councils, and physician groups. Each party has their own policies and programs. Community leaders, service providers and patients expressed frustration with the governance and overarching policy for diabetes care. From the perspective of community leaders and service providers, it was unclear who had governance over diabetes care. One service provider reported over 50 programs providing diabetes care in the First Nations. Respondents reported that these programs did not communicate nor collaborate well which resulted in overlap of services in some communities while creating gaps in others. When asked specifically about communication and collaboration, service providers and community leaders felt that communication was poor across the overall health system. However, communication

within specific teams, including SLDP and CCDC, was perceived favorably.

Additionally, community leaders reported feeling frustrated as they perceived that the health system, in general, lacked accountability to the communities. In particular, nurses employed by Health Canada at the community nursing stations were perceived as lacking good lines of communication with the Band Council.

The importance of focusing on prevention was most prevalent in discussions with community leaders and service providers. It was felt that the health system “currently provides reactive care”. There was a strong desire from community leaders and service providers to look beyond the established clinical model of diabetes care to also focus on addressing broader social, political and cultural aspects of care, particularly the integration of prevention and education into community-based resources.

“And also, we’re not proactive, we’re reactive. Which basically just all our health services are just basically reactive, there’s no proactive because we don’t have the resources, nor the time, to do what we need to do” (Service provider, Female)

“It’s kind of like a sickness management, that’s how they described health care. And it’s almost the exact meaning of the system. Sure, the physicians, the nurses, the communities’ nursing station, they mean well but I think, we don’t do enough to do that, I don’t think the province or the federal government and the system that exists is, it’s not doing enough to provide that [prevention] services” (Community leader, Male)

Human Resources

Generally, the skill levels of diabetes service providers were viewed favorably by all 3 groups of respondents. The biggest criticism of the state of human resources in the health system was that there were too few workers. For example, one pharmacist reported a case load of 800 patients. Additionally, only 7-8 workers from SLDP service both SLA communities and the town of Sioux Lookout. Respondents reported shortages of nurses their communities, which was felt to perpetuate a reactive health model. For diabetes care, specialized teams stated that they relied on diabetes workers in the community to do the “hard work”: intensive diabetic management. However, respondents perceived a wide variability in skill level of diabetes workers in each community. Perceived confidence in CHWs’ skill level varied greatly among service providers, community leaders and patients. Service providers and community leaders pointed out the need to re-examine the capacity of community members in community positions, particularly CHWs, and how to better support them.

“We have a staff that truly cares about the health and well-being of the clients that we serve” (Service provider, Female)

“And that turnover, I think results in a more medicalization of diabetes because you can focus on the things that are more consistent around numbers and the medication and pills to try and you

start losing the, the more nuanced sides of chronic disease, it's not just diabetes, it's similar to chronic pain, or hypertension, or smoking or these sort of thing. The more nuanced things that are really dependent on that strong, the strong relationship between the care providers and the individuals, so, the high turnover rate certainly affects that, but then it also affects the cohesion of the team, when people are coming and going and there isn't the establishment of rhythm and routines and expectations and things aren't as predictable, the comings and goings can really be disruptive to that and it propagates the siloization of the care rather than the integration of the care when people are turning over" (Service provider, Female)

Perceptions of Funding

Community leaders and service providers reported a lack of available resources for diabetes care, particularly for training community-level workers. Community leaders felt they had the resources to hire community-level workers, yet were not financially supported to send workers for additional, necessary training. Supervisors of ADI workers stated they did not have funding for diabetes training. Additionally, community leaders expressed the need for more funding at the community level for diabetes educators and community education.

Diabetes workers who traveled from Sioux Lookout to First Nations reported being dependent on funding from Health Canada. Policy restrictions have halted travel for allied health professionals from the SLDP to northern communities, which was perceived to limit access to diabetes services in First Nations. Telehealth was reported as unreliable, resulting in major delays at the patient level.

Use of CHWs

The role of CHWs in the SLA varied depending on the position, which may include ADI workers, CHR, and Home and Community Care workers. Respondents appeared confused when asked about specific role descriptions or roles and responsibilities of CHWs. Most respondents listed specific activities, such as blueberry picking with clients, interpreting, or talking on the radio. When CHWs were asked if they had a copy of their role description, or any documentation delineating specific tasks, most CHWs reported that they had never seen a description of their role, nor had they ever been told what tasks they were accountable for.

One of the greatest perceived strengths of the CHWs, from the perspective of community leaders, was that CHWs are accountable to and intergrated in the community, culturally aware, and speak traditional languages.

CHWs reported feeling restricted in what they could offer patients due to resource limitations and community members reluctance to engage in activities or services. Several CHWs stated their desire to see traditional foods advertised, but the ADI program follows Health Canada guidelines and it is perceived that dieticians and nurses do not encourage patients to eat a traditional diet. One ADI worker expressed that the diabetes manual written in English was hard to comprehend, which made it difficult for them to relay information to community members in

their own language.

The experience of other service providers and patients varied by community when it came to CHWs. Participants felt that CHWs were underutilized, under-trained and under-supervised, yet participants felt there was potential to build CHWs' capacity to assist clients in the community with diabetes care and management. Most of the reported work done by the CHWs (regardless of title) was aimed at the individual patient level, although there was an emerging theme that CHWs should have more of a presence in the community and could be utilized to provide education in schools, talk on the radio, organize community events and work with elders. Community leaders felt that the work of the CHWs should be aimed at the family unit and the broader community, not just on a one-to-one basis.

