Shookaawaapinewin Mamow Wicihiwewin: Anishinininowak Ka-ishimamitinentamowaac

Diabetes connections: Community member perspectives

Sioux Lookout First Nations Health Authority | August 2023

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SPECIAL THANKS

We would like to extend the most sincere gratitude to all the community members and community workers who contributed their time, thoughts, perspectives, and experiences to this work. Thank you to the Health Directors and Community Health Workers who helped us arrange these conversations, and seeing the value in participating. To the Community Health Workers (CHW) Diabetes Program at the Sioux Lookout First Nations Health Authority SLFNHA and our partners at University of Toronto, thank you for your support to conduct this work, as well as your ongoing support to improve delivery of care for community members living with diabetes in the region. This work was in part funded by the Canadian Institutes of Health Research (CIHR).

OWNERSHIP

The data in this report is owned by the individuals who contributed to this work, and stored by SLFNHA who is acting as a data steward on their behalf.

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Suggested Citation

Sioux Lookout First Nations Health Authority. (2023). Shookaawaapinewin Mamow Wicihiwewin: Anishinininowak Ka-ishimamitinentamowaac- Diabetes connections: Community member perspectives Report. Sioux Lookout, ON.

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Message from

JANET GORDON

Vice President, Community Health

The first time I read this report, I thought "This. This is why we do community engagement. This is why our work must be informed by community perspective. Anishinininowak ka-ishimamitinentamowaac." My involvement in health care delivery began at a young age, watching my mom, the Community Health Representative, deliver care in Kasabonika. We lived as a community, ate mostly Traditional food, and hardly saw any cases (if any) of diabetes. Since my training as a nurse and through transitions of various roles with the health authority, we've seen a steady increase in diabetes.

Despite working alongside the local hospital programs, Tribal Councils, and external organizations to enhance diabetes care delivered in community, we continue to see a rise in complications, amputations, and deaths due to diabetes in this region. And unfortunately, chronic conditions like diabetes often get overshadowed by other immediate or acute health conditions and tragic deaths.

We understand the need to work towards a better and more integrated system of care for community members that is sustainable, interdependent, interconnected, responsive, and above all, community focused. This report will help ensure that our work towards a regional diabetes strategy and beyond is informed by Anishinininowak ka-ishimamitinentamowaac. It helps us better understand how we must conceptualize systemic barriers, advocate for community services, and support communities to reduce the impacts of diabetes for individuals, their families, and the communities.

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ABOUT THIS REPORT

Data in this report were collected to inform submission of a research grant, Shookaawaapinewin Mamow Wicihiwewin (Diabetes Connections), in June 2022. Many community members who contributed to this work told us how they are often asked the same questions about diabetes health care to inform proposals, program activity planning, or grant applications. We wanted to ensure that the information they shared with us for this grant could remain in its own report that could be used: for future reference when developing or refining program activities; to help reduce the number of repeat questions we ask community members; and to honour the knowledge shared and perspectives gained in the development of this grant. Therefore, this report is written to include as much of the original words as possible to most accurately capture community voices. It was written for them, as well as for health care and service providers seeking to improve the care they deliver to the communities served by

This work was guided by three main questions:

01 How is diabetes care being delivered in community and what is desired?

02 What are the indicators of success? Or, how do we know we're doing it (support/programming for people living with diabetes) right?

03 How can SLFNHA teams CHW Diabetes Program, A , PCT , Research Program, etc.) better support community goals related to diabetes prevention and care?

To answer these questions, we met with a total of 29 people from 3 different communities served by SLFNHA who have a diabetes diagnosis, have a family member with a diabetes diagnosis, provide health care support to community members living with diabetes, or had perspectives about diabetes in their community that they wanted to share. invited community members to share, each of whom was provided a snack bag during the interview, as well as a $30 gift card. Two SLFNHA staff were able to meet with community members who shared stories in English, Ojicree, or both. With consent, these conversations were recorded, and then transcribed near verbatim by SLFNHA staff. When preferred, note-taking was used in lieu of recording, and in some cases, conversations were had without recording or note-taking. Translation of recordings was conducted by SLFNHA staff when needed. Four SLFNHA staff (including those who conducted interviews) reviewed transcripts independently, and then compared notes used to describe the findings summarized below.

To maintain anonymity, each community member was assigned a number. Numbers are included in brackets following quotations to illustrate the diversity of stories shared, as well as the frequency of similar perspectives, experiences, or thoughts shared. Otherwise, any identifying information has been removed, and results are presented in aggregate (i.e., not specific to one person or community).

All data from this project are stored For research related inquiries, please email research@slfnha.com.

INTRODUCTION

> Diabetes Complications
> Diabetes Health Care Service Delivery

SLFNHA published the Shookaawaapinewini Maawantoonikewin (Diabetes) Report in September 2022 to inform community leadership and health workers about the current diabetes and health status of community members. Overall, diabetes remains higher among all age groups of First Nations people in communities served by SLFNHA, where 14% of the population has a diabetes diagnosis, compared to 9.7% of the Ontario population (SLFNHA, 2022)[1]. Reported numbers found that among the communities served by SLFNHA:

> Almost half of the population between 60 and 69yr have a diabetes diagnosis
>
> 8% of adults with a diabetes diagnosis are between ages of 20 and 39yrs
>
> More than half of children and youth with diabetes received a diagnosis between the ages of 10 and 16 (SLFNHA, 2022)

1 Sioux Lookout First Nations Health Authority (2022). Shookaawaapinewini Maawantoonikewin - Diabetes Report. Sioux Lookout, Ontario

In conversations, community members confirmed that in their communities, the number of people living with diabetes is "going high. You can tell... there's over about 100 to 200 people. Even now, it's becoming an issue for the young people... more young people [are] getting diabetes. It tells you that something is not going right" (101), highlighting the spread of, and increasing concerns about, diabetes in community.

