



INSTITUTE OF
HEALTH ECONOMICS
ALBERTA CANADA

Diabetes care and management in Indigenous populations in Canada

A pan-Canadian policy roundtable

November 1, 2017



Background Report

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This background report was prepared for the roundtable hosted by the IHE, to provide a snapshot of the burden of disease and an overview of the costs of diabetes in Indigenous populations in Canada.

The roundtable was supported financially by Boehringer Ingelheim Canada. The views expressed herein do not necessarily represent the official policy of Boehringer Ingelheim Canada.

Acknowledgements

The Institute of Health Economics is grateful to:

- Dr. Lindsay Crowshoe (University of Calgary)
- Dr. Keith Dawson (University of British Columbia)
- Dr. Dean Eurich (University of Alberta)
- Dr. Malcolm King (Simon Fraser University)
- Dr. Braden Manns (University of Calgary)
- Dr. Angela Mashford-Pringle (University of Toronto)
- Ms. Lara McClelland (Alberta Health)
- Dr. Alex McComber (Kahnawake Schools Diabetes Prevention Project)
- Ms. Kari Meneen (Okaki Health Intelligence Inc.)
- Dr. Jeff Reading (Simon Fraser University)

The views expressed in this report are not necessarily of the Institute of Health Economics.

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Abbreviations

All abbreviations that have been used in this report are listed here unless the abbreviation is well known, has been used only once, or has been used only in tables or appendices, in which case the abbreviation is defined in the figure legend or in the notes at the end of the table.

CI	confidence interval
HbA1c	glycated hemoglobin
OR	odds ratio
RR	relative risk
SMR	standardized mortality ratio

Glossary

The glossary terms listed below were obtained and adapted from the following sources:

- *International Journal of Indigenous Health; National Aboriginal Health Organization Terminology Guidelines*
(journals.uvic.ca/journalinfo/ijih/IJHDefiningIndigenousPeoplesWithinCanada.pdf)
- *Diabetes Canada* (www.diabetes.ca/diabetes-and-you/complications)

Aboriginal Peoples – A collective name for all of the original peoples of Canada and their descendants. Section 35 of the *Constitution Act of 1982* specifies that the Aboriginal Peoples in Canada consist of three groups – Indian (First Nations), Inuit, and Métis. It should not be used to describe only one or two of the groups.

Diabetes (diabetes mellitus) – A chronic, often debilitating, and sometimes fatal disease, in which the body either cannot produce insulin or cannot properly use the insulin it produces. Insulin is a hormone that controls the amount of glucose (sugar) in the blood. Diabetes leads to high blood glucose levels, which can damage organs, blood vessels, and nerves. The body needs insulin to use sugar as an energy source. *Note:* throughout this report we examine the impacts of type 2 diabetes (see below), and use *diabetes* to refer to type 2 diabetes.

First Nations – A commonly preferred term to *Indians*. The term should not be used as a synonym for *Aboriginal*, as it does not include Inuit or Métis. The term generally applies to both Status and non-Status Indians.

Indigenous – A term that means *native to the area*. In the context of North America, its meaning is similar to *Aboriginal Peoples*, *Native Peoples* or *First Peoples*.

Inuit – A circumpolar people, inhabiting regions in Russia, Alaska, Canada, and Greenland, united by a common culture and language. There are approximately 55,000 Inuit living in Canada, primarily in the Northwest Territories, Nunavut, and northern parts of Quebec and

coastal Labrador. The *Indian Act* does not cover Inuit. However, in 1939, the Supreme Court of Canada interpreted the federal government's power to make laws affecting "Indians and Lands reserved for the Indians" as extending to Inuit.

Métis – A term used broadly to describe people with mixed First Nations and European ancestry who identify themselves as Métis. Note that Métis organizations in Canada have differing criteria about who qualifies as a Métis person.

Nephropathy – A kidney disease that is a serious complication associated with long-term diabetes. Over the years, high blood glucose levels and high blood pressure can damage the kidneys and prevent them from functioning properly or even cause them to fail completely.

Neuropathy – A long-term complication of diabetes. Exposure to high blood glucose levels over an extended period of time causes damage to the peripheral nerves (nerves that go to the arms, hands, legs, and feet).