“Um since those workers are from the community and stay in the community, they know the needs of the community, of their programs and what needs to be done. I think that’s one of the strongest points that we have. And they’re also able to interact with the people and their language as well, especially with the elders” (Community leader, male)

Services Utilized

The most frequently utilized diabetes services reported by community leaders and service providers was foot care, followed by accessing diagnostics at the nursing station, and utilizing the dietician services through SLDP. Underutilized services were reported as diabetes education, exercise support, social support, counseling and psychosocial support.

“When patients come they want foot care, because that was what we sold for the last 15 years, ‘you need to get foot care, you need to get foot care’. And so patients know that diabetes and feet go together and they don't really recognize the rest of the stuff” (Service provider, female)

Access in Remote Communities

Access to services for remote communities was reported as extremely challenging. Discussions with community leaders, service providers and patients revealed frustration with Non-Insured Health Benefits (NIHB). NIHB was perceived as a barrier to access due to policy restrictions. Although NIHB was reported to have a regional exception for foot care and eye tests, respondents reported that the transportation for the diabetes program was not covered by NIHB, which was perceived as a major barrier.

Although SLDP workers travel to communities, participants reported that the small number of program staff resulted in limited community visits (once or twice a year, on average) and although the visits were cited as helpful, they were not perceived as resulting in widespread community benefit. Participants reported that visits to the community by the SLDP were subjected to getting “bumped” in favour of other visiting health care providers. Additionally, CCDC staff did not travel to remote communities, which was cited as another barrier to access.

Service providers, too, expressed frustration with accessing communities and rebooking visits.

Telehealth was reported as one strategy for ensuring greater access to diabetes services for remote communities. However, service providers and patients expressed that the Telehealth system was subject to massive delays (up to 2-3 months), diabetes-related consults were often cancelled depending on other medical priorities in the community, and specialized services were commonly not accessible through the system.

Accessing specialized services related to diabetes was viewed as a major weakness. Patients and service providers reported delayed specialist appointments, limited access to wound care at the community level and irregular scheduling for various services. Lastly, patients and service providers reported major challenges for community members in securing childcare and escorts when traveling out of the community for specialist appointments.

“I think it’s specialized care, like say foot care nurse, or other people that specialize in diabetes. We have very limited access to that resource. Like I said before, they come in at their convenience or by invitation, there’s not a regular, like, it would be nice to have a regular visit by a foot care nurse. Like not twice a year, not once a year. And like consistency. You know, because if it’s consistent people are more open, receptive to that service. But if they come like once a year, there not continuity, there’s no contact, and because it’s a strange face, some people [are] reluctant” (Community leader, Male)

Research

From participants, there was a general apathy toward research, and diabetes research in particular. Community participants reported frustration toward past researchers who did not follow a consultative process, nor disseminate research findings to the communities. Although diabetes research was perceived as contributing to the development of best practice guidelines, it was unclear to most participants how research influenced actual diabetes service provision in the SLA.

“We’re being researched to death. And personally, what’s going to come out of it? What’s this research going to come out of it? What is my community going to benefit from it? And is it just another research that is going to sit on the shelf and collect dust? Because majority of studies, that’s how they end up, there’s never a change. And I think in order for the research to make a difference, change has to be implemented” (Community leader, Male)

Data and Information Sharing

Data and information sharing was cited by a majority of participants as a challenge. Perhaps most worrisome for community leaders, in terms of data and information sharing, was that they lacked access to data regarding rates of diabetes in their communities. They cited the difficulty in trying to plan and fund diabetes initiatives when they were unsure of the current burden.

“I would like to kind of know that, because that way we know, as leaders, who is most affected, whether it’s children under 10 or teenagers or people up to you know, up to sixties and all that stuff. That way we know the most affected and why I don’t have that till this day. I don’t need names, I just need the number, the stats, age, male, female and also type 1 or on the verge of being on you know, then we can plan” (Community leader, Male)

Additionally, community health centres were reported as not having access to SLDP notes, mainly relying on fax or paper charting. Service providers reported that the circle of care team did not have access to the same information or each other’s notes, with ADI workers being left out completely. Generally, EMRs were viewed positively among service providers. However, several providers noted the unrealized potential of EMRs given that different EMR systems were not integrated, which was a perceived barrier to optimal care.

3.2.2 HEALTH SERVICES

Cascade of care for Diabetes

The cascade of care for diabetes includes screening, diagnosis, referral, treatment and follow-up. Patients were diagnosed with diabetes in a variety of ways. Some female patients were initially diagnosed with gestational diabetes and, after pregnancy, were diagnosed with type 2 diabetes. Other patients were diagnosed through routine screening, while several patients reported to the nursing station for other conditions including urinary tract infection (UTI), women’s checkup and numbness in extremities, at which point they were tested and diagnosed. A perceived strength of diabetes care was opportunistic screening. Patients reported being offered random glucose checks by nurses in the nursing station.