Diabetes Complications

One community member discussed a case of an Elder with diabetes who "got taken to the hospital" (101), supporting reported numbers of diabetes complications among First Nations living in community resulting in hospital visits at twice the rate of people living with diabetes elsewhere in Ontario (SLFNHA, 2022). Community members identified diabetes complications commonly experienced in community, including many amputations (100, 102, 115), ulcers and infections (115), hearing and vision (99, 105), and that overall, communities "have lost lots of people to diabetes complications" (100). Similar findings were reported from regional hospital data, in that:

> Foot and leg amputations among First Nations community members are about 5 times higher than other Ontario communities, and the rate of these amputations almost doubled from 2008 to 2019.
>
> Retinopathy (a disease of the retina that leads to vision impairment or loss) rates among First Nations community members remain higher than other Ontario communities (SLFNHA, 2022).

Reported numbers also found that rates of heart attacks and strokes remain higher among First Nations community members with diabetes compared to others living elsewhere in Ontario. Though these findings were not discussed among community members, denial of diagnosis, mismanagement of medications, unavailable health services, and underutilized health services were shared as speculations contributing to diabetes complications in community (99, 101, 102, 105, 115).

Diabetes Health Care Service Delivery

Current health care service delivery to First Nations communities in northwestern Ontario are provided by federal, provincial, and First Nations governed organizations, though jurisdictional ambiguity has resulted in inequities, service gaps, and fragmented services (SLFNHA, 2022). Primary care services for diabetes (such as bloodwork, appointments with physicians or nurses) are accessed via federally funded nursing stations for 24 of the 31 communities served by SLFNHA. The remaining communities access these services at hospitals or clinics in Sioux Lookout, Dryden, Red Lake, or surrounding municipalities. Emergency services are accessed at municipal hospitals by plane only for 25 of the communities, or by driving between 15minutes to 3hours for the remaining communities served by SLFNHA (SLFNHA, 2022).

Some of these hospitals or clinics may provide additional health services for people living with diabetes, including dietetics and foot care among other services. To provide access for remote communities, and to better support continuity of care, additional diabetes prevention and support is also provided by:

Tribal Councils and organizations (like SLFNHA) with mandates from communities to: support healing and wellness through culturally safe care; provide information and resources to support Traditional foods and active living; support teachings related to diabetes healing services; provide education and curriculum for young people regarding food knowledge.

Aboriginal Diabetes Initiative (ADI), which is a federally-funded and designed program that funds community-led programs and activities regarding diabetes care, prevention, and lifestyle support (SLFNHA, 2022).

These services vary among communities. They most often rely on targeted, short-term funding that cannot necessarily be guaranteed for subsequent years. Additionally, some communities do not receive enough funding to employ community-based workers. Community members noted concerns with the inconsistency in care, finding that it discourages people from adhering to treatment plans (114). Despite community members citing positive experiences with clinicians or health care to support people living with diabetes, many community members also recounted irregular or inconsistent follow up (99, 105), high staff turn-over (111, 114), inconsistent or changing medication treatment plan (114), and miscommunication between providers, at times resulting in unfilled prescriptions (113). Additionally, despite various providers, access to care remains limited, and community members cited low coverage and access to tools to support prevention of complication such as dressing changes (115) and testing strips (112, 115). While some communities can provide certain dialysis treatments in-community, most community members requiring dialysis must still relocate to municipalities to receive dialysis (105).

FINDINGS

When community members were asked what changes they'd like to see regarding care provided to people living with diabetes, they provided specific examples that were sorted into broader categories of program changes and system changes. They also provided guidance to, and wisdom in, looking back to go forward.

PROGRAM CHANGES

"Program changes" is used here to capture specific requests from community members that can be carried out by, delivered by, or incorporated into existing health care providers' ongoing diabetes health care and wellness programming. These requests were further described by those related to the ways in which primary care providers deliver care, content or curriculum related to diabetes education, content or curriculum related to nutrition education, and support group programming.

01 Primary Care Providers
02 Diabetes Education
03 Nutrition Education
04 Support for People Living with Diabetes

01 PRIMARY CARE PROVIDERS

Community members highlighted a need for increased prevention work among primary care providers, specifically identifying a need for more regular screening and preventative assessments, providing suggestions "like having a screening day once a month or something" (115) and "more screening... not just for young ones, but for all ages right up to 60 plus.. [offering] screening at the store entrance, and at the band office. In the summertime, we hold a lot of derbies for all ages, pow wows, dancing, [and] all ages participate in those events" (105), suggesting those may be good venues to host screening.

Community members highlighted the need for ongoing screening as an important aspect of diabetes prevention, especially considering

> **"It's really hard to get an appointment [with a physician] some of the time, because they're already booked up when they do come.** (113) **"**