Proteinuria – Urinary protein excretion of greater than 150 mg per day, which may be an early indicator of kidney disease.

Retinopathy – Changes in the retina at the back of the eye that can be caused by diabetes. There are a couple of different types of retinopathy that affect people with diabetes.

Type 2 diabetes – Occurs when the body cannot properly use the insulin that is released (insulin insensitivity) or does not make enough insulin. As a result, sugar builds up in the blood instead of being used as energy. About 90% of people with diabetes have type 2 diabetes. Type 2 diabetes more often develops in adults, but children can be affected.

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SECTION 1: Overview

Just 70 years ago, type 2 diabetes (herein referred to as *diabetes*) was rare in Indigenous peoples in Canada.¹ However, diabetes now affects a significant proportion of First Nations, Métis, and Inuit, and has risen to epidemic proportions in many communities.¹ The rapid spread of diabetes in Indigenous populations across Canada is especially concerning considering that Indigenous people are disproportionately affected by diabetes and experience higher rates of complications, hospitalization, and mortality in comparison to non-Indigenous populations in Canada.

Unchecked and unmanaged, there are systematic breakdowns along the entire care pathway for many Indigenous people with diabetes. As a result, care is often reactive and episodic,² with Indigenous patients experiencing comparatively high rates of emergency interventions and hospitalization, which are key drivers of healthcare costs for Indigenous people with diabetes.³⁻⁵

This report examines recently published literature (since 2000) to provide a snapshot of the burden of disease and an overview of the economic costs of diabetes in Indigenous populations. We explore factors contributing to the alarming rise of diabetes in Indigenous peoples across Canada and, specifically, characteristics influencing the effectiveness of care and management programs, ending with a brief description of effective diabetes care programs that have been implemented across Canada.

Although we aim to describe the burden and economic costs of diabetes in all Indigenous populations in Canada, there is a notable absence of published research on diabetes in Métis and Inuit populations. Subsequently, this report focuses primarily on First Nations populations in Canada.

The content contained in this background report provides a common foundation for discussions at an upcoming pan-Canadian policy roundtable being held in Edmonton, Alberta on November 1, 2017. The roundtable was sponsored through an educational grant from Boehringer Ingelheim Canada, and was developed in consultation with an advisory committee including: Mr. Mehmood Alibhai (Boehringer Ingelheim Canada), Dr. Lindsay Crowshoe (University of Calgary), Dr. Keith Dawson (University of British Columbia), Dr. Dean Eurich (University of Alberta), Dr. Malcolm King (Simon Fraser University), Dr. Braden Manns (University of Calgary), Dr. Angela Mashford-Pringle (University of Toronto), Ms. Lara McClelland (Alberta Health), Ms. Kari Meneen (Okaki Health Intelligence Inc.), Dr. Alex McComber (Kahnawake Schools Diabetes Prevention Project), and Dr. Jeff Reading (Simon Fraser University).

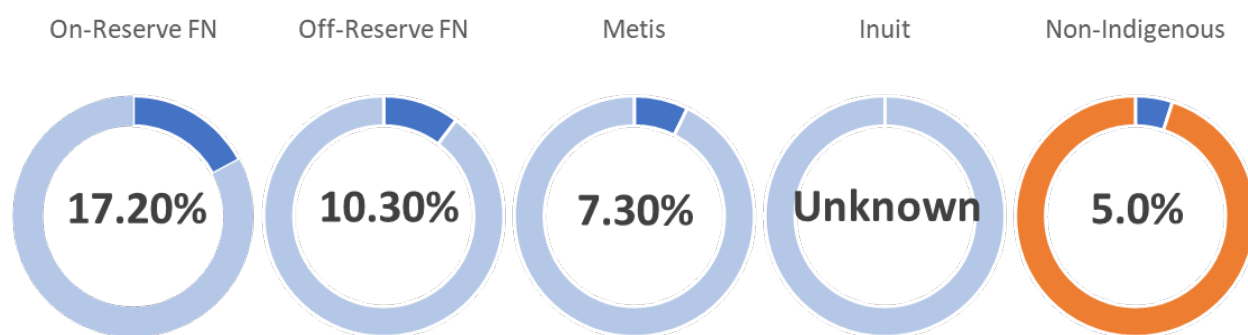
1.1. Disease burden

In Canada, diabetes affects approximately 6.9% (95% confidence interval [CI]: 6.5-7.2%) of the population,⁶ and has been projected to affect 11.4% of Canadians by 2025.⁷ However, in

comparison to the non-Indigenous Canadian population, Indigenous peoples in Canada, including First Nations, Métis, and Inuit, have disproportionately high rates of diabetes.^{1, 8}