“Screening is probably higher than they would access in many places because it’s, it’s often treated as one of the vital signs and then if their glucose is high that can prompt more definitive screening and testing” (Service provider, Female)

In terms of referral processes, service providers reported that over the past year and a half there has been an effort to implement an electronic generic referral. Physicians were reported to send formal referrals for patients to SLDP and diabetes specialists, because of Health Canada requirements for a physician’s referral in order to approve travel. The patient self-referral process of the SLDP was perceived as a strength of the program by patients and service providers. Additionally, patients who were recently diagnosed with Type 2 diabetes (>3 years) reported an efficient and effective referral process to SLDP, and people who were already physically present in Sioux Lookout could self-refer to SLDP without needing a physician referral.

Diagnosis, screening and referral process were generally perceived as favorable among service providers and patients, while follow-up was perceived as a weakness of service provision. Service providers reported that there was no systematic approach to managing follow-up.

Service providers also reported the lack of a patient database as one of the greatest barriers to managing follow-up, resulting in a perceived higher probability of “human error”. Additionally, the processes of follow-up were reportedly made more difficult when patients were unaware of who/when they were scheduled to see someone from the SLDP, either in person or via Telehealth. Patients reported being “bumped” from the list to see the visiting physician. Service providers reported that diabetes patients waited, on average, 2-3 months before seeing a physician in the community.

Most patients reported that they were happy with the care they were provided at the nursing station, and did not identify access to specialty services, testing or regular follow-up appointments as issues. Patients who were recently diagnosed (>3 years) reported receiving a diabetes care plan, support in implementing the plan and compliance with the plan. However, patients who were diagnosed with diabetes over 5 years ago reported that, for the most part, they were not given a diabetes plan. These patients reported no support in the form of set targets for blood pressure, weight goals, diet or exercise. Of the patients interviewed, only a few reported having been contacted by SLDP. Compliance with medication varied amongst participating patients; the most cited reason for non-compliance was that the client forgot due to a busy schedule.

Discussions with community leaders and patients revealed that the most common suggestion for improving the state of diabetes in the community was the need for education. Community leaders and patients desired more community resources, radio programs, and education in the schools with the focus on prevention.

Provider Collaboration

Respondents reported a wide variability amongst provider collaboration. That being said, there was a strong desire amongst service providers to utilize the role of CHW in the community to a greater extent.

Diabetes Flowsheet

Service providers were asked specifically about their use of the diabetes flowsheet. Flowsheet use by service providers varied and was reportedly used inconsistently by those who did report employing it. Provider perceptions regarding the usefulness of the flowsheet correlated to how often providers used the flowsheet. Other providers reported time and resource constraints as reasons for not utilizing the flowsheet.

“Again, we don’t have the resources, our diabetic care nurse, chronic care nurse, the position isn’t consistently funded, it’s; you know, kind of, one of those things that people get to if they have time. And they often don’t have time; they mostly don’t have time” (Service provider, female)

Patient Engagement and Support

Patient engagement and patient adherence to treatment plans were reported as significant issues for service providers. Physicians, nurses and ADI/CHR workers stated that increasing community participation in activities was challenging; some workers even offered incentives, but did not have good turnout to community activities.

Many ADI, CHR and Home and Community Care workers reported that they struggled to motivate their clients to adhere to their medications and change their lifestyle habits, including healthier diets and greater participation in some form of exercise. Adequate space and equipment (e.g. cooking equipment) to host people in the community were also cited as a major barrier to patient engagement.

Non-patient participants were uncertain as to why patient engagement and compliance has been such a challenge. The most reported possible explanation was denial from the patient. Many service providers perceived that patients were in denial of their diagnosis and thus, unable to make changes to their lifestyles. Shame and stigma were also perceived to contribute to lack of both patient engagement and adherence to treatment plans. Stigma was a prominent theme for both patients and community workers. Patients reported a lot of judgment around being labeled as a diabetic, and fear of people judging what they did or did not eat.

“People have said it’s shameful for them to walk around the community because people know they have diabetes so they don’t want to exercise. So it’s, I don’t know what, they’re embarrassed, they don’t want people to know, they’re just private and it’s kind of things like ‘oh, that persons walking, they much have diabetes or they must’ve gotten diagnosed with something’. So it’s really, it’s a really negative view” (Patient, Male)

Additionally, several respondents reported that the perceived slow onset and progression of diabetes symptoms made it harder to engage community members. There were suggestions from community leaders and services providers that social workers or community workers may be better able to address patient engagement and compliance through intensive case management. Patients themselves reported their non-adherence but did not offer possible solutions that would enable them to be more compliant or engaged with their diabetes care.

Interestingly, patients reported the desire for more support in terms of diet and exercise, and for more information, generally, about managing their diabetes. This was consistent among all patients, regardless of compliance to their diabetes treatment plan. Patients reported feeling isolated due to their diagnosis, and wanted more support from community resources.

“Gee, I don’t know. You know, it would be nice if there was more support, you know. You know, like alcoholics, they have alcoholics anonymous. They have a made up program in the communities, you know. Diabetes is, you know, is such a faster growing epidemic than alcoholism. And, and, you know, there, I believe there’s, uh, similar underlying issues to that as well” (Patient, Female)

3.2.3 COMMUNITY

Role of culture and history

The role and importance of culture was a prevalent theme amongst community leaders, patients and some service providers. Many participants from all groups felt that historical roots of cultural assimilation were present in services provision, which was perceived as not being culturally competent, nor treating First Nations communities as partners in care, but merely consumers of care.