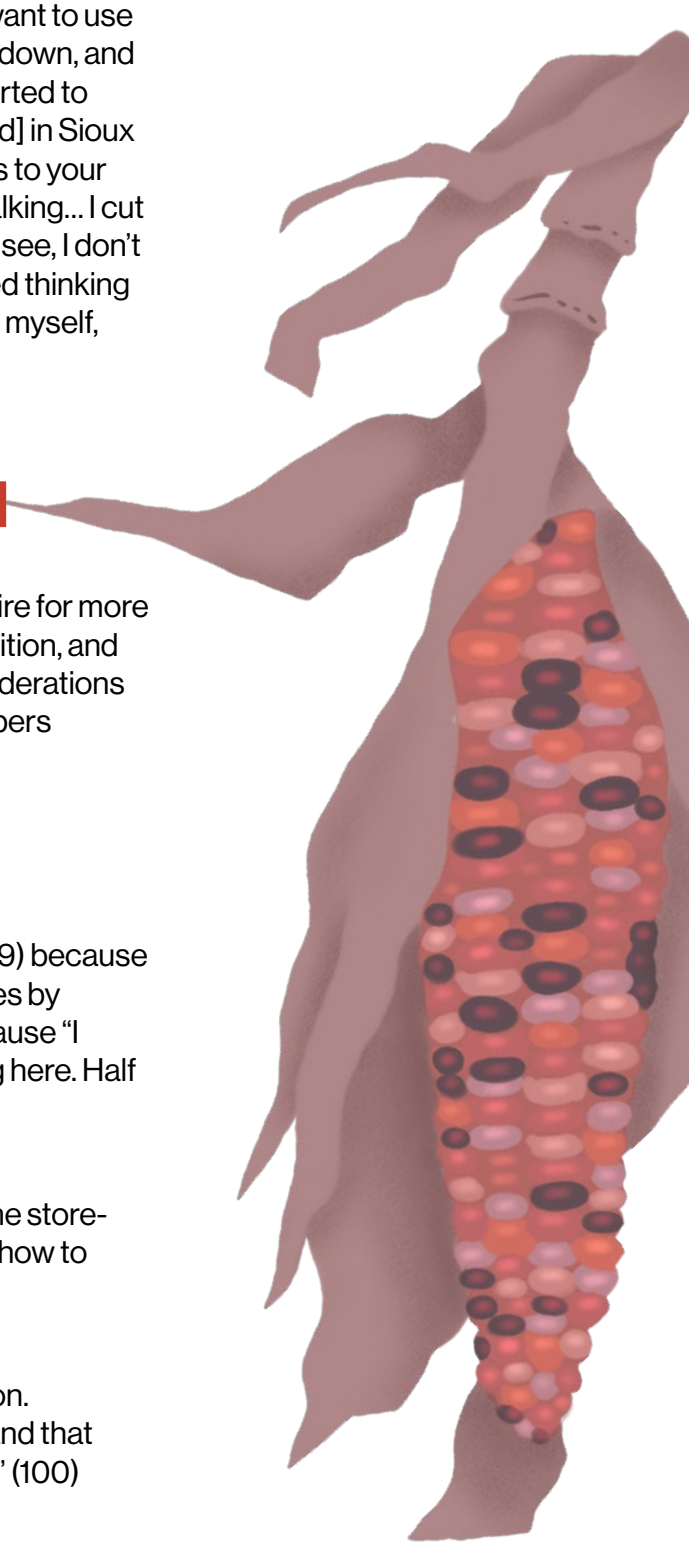
Other community members described only being able to secure an appointment with a physician when "things get worse for you... they always tell me 'wait till you see the doctor' then they put me on the list for the doctor but sometimes I don't even see the doctor, and I have to wait another month... My husband, I guess they never take him seriously when he says his chest is hurting, and they always say 'oh its gonna go away, just come back when you're feeling much worse" (102). In some cases, community members described feelings of being dismissed as a deterrent to seeking preventative appointments with physicians, highlighting a role for other health care professionals in diabetes prevention initiatives. "If we could get like, even Telehealth, with diabetes [workers], so that way we wouldn't have to go out, with work and kids, we wouldn't have to travel so far to see someone" (118).

02 DIABETES EDUCATION

Almost all community members requested more information and education in-community about diabetes and nutrition. Regarding diabetes education, community members wanted more knowledge and teaching about:

Diabetes	"What diabetes is, for more people to learn about the disease" (106), as well as early signs or "what to look for" (117)
Causes/Risk Factors	"I don't know what causes it. There's a lot of stress here, with what's going on, a lot of mental health and addiction issues in community, I don't know if those are factors or causes" (105)
Diabetes Management	"How they can start changing their diet, or what else they can do to start changing their lifestyle, like exercising, staying hydrated, eating more healthy foods, managing their sugar levels" (115).
Medications	Limitations or purpose of medications, as "when they're prescribed to us, 'they're going to help you', that's all they say. It's going to help, but it's not going to cure" (101), and "insulin management.. because I'm not sure if he's supposed to keep taking it still because it makes his sugars go down" (118).
Complications	About "what happens if you don't control your sugars" (121) because "we have lots of people with diabetes complications, and lots of amputations" (100), and the "long-term effects are very concerning" (117)

Reflecting on their own experiences, community members highlighted the importance of more education about diabetes in-community because "when I first found out I had diabetes, I didn't follow what the doctor told me to do. I didn't take medication at first... I didn't want to use them. About 10yrs ago is when my sugars were going up and down, and I was sick all the time, I started helping myself on my own. I started to look for something where I can learn about diabetes. I [learned] in Sioux Lookout from a dietician a lot about sugar. I asked what it does to your body. I was active at that time, playing broomball, baseball, walking... I cut out a lot of foods for the past 3-4years. I don't eat every food I see, I don't drink pop or use sugar. I don't smoke or drink alcohol... I started thinking about diabetes, but there was never a worker. I had to do it for myself, and my health." (99).



03 NUTRITION EDUCATION

Almost every community member discussed a need and desire for more knowledge and education in-community regarding food, nutrition, and healthy eating for people living with diabetes, as well as considerations about sharing this information. Specifically, community members wanted more knowledge and education about:

How food choices influence blood sugar levels

"What to eat, what not to eat, and how to portion food" (99) because "there's this one lady who said...she manages her diabetes by eating well" (102). Include information about alcohol because "I found out it has lots of sugar" (99) and "brew is a big thing here. Half of the brew being made is sugar" (120).