Type 2 diabetes is a major concern that has rapidly emerged and has had devastating effects on the health and wellbeing of Indigenous peoples.^{1, 9} In national surveys, diabetes has been estimated to effect 15.3% (95%CI: 14.2-16.4%) of on-reserve First Nations people, 8.7% (95%CI: 7.0-10.4%) of First Nations who live off-reserve, 4% (95%CI: 3.3-5.6%) of Inuit, and 5.8% (95%CI: 4.4-7.3%) of Métis, with age-adjusted estimates of 5.0% (95%CI: 4.3-5.7%) for the non-Indigenous population, 17.2% (95%CI: 16.5%-19.0%) for on-reserve First Nations, 10.3% (95%CI: 3.4-17.2%) for First Nations living off reserve, and 7.3% (95%CI: 3.2-12.5%) for Métis populations.¹ Recent, age-adjusted rates have not been described for Inuit peoples in Canada.

Figure 1: National age-adjusted prevalence of diabetes by population



FN: First Nations

However, there is considerable diversity amongst Indigenous communities, and aggregate figures of diabetes rates, risk factors, and complications may be misleading.¹ Another challenge is the limitations of surveillance data.¹⁰ Reserve populations and homeless individuals are excluded from national health surveys such as the Canadian Community Health Survey (CCHS) and the Canadian Health Measures Survey (CHMS). Although the First Nations Regional Health Survey (RHS) captures data for First Nations living on-reserve and the Aboriginal Peoples Survey (APS) captures data on Indigenous people living off-reserve, there is limited data on Métis and Inuit people, and challenges persist in gathering representative data of First Nations individuals. Furthermore, health data for non-Status Indigenous peoples and Métis are not commonly available, and Aboriginal identifiers are rarely included in administrative databases.¹

In studies of individual communities, recent estimates of the prevalence of diabetes in First Nations range from 13.5%¹¹ to 29%,¹² or 2.25¹¹ to 3.5¹³ times higher than in the non-Indigenous population, with variation between communities and populations (see Table 1). In Métis communities, the prevalence of diabetes has also been shown to range from 4.6% (based on a study completed in Alberta¹⁴) to 10.4% (in Ontario),¹⁵ with age-standardized rates between 6.9%¹⁴ and 11.2%.¹⁵ In Inuit, the prevalence has been estimated at 5.1%.¹⁶

Table 1: Recent estimates of the incidence and prevalence of diabetes in First Nations, Métis, and Inuit from across Canada

Data source	Study details	Study population	Estimate(s)
Bruce et al. ¹² 2008	Data source(s): Community screening program Region: Sandy Bay First Nation, Manitoba	Study population: First Nations Ages: 18+	Prevalence: 29% had diabetes, 7% were new diagnoses; an additional 7% had impaired fasting glucose
Dannenbaum et al. ¹³ 2008	Data source(s): Physician diagnosed cases Region: Eeyou Istchee, Quebec	Study population: First Nations Ages: 20+	Crude prevalence: 17.3% Age-adjusted prevalence: 22.4% (3.5 times higher than Quebec age-adjusted prevalence of 6.4%)
Firestone et al. ¹⁷ 2014	Data source(s): Self-reported diabetes Region: Urban First Nation; Hamilton, Ontario	Study population: First Nations Ages: 18+	Self-reported prevalence: 15.6% (approximately 3 times the rate of Hamilton population, 95%CI: 11.2-21.1%)
Oster et al. ¹⁸ 2012	Data source(s): Administrative data Region: Alberta	Study population: Status Indian, Inuit (exclude Métis and non-Status First Nations) Ages: 0-20	Crude prevalence: 0.27% in Aboriginal population (no difference with non-Indigenous youth) Incidence rate: 0.59 per 1,000 population (not significantly different from non-Indigenous)
Oster et al. ¹¹ 2011	Data source(s): Administrative data Region: Alberta	Study population: Status Indian, Inuit (exclude Métis and non-Status First Nations) Ages: 20+	Crude prevalence: 13.5% (2.25 times higher than general population, 95%CI: 2.23-2.27) Incidence rate: 11.1 per 1,000 population (1.72 times higher than general population, 95%CI: 1.69-1.75)
Ralph-Campbell et al. ¹⁴ 2009	Data source(s): Census survey data; direct measures Region: Alberta	Study population: Métis Ages: 0+	Crude prevalence: 4.6% Age-adjusted prevalence: 6.9% Prevalence undiagnosed diabetes: 5.3% Prevalence of pre-diabetes: 20.3%
Shah et al. ¹⁵ 2011	Data source(s): Administrative data Region: Ontario	Study population: Métis Ages: 18+	Crude prevalence: 10.4% Age/sex standardized prevalence: 11.2%
Egeland et al. ¹⁶ 2011	Data source(s): Health measures survey Region: Northwest Territories, Nunavut, Nunatsiavut, Inuvialuit	Study population: Inuit Ages: 18+	Crude prevalence: 5.1% (3.8-6.4%)