Community leaders noted that the health system was still perceived as a “white man’s health system”, and that First Nations cultural norms were not reflected by the health system in the community. Service providers believed that negative perceptions of the health system and Western medicine/disease conceptualization, as well as poor past health care experiences, resulted in patients not actively engaging with diabetes services, which patients may feel do not translate linguistically or culturally. Community leaders and patients stated that when the community did not receive educational instruction in their traditional language, there was a disconnect of meaning. Similarly, service providers noted that helping patients to understand diabetes, even with interpreters, was challenging.

“How did we manage to survive for the last 10,000 years? We must have done something right. But the mentality is that we can’t do things. The thing is, the difference is, we know what’s right for us, we know how to take care of ourselves. But there’s always somebody outside saying, no that’s not the right way, this is the way it’s done. But people have to realize we’re different people. We’re different. We do things differently, we think different, we say, this is the way things are done. And like I said, we’ve been around at least, white man science is telling us, we’ve been here at least 10,500 years. That’s even older than the pyramids” (Community leader, Male)

Community leaders reported a strong desire to implement and focus on traditional foods, health practices, spiritual practices and medicines as a means of addressing diabetes and other illnesses in the community. Community leaders felt that traditional foods came with a “lifestyle too, it’s not a simple matter of going over to the store and buying food. You have to work for it. It’s not easy”. Other community leaders equated traditional food and lifestyle to living “clean” and connected to the land, which they felt was when an individual was most healthy.

“Yeah, yeah more of you know, uh, I guess a human approach to it, you know, rather than a clinical. And stop comparing, you know. I don’t know what western society infatuation with, you know, comparing one against the other. You know, in First Nations, we were never like that, you know, we did what we needed to do to ensure our quality of life. It’s not, you know, to become worried comparing us to other First nations that, you know, that were around us” (Community leader, Male)

*“I was talking to a foot care nurse last week...I was asking her, like their food [service providers] is different from ours. Like their diet. We don't have access to any of the stuff that they use”
(Patient, Male)*

CHWs were highly regarded as the most appropriate person to bridge the gap between clinical interventions and cultural values at the community level. Participants noted the importance of recognizing each community's unique values, processes and protocols, and of delivering support that adheres to them. The strength CHWs from the community was their understanding of cultural community values and the subtle nuances of their own community culture.

Location

Geographic factors, including remoteness and climate, were reported by patients, community leaders and service providers as a significant challenge for diabetes patients. Long winters with limited daylight made it difficult for participants to secure local fresh fruits and vegetables. Patients reported lack of indoor exercise facilities in community as a major challenge, given the cold temperature in the winter and the intense amount of bugs in the summertime that dissuade people for exercising outdoors.

Food Insecurity

Community leaders, service providers and patients recognized food insecurity as a major challenge for controlling diabetes in communities. As previously stated, the climate and remoteness of northern communities made it challenging to cultivate fresh fruits and vegetables. Respondents noted additional challenges including high prices of food in the Northern Stores, and the impact of these on their ability to follow diabetes plans that include specific food choices that could be too expensive for people to afford regularly.

“Still trying to watch what I eat but it's hard, it's very hard when you're a single mom of five. I'm the only provider for my children, you know, I can't really buy health foods. You know we went grocery shopping and my daughter wanted cherries and I couldn't buy them because they were \$25.00 a bag” (Patient, Female)

Additionally, as previously mentioned, Health Canada Food Guidelines were reported as incompatible with a traditional diet.

“We have to meet the Canada Food Guidelines. Well, when you look at traditional foods, it's not Canada guideline friendly. We're double starching all over the place. For example, moose meat, when you boil it we put rice in there and then potato and that's it. Well you're double starching then” (Community leader, Female)

Mental Health

Lack of social support generally and for mental health and addictions, specifically, was reported from all three groups of respondents. Discussions with patients revealed their own struggle with mental health, in particular, depression. Some reported that they were in a depressive state after diagnosis, while others struggled to manage diabetes due to preexisting mental health challenges. Generally, respondents reported a lack of mental health support resources in the community, especially with regard to counseling for diabetes patients. One community leader noted that “support within mental health is non-existent”.

“The first time I got diabetes I was really scared; is this it or am I going to die soon? Like what all the complications I’ve been hearing about. But then I realized that that was going to happen, like if I didn’t look after myself” (Patient, Female)

“It would be nice if, you know, the community mental health worker, you know, was there, you know, to help or at least be available to offer counselling, you know, cause there is, there is a wide, wide range of emotions that you have to deal with for diabetes. You know, but there’s no supports in, in how to address that” (Community leader, Male)

Service providers reported that many diabetes patients in the SLA were struggling with mental health issues with no support, rendering diabetes “way down on the list of health needs”. One service provider estimated that 80% of their diabetes patients were not self-managing due to other issues, in particular, mental health issues.

“The very close relationship between diabetes as chronic disease, and, you know, mental health and the, the role that mood disorders like depression, or even just working through grief and loss and the ways that those sorts of things impact our lifestyle choice’s and our behaviors both nutritionally and exercise driven, we can, it’s much easier to just give somebody a pill than to really try any focus on some of those broader issues that I think are really underlying diabetes in many of these communities” (Service provider, Female)

3.3 PATIENT SURVEY RESULTS

3.3.1 DIABETES DISTRESS SCALE

The Diabetes Distress Scale measures the impact of managing diabetes on a day-to-day basis for a patient. The survey asked respondents to rank to what degree they related to statements in the survey as a way of measuring diabetes-related emotional stress. Lowest score = 1, “No problem”; highest score = 6, “Serious Problem”.