How to read nutrition labels

Because "a couple years ago I stopped eating some of the store-bought stuff and started looking at labels... teach people how to read nutrition labels" (99)

Traditional food guidance

Because "in the '60s to '80s, Traditional food was relied on. Everyone was healthy, and there was no diabetes" (111), and that "Traditional foods should be used more than store foods" (100)

Store shopping guidance

"What to buy at the store, like produce" (103) or "talk about food choices [by] going to the Northern and looking at packaging" (104).

Community members cautioned that this education must be:

Feasible in that "there's not a lot of options up here for buying healthy food, and when you do, it's really expensive" (113), especially considering many "families [have] a lot of kids, I'd say 3-4 kids, so cooking things has to be easier" (102)

Affordable because "food here is expensive" (102) and "people can't afford fruit, vegetables, and all of this other stuff" (114)

Relevant because "like for me, I have a bland palate. So a lot of the stuff they want you to eat... I can't eat it. It doesn't sit well in my stomach" (113)

Many people highlighted an interest in cooking classes or cooking education, with various ideas of how this could take place, including:

In-community "and get people from out of town [to] come and show...how to cook food on a budget" (114)

Online videos including from people living in community because "my mom, she could start cooking classes because she makes really nice soups. I told her to make videos on how to make these soups online like maybe [go] live or post them after... they're really good like veggies, meats, and chicken... most people just boil their foods" (102)

Live Tutorials "if [cooking classes] were live, people could come in person, [or] they could do it themselves at home too, like they could tell them to buy this and that [beforehand] and they could make it at home" (102)

Overall, community members had many ideas for how nutrition education could be shared across and within communities, suggesting ongoing efforts that combine or include opportunities to:

Learn from others living with diabetes (106), including personal stories and experiences (121)

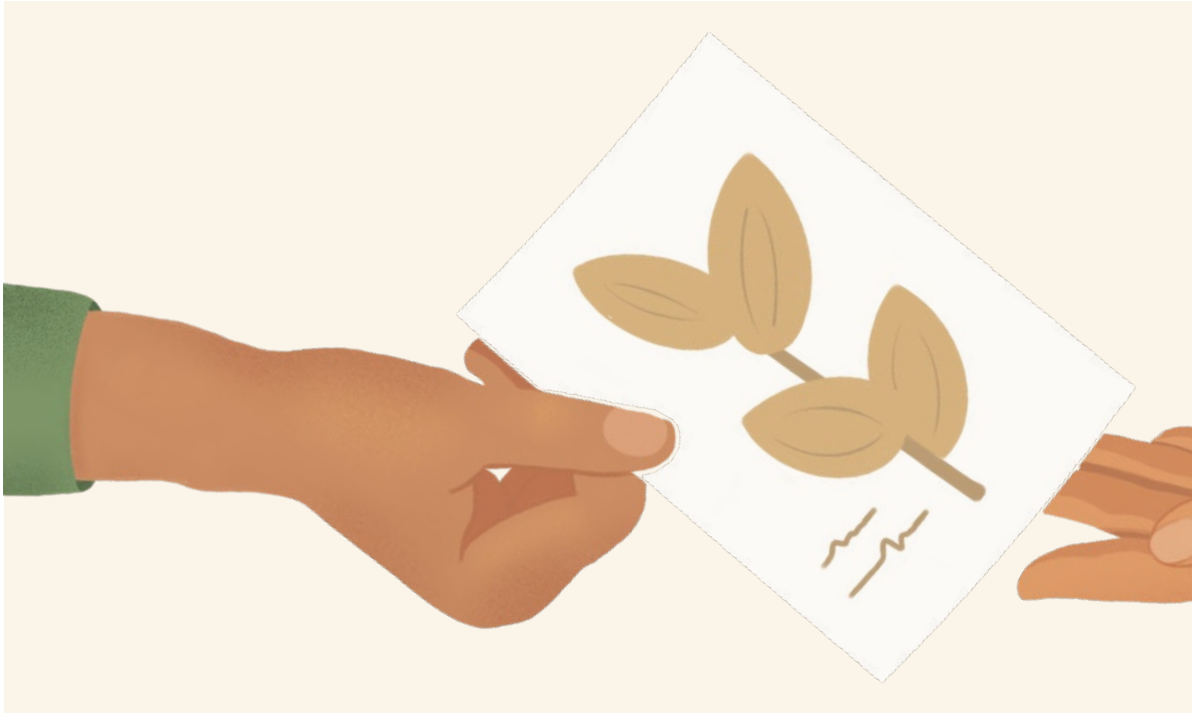
Learn through games, so long as explanations are provided throughout the games to support learning (116)

Integrate teachings about diabetes and healthy eating into schools, and tailored to children and youth (99)

Share recipes and relevant meal ideas, including information about what foods can help increase or decrease sugars (118)

People listed many ways that information could be shared, or education could be provided, to reach the widest amount of community members including in-person workshops (116, 101), on the radio (including the black radio and Wawatay; 99, 121, 101), Facebook (101), and pamphlets (primarily requested in Sioux Lookout health offices and hostels; 111, 121). Community members highlighted the value of including visual aids, pictures, and videos to support teachings (106), and hoped to see a list of resources with ordering/accessing information because "we lack resources [and] we need to know where we can get different resources, like from SLFNHA, [Tribal Councils]... we need to know where we can purchase different items. There's always change of staffing that we have to keep up with... we need more visibility in our communities" (116).

"There's always change of staffing that we have to keep up with... we need more visibility in our communities."