CI: confidence interval

The high rate of diabetes in many Indigenous communities is staggering considering that diabetes was rare in Indigenous peoples prior to 1940.¹ However, even more alarming is that the rate of new diabetes cases in Indigenous populations continues to outpace those in non-Indigenous Canadians. In two recent studies of First Nations people in Alberta, the risk of

developing diabetes was estimated to be between 60%¹⁹ and 72%¹¹ higher in First Nations people than in non-Indigenous patients.

Adding to the epidemic is the rapid rise and high rates of obesity and other cardiometabolic risk factors associated with metabolic dysfunction, impaired glucose tolerance, and diabetes.¹ In addition, First Nations, Métis, and Inuit tend to develop diabetes at a younger age,^{17, 20-22} and have increased rates of complications, hospitalization, and mortality in comparison to the non-Indigenous population in Canada.^{10, 12, 13, 17, 20, 21, 23-33}

1.2. Diabetes-related complications

Untreated or improperly managed diabetes can cause extensive damage to the kidneys, eyes, circulatory system, and peripheral nerves, and prolonged mismanagement can result in kidney failure, blindness, and amputation.¹

In a study of First Nations youth diagnosed with diabetes before age 20, Dyck et al. (2014)²³ found that the risk of developing end-stage renal disease was 2.59 (relative risk [RR]=2.59, 95%CI: 1.11-6.04) times higher, and the risk of death was 2.64 (RR=2.64, 95% CI: 1.44-4.87) times higher for First Nations patients living with diabetes compared to non-First Nations people. Additionally, after 25 years, the cumulative incidence of end-stage renal disease was 12.3% for First Nations, compared to 4.3% in their non-First Nations counterparts.¹¹ Similarly, in another study conducted in Saskatchewan, the risk of end-stage renal disease was 2.66 (RR=2.66, 95%CI: 2.24-3.16) times higher in First Nations adults compared to non-Indigenous individuals.²⁴ Harris et al. (2011)¹⁰ also found that 55.1% of First Nations individuals diagnosed with diabetes had chronic kidney disease (range across communities: 26.0-86.0%), and 17.7% had a diagnosed eye disease including blindness, cataracts, glaucoma, retinopathy, or others (range across communities: 0.0-48.0%). Nephropathy was also highly prevalent in diabetes patients in Cree communities in Northern Quebec (53.3%), and nearly 25% of all patients had two or more diabetes-related complications.¹³