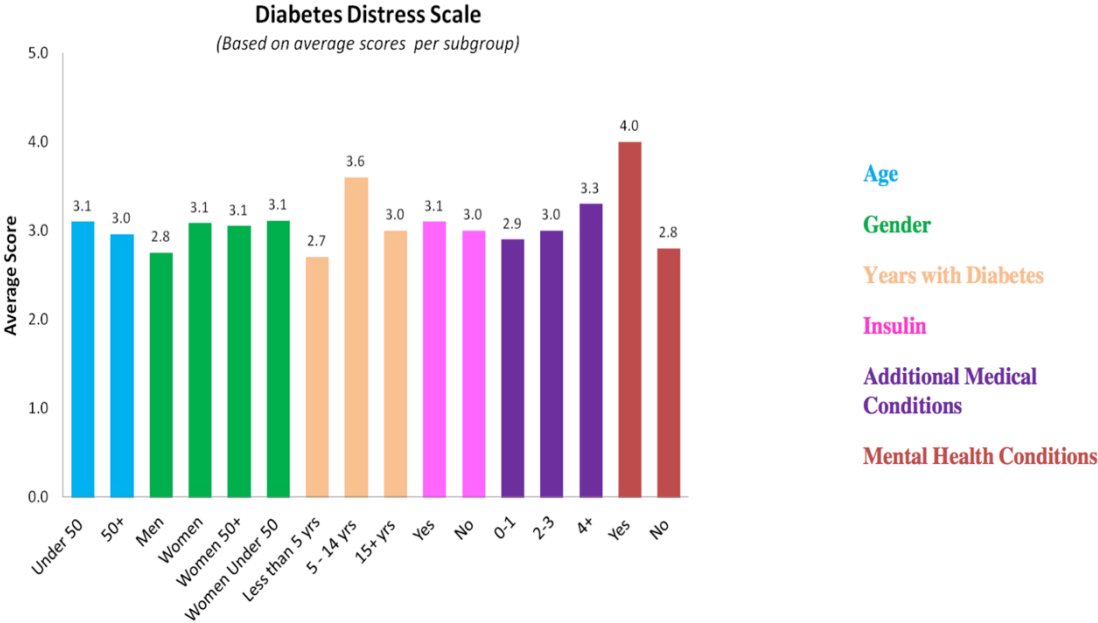
Communication and support from health care providers, family and friends were strongly identified as positive areas of current practice (i.e., “No problem”). Difficulty maintaining a diabetes regimen, including testing blood sugar frequently, feelings of failure with regard to

maintaining one’s treatment plan, and mental and physical exhaustion related to living with diabetes, was strongly identified as a “Serious Problem”.

Summary of Key Results

- Age did not strongly affect distress score.
- Women had a higher distress score than men.
- People who have lived with diabetes for 5-14 years had the highest distress score, followed by 15+ years, then >5 years.
- Insulin use did not strongly affect distress score.
- Predictably, additional medical conditions, especially mental health conditions (n=3), increased distress scores.

Figure 2: Diabetes Distress Scale Scores



3.3.2 ASSESSMENT OF CARE FOR CHRONIC CONDITIONS

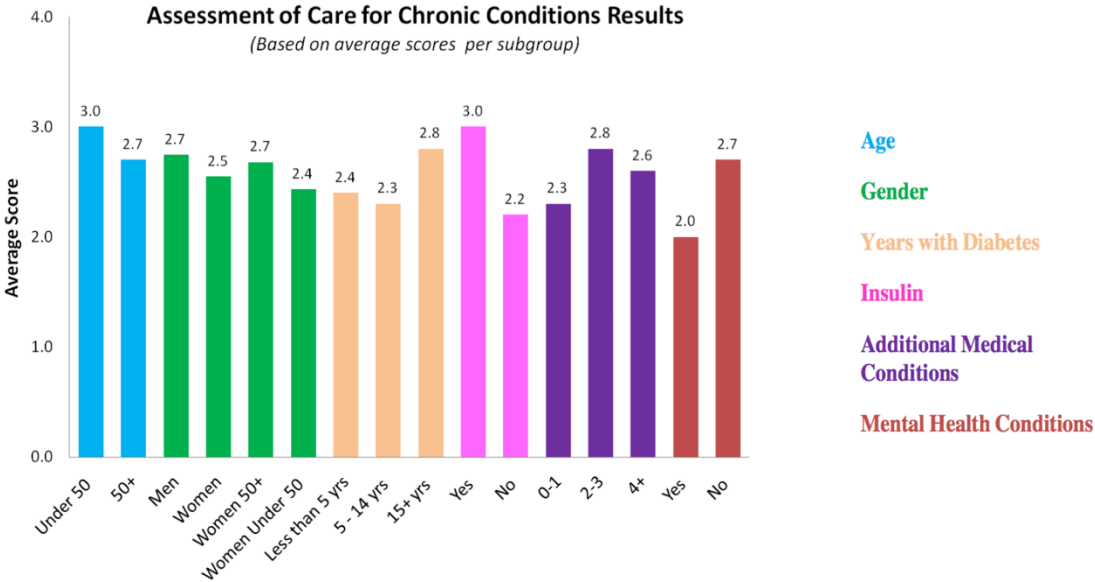
The Assessment of Care for Chronic Conditions captures the characteristics of non-clinical aspects of care patients receive from service providers to address the unique needs of living with a chronic condition such as diabetes or hypertension.