04 SUPPORT FOR PEOPLE LIVING WITH DIABETES

Community members recounted their diabetes diagnosis, and that "I was just told I was diabetic" (101) and that "some people are so terrified of getting [diabetes]" (118) because it's perceived "like a death sentence" (118).

Community members requested more support for people living with diabetes, and provided different examples of what this support could look like. "Maybe having a group gathering where we can discuss with other people... share their stories and have a group discussion, how they deal with [diabetes] or what [symptoms] they deal with daily" (114) so that "we could learn from each other" (106).

GROUP SUPPORT

Group support was discussed by many different community members, "like what they do in AA meetings. How things are going and how they manage their sugars" (121). People thought group sessions or workshops could be led by "someone qualified enough that can work with people with diabetes" (121), but also "it would be really good to have somebody who has diabetes who's doing well with their disease to speak openly, maybe even lead a cooking class for example, lead a walking group, or activities, even just getting together and doing a craft" (104). This type of support was highlighted as potentially very helpful, because "I'd rather hear something positive. That is, hope that you [can] have a better life when an individual has diabetes... rather than say, this is how many months you're going to be healthy if you don't do this" (101).

> **“Motivation from somebody is what helps... I try to let them know that they can do it. They can start with little steps to start going on the journey to managing their diabetes.”**

Community members also identified a need for sessions that educate “families or the person who has been diagnosed [for] how the families can help their family member who’s been diagnosed, and to help them manage their diabetes” (115), in part because “some people are kinda shy that they have diabetes. They don’t want to tell people. They find it discriminating, I guess” (114).

One person found that “motivation from somebody is what helps... I do try to let them know that they can manage their diabetes. Even the ones that put themselves down [and say] they can’t do it. They talk about their weight, their image... I try to let them know that they can do it. They can start with little steps to start going on the journey to managing their diabetes” (115).

GROUP ACTIVITIES

Group activities were highlighted as an opportunity for knowledge and information sharing in a good way that could be engaging. For example, many people suggested running little programs or competitions to “try to have people moving and getting them to stay healthy, stay fit” (115) such as “having a walking club” (104) or “a walking program...measure steps” (116). “Maybe do like a monthly weight loss challenge or something. Just to push people to be more active” (102).

Even though “we have to walk on the road if we want to go for a walk. We have these side trails but they don’t last very long... [and] it’s hard for people to go out with the dust from driving like that” (102), community members still thought it may be helpful to encourage “walking and doing stuff at their house to keep themselves [active], like decluttering their homes, cleaning up their yard, all that stuff” (115).

In addition to many examples of program changes needed for people living with diabetes, community members strongly identified many system changes that are required to have a true impact on diabetes in community, specifically identifying food systems, health care access, integrated health systems, and resources in community.

SYSTEM CHANGES

Community members highlighted challenges to diabetes prevention, care, and management due to barriers beyond health programming. “System changes” is used here to capture these challenges and barriers, and are further grouped into those related to food systems, health care access, and resources (both human resources and infrastructure) in community.

01 FOOD SYSTEMS

Almost every community member discussed the ways in which the current food system directly impacts management of diabetes, specifically regarding food cost, quality, and availability, and ultimately, the specific impacts of food insecurity in community. “When we look at the healthy meals, it costs money.

> **“How can you promote healthy meals when you can’t afford it?** (101) **”**

“Food is expensive here” (114), and in fact, many people found that “there’s not a lot of option up here for buying healthy food. And when you do, it’s really expensive. Fruits and veggies are horrendous at the Northern Store” (113). The cost of food was discussed as a challenge when “this dietician, they said they’ll teach me how to eat, but food is expensive, I have to do it myself. And I have to eat with my grandkids” (113), highlighting the prevalence of intergenerational living and “families with a lot of kids” (102).

"When you look at prices here, it becomes an issue. Maybe you have enough money for Bannock and klik" (101), because

> **"I bought $80 worth of fruit and vegetables, and it came up to only two days. (102)"**

When asked what support for people living with diabetes would be desirable in an ideal world, 1 community member said "just affordable fruits and vegetables" (102).

In fact, community members found that "it's pretty hard to get the right [foods] from the store" (121) because of high prices, but also because "there's a lot of bad stuff there. I'd rather see healthy stuff like vegetables, fresh ones, fruit. The drinks are mostly sugar. Even in the local shops" (105). "Mostly, it's all processed food. Like fast food. We don't really have fibery protein stuff. So people kind of just do what they can to manage their diet" (115).

In addition to lack of access to healthy foods and high costs, community members also found that "there's mold on the bottom of your strawberries. The quality and quantity are far and few between" (113).

> **"Often by the time fruits and vegetables get here, they've already gone bad..."**

"...like bananas. Sometimes they're already brown by the time they get here. Fruit is soft and brown... and whatever is fresh, people race to the store to grab what they can" (115), meaning that not everyone "has a chance to get what they need" (115).

Given that "the cost of living up here is very high... you're very limited to what you can buy. How can we effectively manage [or] control our diabetes?" (101). While diabetes workers (e.g., CHWs, educators, dieticians, ADI worker) can adapt programming to ensure diet and food suggestions are informed by community store prices and the reality that many "people [living in community] have so little money" (101), efforts are required by advocacy and governmental groups to address food security in remote First Nations communities in northwestern Ontario.