The survey asked respondents to rank levels of care over the past six months to identify area for improvement. Lowest score = 1, care received “None of the Time”; highest score = 5, care

received “Always”. Care in the clinic, including organized care, goal-setting, and discussing how care influences condition, was strongly identified as positive and consistent amongst respondents.

Support to continue care at home or in the community, including a copy of treatment plan, encouragement to attend specific groups or classes in the community to cope with condition, and being queried about health habits (either directly or on a survey), was strongly identified as absent or inconsistent. Individuals 50 years and older reported less care than younger people, and women generally reported less care than men, especially women under the age of 50. Individuals who have lived with diabetes for 5-14 years (n=3) reported the least amount of care, while those who have lived with diabetes for 15+ years reported the greatest amount of care. Individuals not using insulin reported far less care compared to reports from those using insulin. Individuals with additional medical conditions generally reported more care. However, people with mental health conditions (n=3), specifically, reported much less care.

Figure 3: Assessment of Care for Chronic Conditions Results



3.3.3 HEALTH CARE EXPERIENCE SURVEY

The Health Care Experience Survey is a tool designed to capture how a patient interacts with the health system in regards to their primary care. The survey was adapted from the CAHPS American Indian Survey. It was the first tool of its kind tailored to the experiences of First Nations people living on reserves in the SLA. The survey explores the client’s experiences with

the health care system, including but not limited to access to care and patient- provider dynamics. For questions of frequency, respondents had four options: *never*, *sometimes*, *usually* or *always*. Other questions of frequency specified a time frame or number of times. Some questions asked respondents to select one or more options from a list.

Summary of Survey Results:

1. Few respondents visited community providers outside of the nursing clinic, but of those who did, many sought mental health services, including: NNADAP and NODIN workers, personal support workers, and traditional healers.
2. Nearly half of respondents were referred to a specialist outside of their community. Approximately 1 in 4 respondents were unable to attend their appointment. The reasons cited by those who could not attend their appointments were: not being notified of their appointment at all or with enough advance notice, no travel arranged for them, missing escort, no child care, and bad weather preventing travel.
3. The majority of respondents replied that the specialist they saw seemed to *usually* or *always* know their important medical history. However, the majority of respondents replied that their doctor or nurse seemed *never* or *sometimes* informed and up-to-date about the care they received from specialists.
4. Half of all respondents who reported experiencing unfair judgment or disrespectful treatment from their provider felt that they were discriminated against on the basis of their First Nations identity.
5. Nearly one third of respondents required prescription medication, the majority of whom reported that their provider *usually* explained the purpose in a clear way. All respondents reported that it was *definitely* or *somewhat* easy for them to get their medicines through the nursing station.
6. 4 in 5 respondents reported *never* or *sometimes* receiving their test results in a follow up appointment, while 1 in 4 reported this *usually* happening.

3.4 STRENGTHS AND LIMITATIONS

This is the first study of its kind: an in-depth examination of patient, community and provider perspectives of diabetes care in Northwestern Ontario. The mixed-methods study design, including qualitative, quantitative and case study approaches, allowed for the collection of more detailed information, achieving greater depth of description compared to other experimental designs. The convergence of data strengthens the findings of the mixed method study⁴⁶. The study draws on a variety of sources: documentation, semi-structured interviews, direct observation, and survey data. Furthermore, the triangulation of data is an additional strength to the study. The selection of sites and study participants captures maximum variation among possible sites in SLA, with comprehensive sampling across both different geographic regions in the area and different perspectives.

Although the study sites selected represent maximum variation, there is still limited transferability and generalizability of findings due to the small number of communities included, which is a limitation of the study. Additionally, the small sample size of survey respondents further limits generalizability. There is also the risk of selection bias and response bias as we purposefully selected participants.

3.5 SUMMARY OF KEY RESULTS

Generally, health services were perceived as good once they have been accessed. However, diabetes care was perceived as fragmented, and there was confusion regarding which services were available and how to access specific services. That being said, patients who were diagnosed <3 years reported less confusion, quick access to care and establishment of a diabetes care plan. Additionally, service providers were perceived by patients as competent and knowledgeable. However, there was concern regarding some interactions between patients and service providers wherein nurses and doctors were perceived as being “too busy” to address patient concerns.

Apart from clinical services, there was a strong desire from all participants to support community members at the community level. To this end, participants suggested home visits, and greater support to address diabetes care plan compliance and self-management issues, such as behaviour changes, diet and lifestyle. The results of the environmental scan revealed that support at home or in the community, including patients possessing a copy of their treatment plan, encouragement to attend specific groups or classes in the community to cope with their condition, and follow-up from service providers about health habits (either directly or on a survey), were strongly identified as absent or inconsistent. Patients who have lived with diabetes for 5-14 years reported the least amount of care, while those who have lived with diabetes for 3 years or less reported a greater amount of care, as did those who lived with diabetes for 15 years or more. Additionally, greater emphasis on culturally appropriate services and preventative aspects of diabetes care was highly desirable as a way to strengthen community education, participation and engagement. Lack of support for mental health issues was identified as a major challenge in addressing diabetes care. Patients, community leaders and service providers emphasized their desire for expanding mental health support for patients in the community.

Lastly, CHWs were regarded as the most appropriate service provider to bridge the gap between the clinic and the community. From the perspective of community leaders, the greatest strengths of CHWs were their accountability to and integration in the community, and their cultural awareness and fluency in traditional languages. However, the majority of participants felt CHWs were underutilized, under trained and under supported, but there was potential to build CHWs capacities to assist clients in the community with diabetes care and management.

4.0 DISCUSSION

This environmental scan is not a compressive review of diabetes services in the SLA and is presented in accordance with the perspectives of participants. Additionally, all references to services and organizations were presented in accordance with the services and organizations' own self-description. Perspectives and experiences vary by individual, and although we did synthesize findings to draw out themes, other patients, community leaders and service providers who were not part of the study sample may experience different interactions with diabetes services in the SLA.

Interestingly, there were additional themes identified through review of the data, which may warrant a secondary analysis using a more iterative or different theoretical framework. For example, some recurrent themes included paternalistic heritage of health services in First Nations, the legacy of cultural assimilation, and the degradation of traditional practices in favor of a Western biomedical model. Moreover, there is a need to further explore the causal mechanisms of suboptimal interactions between patient and provider, as both groups reported frustration in their interactions.

Lastly, community leaders expressed frustration at not having quantitative statistical data regarding the number of community members who have Type 2 diabetes. Undoubtedly, access to this data can enhance the relationship between health services and community leaders. The data can also assist in determining the amount of funds needed to address the epidemic at the community level. However, given the high rates of diabetes within communities, the specific number may not be more useful than a general idea (e.g. knowing there is a high prevalence) in costing community initiatives.

This environmental scan provided an in-depth examination of patient, community and provider perspectives of diabetes care in SLA. The scan identified facilitators and barriers to optimizing diabetes care at various levels. Additionally, this study contributed to the development of an evidence-based foundation that was previously established through the Sandy Lake Health and Diabetes Project. With the administration of the patient surveys, we have begun to develop a baseline assessment for evaluating future initiatives. Lastly, this scan contributed to strengthening collaboration, coordination and information sharing amongst various parties who are impacted by and involved in diabetes programs and services in the SLA.

“Diabetes in the nature is so integrated with the bigger picture for that person, in terms of what’s happening in their life at the time, what’s happening emotionally, and socially and psychologically, culturally, and all of that, and those sorts of things, it takes time to develop relationships, to really get an understanding of where somebody is coming from” (Service provider, Female)

REFERENCES

1. Dyck, R., Osgood, N., Lin, T., Gao, A. & Stang, M. Epidemiology of diabetes mellitus among First Nations and non-First Nations adults. *Can Med Assoc J* **182**, 249–256 (2010).
2. Harris, S. B., Bhattacharyya, O., Dyck, R., Hayward, M. N. & Toth, E. L. Type 2 Diabetes in Aboriginal Peoples. *Can. J. Diabetes* **37**, S191–S196 (2013).
3. Ghosh, H. & Gomes, J. Type 2 diabetes among Aboriginal peoples in Canada: A focus on direct and associated risk factors. *Pimatisiwin J. Aborig. Community Health* **9**, 245–275 (2011).
4. Morrison, N. & Dooley, J. The Sioux Lookout Diabetes Program: diabetes prevention and management in northwestern Ontario. *Int. J. Circumpolar Health* **57**, 364–369 (1998).
5. Public Health Agency of Canada. in *Diabetes in Canada: Facts and figures from a public health perspective* (2011).
6. Carothers Bell, M. Local Integrated Health Network Diabetes rates in Sioux Lookout Area. (2016).
7. Young, T. K. Primary health care for isolated Indians in Northwestern Ontario. *Public Health Rep.* **96**, 391–397 (1981).
8. Kakekagumick, K. E. *et al.* Sandy Lake Health and Diabetes Project: A Community-Based Intervention Targeting Type 2 Diabetes and Its Risk Factors in a First Nations Community. *Front. Endocrinol.* **4**, (2013).
9. Gittelsohn, J. *et al.* Developing diabetes interventions in an Ojibwa-Cree community in northern Ontario: Linking qualitative and quantitative data. *Chronic Can* **16**, 157–64 (1995).

10. Hanley, A. *et al.* The Sandy Lake Health and Diabetes Project: design, methods, and lessons learned. *Chronic Can* **16**, 149 – 56 (1995).
11. Tobe, S. W., Maar, M., Roy, M. A. & Warburton, D. E. R. Preventing Cardiovascular and Renal Disease in Canada's Aboriginal Populations. *Can. J. Cardiol.* **31**, 1124–1129 (2015).
12. Gates, M. *et al.* Physical Activity and Fitness of First Nations Youth in a Remote and Isolated Northern Ontario Community: A Needs Assessment. *J. Community Health* **41**, 46–56 (2016).
13. Gates, M. *et al.* A Pilot School Sports Program in a Remote Canadian First Nation: Evaluation of Process and Outcomes. *Health Behav. Policy Rev.* **3**, 123–135 (2016).
14. Reeds, J. *et al.* Dietary Patterns and Type 2 Diabetes Mellitus in a First Nations Community. *Can. J. Diabetes* **40**, 304–310 (2016).
15. Khan, S. M. Critique of a Community-Based Population Health Intervention in First Nations Community: Public Health and Cultural Anthropology Perspectives. *Rev. Interdiscip. Sci. Santé - Interdiscip. J. Health Sci.* **6**, 52–61 (2016).
16. Gates, A. The Diets of On-reserve First Nations Youth: An Exploration of the Factors Associated with Healthy Food Choices and the Impact of School and Community Programs. (2016).
17. Mansuri, S. *et al.* Traditional foods and 25(OH)D concentrations in a subarctic First Nations community. *Int. J. Circumpolar Health* **75**, (2016).
18. Theodoratou, E., Tzoulaki, I., Zgaga, L. & Ioannidis, J. P. A. Vitamin D and multiple health outcomes: umbrella review of systematic reviews and meta-analyses of observational studies and randomised trials. *BMJ* **348**, g2035 (2014).