> **"The cost of living up here is very high... you're very limited to what you can buy. How can we effectively manage [or] control our diabetes?"**

02 HEALTH CARE ACCESS

Program Changes

> System Changes

Community members discussed access to health care, referring specifically to both the type of care that is (or is not) available in community, and the ways in which care is accessed. For example, community members discussed how dialysis is most often accessed after moving out of community and residing in municipalities that offer treatment, though "they get lonely out there and they want to come back" (101), or "a lot of people go out, get lonely, and die, especially the older people"
(105). Additionally, "when they can't come home from the hospital, or they have to relocate, another challenge is looking for a place [to live]. Especially if they need a walker or they're Elders, it's hard to find homes for them [...] because they need a ramp or elevator" (105) highlighting the challenge of finding accessible housing, as well as the impact of often needing "to pay first and last month [rent] if they find something" (105).

Community members discussed that in cases where dialysis is accessible in-community, "there's not much support here for them. It's mostly the family members that help with the supplies. It's a lot of work, especially when it's -50oC" (105) because family members must pick-up supplies from the airport, and then load them into "the back of a pick-up truck, but they need to stay warm" (105). Despite access to dialysis in-community supporting people to receive care in community, the logistics and challenges endured by patients and caregivers must be considered when discussing access to health care in community.

PREVENTION TOOLS

> Prevention Tools

> Traditional Medicine

> Community Nurses

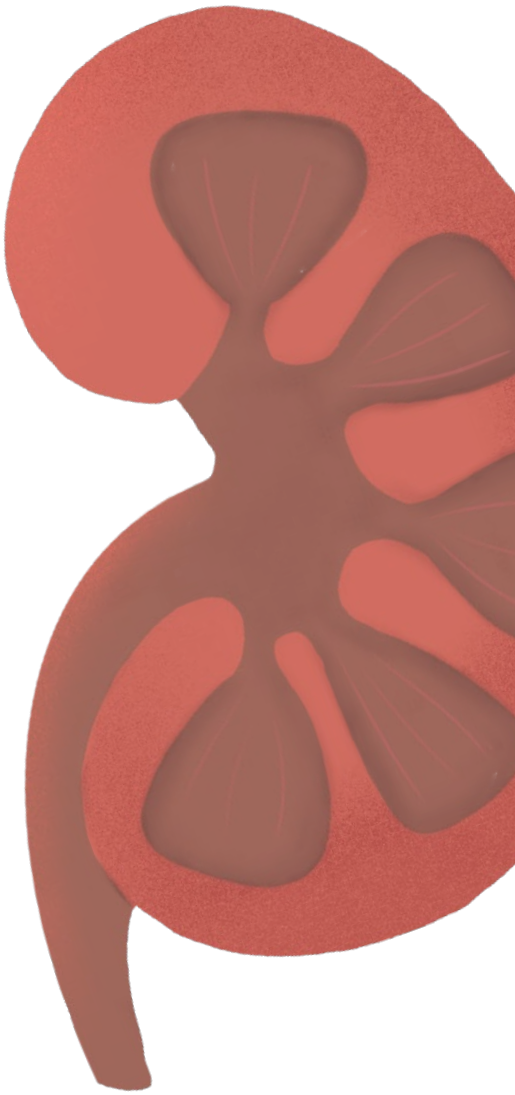
Prevention tools were discussed by 3 community members who highlighted the usefulness of flash glucose monitor systems. "I got the new Libre in my arm now, and it's a lot easier. I don't like to poke myself... I was really scared of needles, and poking myself, I couldn't do it. So maybe making these more accessible for the community" (113). Other community members highlighted the importance of learning "how to check their blood sugars. That's a big part of the managing part for us. You don't have to poke your finger. There's something here (pointing to arm) they put in there that reads their blood glucose. I don't know how they work" (105) and the importance of these readers for the younger generation who "like those sensors because they're easier for people to use" (118). However, insurance coverage for flash glucose monitors remains limited to those who meet specific insurance criteria[2], limiting access for many community members.

In fact, 1 community member discussed looking at grants for "funding for yourself, if you're spending money on buying your [testing] strips yourself, which I normally do ... because the government [insurance] right now only gives you 200 strips a year" (112), where strips are used for people to test their blood sugar.

2 https://www.sac-isc.gc.ca/eng/1578079214611/1578079236012#s23-04-a1

TRADITIONAL MEDICINE AND KNOWLEDGE

Many community members also expressed interest to increase access to Traditional Medicine and Knowledge that can support treatment and management of diabetes in their community. Community members identified that while Traditional Medicine "doesn't cure it...I know there's some medicine that our own Medicine Men use in terms of control... we use that sometimes, it helps to a certain level" (101). Regarding diabetes management, community members were interested in Traditional:



Medicines As some people found that "taking Traditional Medicine and all that stuff works for me. But it's pretty hard to get all that stuff" (121), identifying an interest in Traditional Medicines "instead of using all kinds of medicine, Western medicine" (116)

Foods In the form of "updated Traditional food guide" because when "Traditional food was relied on, everyone was healthy and there was no diabetes" (111)

Knowledge Because "there was a lady that used to come here... she talked quite a bit about different plants. She used to take people out... there are more people using Traditional Medicines now [but] we need someone that has the knowledge. We need someone that will kind of lead the program" (116). Similarly, "we would like to see more land-based teaching and more use of Traditional medicines" (111)

COMMUNITY NURSES

When discussing the ways in which care is accessed, community members described a need for information about services that they can access directly, without needing referral or triage from the Nursing Station first. At times, community members felt that "there isn't anywhere to call sometimes. Which person do I call? There is only the nurse" (106) and that "we lack resources. I think we need to know where we can get different resources [...] we need support from different organizations" (116).

Supporting community members to access care on their own may also support concerns from community members who felt "it hard to trust nurses [because] they're just gonna send me home anyway" (102). Supporting delivery of and access to information, knowledge, and education about diabetes may also ease community members' concerns when "nurses in the community that come in, they give you different information... they'll lower my dose, and another one will jack it all the way up. There's no consistency with them... Randomly they'll tell you this and that... it's always different from each nurse in the community" (114). This often led to community members discussing the need for additional resources in-community.