19. Harris, S. B. *et al.* Major gaps in diabetes clinical care among Canada's First Nations: Results of the CIRCLE study. *Diabetes Res. Clin. Pract.* **92**, 272–279 (2011).
20. Bhattacharyya, O. K. *et al.* Challenges to the provision of diabetes care in first nations communities: results from a national survey of healthcare providers in Canada. *BMC Health Serv. Res.* **11**, 283 (2011).
21. Bhattacharyya, O. K. *et al.* Providers' perceptions of barriers to the management of type 2 diabetes in remote Aboriginal settings. *Int. J. Circumpolar Health* **70**, 552–563 (2011).
22. SLFNHA. Sioux Lookout First Nations Health Authority :: History. Available at: <http://www.slnha.com/about/history/>. (Accessed: 8th July 2016)
23. SLFNHA. The Anishinabe Health Plan. (2006).
24. SLFNHA & Dignitas International. Community Health Worker Diabetes Project - Report from the Health Directors meeting, August 18-19, Frenchman's Head, Lac Seul First Nation. (2015).
25. Dignitas International. Aboriginal Health. *Dignitas International* Available at: <http://dignitasinternational.org/aboriginal-health/>. (Accessed: 8th July 2016)
26. *Resolution #13-07 on Community-Based Diabetes Strategy and Programming.* (2013).
27. Hurley, M. The Indian Act. (2009).
28. Hurley, M. The Crown's Fiduciary Relationship with Aboriginal Peoples. (2002).
29. Government of Canada, H. C. First Nations and Inuit Health - Main Page - Health Canada. (2004). Available at: <http://www.hc-sc.gc.ca/fniah-spnia/index-eng.php>.
30. Allan, B. & Smylie, J. First Peoples, Second Class Treatment. (2015).

31. Verret, I., Messier, J., Carr, L. & King, E. A Guide for First Nations in Ontario: Navigating the Non-Insured Health Benefits & Ontario Health Programs Benefits.
32. Government of Ontario. Ontario Drug Benefit Eligibility. *Ontario.ca* (2016). Available at: <https://www.ontario.ca/page/get-coverage-prescription-drugs#section-0>.
33. Government of Ontario. Assistive Devices Program. *Ontario.ca* (2017). Available at: <https://www.ontario.ca/page/assistive-devices-program#section-1>.
34. Government of Ontario, M. of C. and S. S. From Social Assistance to Income Security. (2012). Available at: http://www.mcass.gov.on.ca/en/mcass/publications/social/sarac/social_security_sarac.aspx. (Accessed: 10th March 2017)
35. Understanding the Health Care System. (2014).
36. Government of Ontario. Local Health Integration Network (LHIN). (2014). Available at: <http://www.lhins.on.ca/>.
37. Government of Canada, H. C. Benefits Information - Non-Insured Health Benefits - First Nations and Inuit Health Canada. (2005). Available at: <http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/benefit-prestatiion/index-eng.php>. (Accessed: 8th July 2016)
38. Government of Ontario, M. of H. and L.-T. C. Northern Health Travel Grants - Ontario Health Insurance (OHIP) - Publications - Public Information - MOHLTC. (2015). Available at: <http://health.gov.on.ca/en/public/publications/ohip/northern.aspx>.
39. Government of Canada, I. and N. A. Health Canada - First Nations and Inuit Health Programs - 2016-2017. (2015). Available at: <https://www.aadnc-aandc.gc.ca/eng/1448306812550/1448306892779>. (Accessed: 24th January 2017)

40. Health Data Branch, D. S. U. OHRIS Chapter 10: Community Support Services. (2016).
41. Sioux Lookout Meno Ya Win Health Centre. Sioux Lookout Diabetes Program.
NorthWesthealthline.ca (2016). Available at:
<http://www.northwesthealthline.ca/displayservice.aspx?id=140510>.
42. Sioux Lookout Meno Ya Win Health Centre. Centre for Complex Diabetes Care. Available at:
<http://www.slmhc.on.ca/centre-for-complex-diabetes-care>.
43. Health Sciences Centre - Winnipeg. Diabetes Education. *Outpatient Clinics - Children* (2017).
Available at: <http://www.hsc.mb.ca/patientsOCChildren.html#DiabetesEdu>.
44. Office of the Auditor General of Canada. *Access to Health Services for Remote First Nations Communities*. (Ministry of Public Works and Government Services, 2015).
45. Arksey, H. & O'Malley, L. Scoping studies: towards a methodological framework. *Int. J. Soc. Res. Methodol.* **8**, 19–32 (2005).
46. Merriam, S. B. & Tisdell, E. J. *Qualitative Research: A Guide to Design and Implementation*. (John Wiley & Sons, 2015).