03 RESOURCES IN COMMUNITY

Community members identified that "one diabetes worker doesn't cut it. Two to three would be ideal. There are currently over 80 clients. It's unrealistic for one person" (111) to provide support, services, and education to the entire community. Having a "diabetes team [in-community] would be helpful" (103), as community members highlighted various healthcare professionals involved in diabetes care. Specifically, community members thought it would be helpful to have community-based diabetes care teams that includes:

Foot Care "is being requested" (111) including "the person who cuts the nails" (106), because "there's a really long list [for] foot care" (118), "toes get amputated" (115), and "having a foot infection scares him because of his diabetes, because he'll get scratches on his feet and is scared that they won't heal" (118).

Dietician because "from a dietician, I learned a lot about sugar" (99) and they can "teach you how to eat" (101) and "how to portion food" (99). Dieticians accessible only from outside of community has meant that "they check up on you every two to three months" (101) but that people wanted "more communication and [increased] frequency" (113).

Diabetes Educator that resides in community could support diabetes prevention through delivery of "workshops relating to diabetes" (116) or "diabetes education in the schools" (111) to provide access to "better awareness in the community... what can be done for people with diabetes, and how to manage it" (121) as well as "about how dangerous diabetes can be if someone doesn't look after themselves" (121).

Medication Counselling both to help explain purpose and dosage of medications prescribed, and to support people living with diabetes who have challenges accessing medication, because "they get mad at me when I don't take my pills, but how can I take my pills if I don't get them" (114) when "I call the pharmacy...and they said they haven't gotten [my prescription] yet... he hasn't sent it to the pharmacy" (113).

Mental Health Counselling was requested for "anybody who wants to get counselling for people that have diabetes" (121) because "all I was told was 'you're diabetic' and then the nurse on the phone started giving me medication" (113). Having "even just a counsellor to talk to, to have that outlet" (113) would be helpful.

Some community members identified existing health workers in their community that they found helpful and supportive, including an Aboriginal Diabetes Initiative (ADI) Worker and a Community Health Worker[3]. However, these positions vary between communities in that very few communities served by SLFNHA have both or either of these professionals, and the longevity of these positions in community depends on short-term funding sources from either the federal or provincial sources, respectively.

Having a team of workers hired in community and who reside in community may improve relevance of programming, and improve access to routine care. This is important, given that some community members found that "I'm supposed to get assessed and now I never got assessed for one whole year, so I just didn't bother taking my pills no more. [Diabetes] is not really properly managed, and that discourages people that live with diabetes" (114).

Others similarly recalled how "there were people that were missed that were never really followed up regularly, like three or five years. I think we need to assist them" (105) including "foot and eyes. They really should be monitored for each person with diabetes" (105) because right now, "by the time they hit an optometry check, I know one guy who got recently [diagnosed with] diabetes, and already has problems with their eyesight" (105). Community members noted the importance of wrap around services for people living with diabetes, and the current lacking access to these health professionals, including "physio. I haven't had physio. Long ago I had physio, but not recently" (119), that could otherwise support overall wellbeing of community members living with diabetes.

Community members also stressed the importance of integrating community-based diabetes workers among health systems. "You can't just hire someone and go. We have to focus on helping each other" (101), in that programs and organizations aimed at supporting people living with diabetes cannot work in isolation, and must coordinate together.

In fact, many community members wanted to see integration of diabetes education and knowledge sharing in community schools and curriculum (111), because "we need more awareness, especially with our kids" (100).

> **"Diabetes is "becoming an issue for the young people... more young people [are] getting diabetes. It tells you that something is not going right.... there has to be more education." (101)**

As well as supporting access to healthy food options. While "the school used to have a healthy breakfast program, I'm not sure why they stopped, but I would like to see it come back" (99) as this program could be an applied way of supporting both education about and access to health eating.

3 Program operated by Sioux Lookout First Nations Health Authority via provincial funding

To support the success of community-based diabetes care teams, community members highlighted the importance of "training needs. We got people. We hire people and they don't know where to go. They don't know how to start the process. That's important for training initiatives... When we hire somebody, we just hire them, and be ready to go... they need to be taught the basics on how to function in that role" (101) because often "those people lack training" (116), which can influence worker confidence, delivery of programming, and staffing longevity.

The other resource requested by most community members was related to fitness and recreation. Though walking was identified as a common activity for people, 3 community members found "it's hard to walk in the community due to dust" (99), in some cases restricting walking times to early "in the morning or the evening" (105) when there's less dust "from the driving" (102).

As result, many people wanted "a place to workout" (118), most often a gym or workout room (99, 103, 115, 116, 118) that would have weights, treadmills, and stationary bikes because many people have "been wanting to workout, but we don't have stuff for him to use" (118). Because "there's crowded homes here... [there's] not a lot of

space to have equipment in there" (105), and so having "a space to do activities would be useful" (100).

Some communities have a gym or recreational areas, but community members found that sometimes, access is limited for the general public (113, 116), or space is limited so that "there's a whole schedule thing at the gym, and all those slots are usually taken. People can't just go there and workout if they want to" (118) because "the schedule is most of the time booked" (115). For these reasons, community members identified a "lack of space" (116), requesting access to both more equipment, and a place to workout with flexible hours (103, 118). Community members also suggested group fitness programming or activities, such as walking programs (100, 113, 116), organized sports (103), and general exercise programs (103, 105, 113, 116) to encourage "people moving and getting them to stay healthy, stay fit" (115).

In addition to organized fitness activities, community members also discussed the importance of promoting active lifestyles, where some people recounted personal experiences of lifestyle on diabetes management, and a need to look back on Traditional lifestyles in order to move forward towards healthy communities.

LOOKING BACK TO GO FORWARD

Some community members and Elders reflected on changes in community that have had profound impacts on lifestyle and overall community health.

For example, in discussing how "it's hard for people to go out [walking] with the driving and the dust" (102), one community continued to reflect that "there's been lots of vehicles coming into the reserve the past two years. There used to only be like 6 [trucks], now there's 50 or 60, and it's a small community... I've got a vehicle too, I think that's part of why I got diabetic, 'cause less walking, less exercising, like why not just drive there instead" (102).

Others shared how "this winter... not one single hockey and no broomball. There used to be hockey every night every year. A lot has to do with the technology. A lot of the kids now play the games like Minecraft... 20-30years ago, they used to have [hockey] games every evening" (105). In part, this could have been exaggerated due to the COVID-19 pandemic, where community lockdowns disallowed people from engaging in group activities, including hockey or sports, and at times restricted people from leaving their homes, which had "a significant [influence] on daily living in our community and programming" (111). However, community members have noticed changes in lifestyle that have had impacts on younger generations, whereby "on a Cultural Day, we're cooking all these Traditional foods, and they come up and ask 'where are the hotdogs?' We have to change that somehow" (101).

For some people, discussing food also included the ways in which foods are prepared and preserved. "In our family, we use a lot of Traditional food. Like moose, ducks, geese, and we try to cook them in a way that is helpful. Rather than frying them all the time... If there were additional programs... trying to promote a community where things can be stored. A freezer. How to preserve food longer. Those are the challenges. Those teachings have to be taught. Our Elders are depleting. Hardly any Elders around now" (101).

"There's a lot of change over the years when you look at the history of what our Elders used to do. They had a habit of planting potatoes and carrots. All these [vegetables] for a number of years. That sort of discontinued when we got a number of services [like] running water... You don't see any gardens [now]. But before, my grandfather had a garden. Other neighbours had gardens. Potatoes, all around this area. Now you don't see that. Now it's more readily bought at Northern Store. You just go there, but it's costly. Things are expensive" (101).

Community members have been "told to be more active" (101), and identify that "exercise is probably key to trying to control diabetes" (112), however only 1 person shared a personal experience of "when I go to my trapline, I'm always doing everything, right? Then my sugar always goes right down to 8 or 7, and it stays there till I come back...But then with all this happening, with lockdowns, kinda dragged me down after that. I didn't want to continue, because every time I wanted to go for a walk, they would tell me, 'you have to go home and stay at your house'. I used to walk a lot, and it helped keep my sugars down, but now I can't. Now [lockdowns have lifted] again, but I don't want to do it anymore because I'm too tired" (113).

Some community members discussed the importance of supporting people living with diabetes to deliver a message of hope, "that you're going to have a better life" (101) and that to do so may require "doing something together. That is changing too, because of the way families are. Families are not close knit anymore. Before as a community, we did some things together like a big family. It's different now. Families grow, and they do things [on their own]" (101).

RECOMMENDATIONS

Community members identified specific program changes that should be actioned immediately by respective care providers, and include:

01 Increase routine early screening and preventative assessments for diabetes

Make this accessible for young people, through adulthood, and include Elders

Consider frequency of screening clinics at once per month

Consider screening clinic at store entrances, band office, community derbies, social events, and gatherings (see more pg 11)

02 Increase public health and education about diabetes and nutrition

What is diabetes, causes and risk factors, management, medications, complications (see more, pg 12)

What foods influence diabetes and glucose levels, reading and understanding nutrition labels, Traditional food guidance, store shopping guidance (see more, pg 13-15)

Ensure recommendations are feasible, affordable, relevant (see more, pg 14)

03 Support development and inclusion of group session, activities, gatherings

To foster connection with others by sharing stories, experiences, challenges, and strategies for diabetes management

To support feelings of hope from those who are managing diabetes successfully

To share recipes and activities, as well as means to support family members who've been diagnosed with diabetes (see more pg 16-17)

Advocacy Recommendations:

04 **Advocacy regarding food systems**

05 **Advocacy regarding dialysis accessibility and support in community**

06 **Advocacy regarding flash glucose monitor insurance eligibility**

07 **Advocacy for funding for fitness and recreation spaces**

Design of diabetes models of care must consider:

08 **Community-based diabetes care teams**

> Must include multiple providers that could deliver foot care, dietetics, education, medication counselling, mental health counselling (see more, pg 22)
>
> Must be integrated with and a part of wider health system teams including physicians and nurses, and schools (see more, pg 23-25)

FINAL THOUGHTS

Community members who contributed to this work noted major changes across the last 2 decades regarding the number of vehicles, food sources, recreational activities, and overall changes to lifestyle that have had profound effects on communities. More recently the COVID-19 pandemic had stark impacts on lifestyles given public health and safety restrictions, but even before this pandemic, community members recalled changes in connection regarding the ways families work,
live, and interact. Diabetes care and programming cannot necessarily address the social structures within community that may have influence on overall wellbeing. But when discussing health strategies that intend to be integrated, relevant, and community focused, health programming planners do have a responsibility to consider integration of connection, community, and family.

Anishinininowak ka-ishimamitinentamowaac is important to health planning. As this report has outlined, community members are well aware of the very real barriers to programming and care that is planned on their behalf. Not only is it the responsibility of health organizations to learn and understand Anishinininowak ka-ishimamitinentamowaac, it is also their responsibility to document, share, and action the thoughts, reflections, preferences, and ideas shared.