Table 2: Diabetes-related complications in Indigenous populations

Data source	Study details	Study population	Outcomes
Dyck et al. ²³ 2014	Data source(s): Administrative data Region: Saskatchewan	Population(s): First Nations Age(s): Diagnosed before 20	Risk of developing end-stage renal disease: HR=2.59 (95%CI: 1.11-6.04) Risk of mortality: HR=2.64 (95%CI: 1.44-4.87)
Jiang et al. ²⁴ 2014	Data source(s): Administrative data Region: Saskatchewan	Population(s): Status First Nations Age(s): 18+	Risk of developing end-stage renal disease: HR=2.66 (95%CI: 2.24-3.16)
Lowewen et al. ²⁵ 2017	Data source(s): Administrative data Region: Ontario	Population(s): First Nations Age(s): 18+	Risk of lower limb amputation in diabetic patients: RR=7.36
Harris et al. ¹⁰ 2011	Data source(s): Medical charts Region: British Columbia, Alberta, Saskatchewan, Manitoba, Ontario, Quebec, Newfoundland	Population(s): First Nations Age(s): 18+	Prevalence of chronic kidney disease: 55.1% Prevalence of eye disease: 17.7%
Dannenbaum et al. ¹³ 2008	Data source(s): Administrative data Region: Quebec	Population(s): First Nations Age(s): 10+	Prevalence of nephropathy: 53.3% Individuals with 2+ complications: 23.2%

CI: confidence interval; HR: hazard ratio; RR: relative risk

1.3. Hospitalization, access to care, and mortality

High rates of diabetes and diabetes-related complications such as neuropathy, retinopathy, nephropathy, macrovascular disease, and lower limb amputation in Indigenous populations have been reported across Canada,^{10, 12, 13, 27, 33} and the prevalence of these co-morbidities may result from delayed diagnosis or issues accessing effective treatment and care.¹² Specifically, studies have shown a high utilization of emergency care,^{26, 27} decreased access to multidisciplinary care teams and home care,^{21, 27} decreased access to treatments to prevent the emergence of complications,^{20, 27, 29, 30} low levels of screening for complications,^{10, 17} and increased rates of undiagnosed complications for First Nations people.^{12, 27}

1.3.1. Hospitalization

Across Canada, First Nations have higher rates of hospitalization and emergency department utilization for diabetes, which may indicate issues accessing effective outpatient treatment programs.^{26, 32, 34} In Ontario, the odds of developing an acute diabetic complication resulting in an emergency department visit or hospitalization was 1.8 times higher for adults with diabetes from First Nation's communities in comparison to diabetic adults from non-First Nations communities (odds ratio [OR]=1.84, 95%CI: 1.65-2.05).²⁶ Similarly, in British Columbia, Jin et al.³⁵ found that Status First Nations males and pregnant females were twice as likely to be hospitalized for diabetes-related illness than other non-Indigenous males, and that Status First

Nations females (non-pregnant) were three times more likely to be hospitalized than their non-Indigenous counterparts.

Comparable results were also found in Alberta. In Alberta, First Nations had higher odds of a diabetes-specific hospitalization or emergency department visit than non-First Nations populations at age 30 (OR=3.94, 95% CI: 3.11-4.99), and by age 80, the odds were 5.74 times higher in First Nations populations.³¹ In another study in Alberta, Oster et al.²⁷ found that diabetes-related concerns were responsible for 24% of all hospitalizations and emergency department visits for a sample of First Nations people with diabetes. Campbell et al. (2012)³² also found that First Nations and low-socioeconomic status patients were more than twice as likely to be hospitalized or to visit the emergency department for diabetes-specific ambulatory care sensitive conditions (ACSCs) than the general population.

"...most diabetes care tends to be reactive to clients seeking care rather than proactively in accordance with clinical practice guidelines. Many clients do not receive ongoing diabetes care and do not have a regular general practitioner who coordinates care."

Eurich et al. (2017)²

1.3.2. Access to care

Research has also shown that First Nations are less likely to receive guideline-recommended care, including measurement of glycated hemoglobin (HbA1c) and retinal screening,³² and similar findings have been reported across Canada. In an Alberta study, approximately only half (46%) and one-fifth (21%) of participants had recommended HbA1c testing and foot examinations, respectively.²⁷

Additionally, First Nations have been reported to have decreased access to home care²¹ and to multidisciplinary diabetes care teams,²⁷ which may contribute to fragmented and sub-optimal care and management for Indigenous individuals, as well as poorer disease outcomes. Studies have shown that, in comparison to non-Indigenous populations, First Nations have poorer glycemic control,³⁰ a greater risk of highly elevated glycemic levels (HbA1c>8.5%),²⁰ and decreased attainment of target HbA1c.²⁸ Descriptive studies have also reported poor management of comorbidities such as dyslipidemia, hypertension, high blood pressure,^{10, 29} and kidney disease.²⁷ Challenges in managing diabetes and complications can also be linked to variability across the country in terms of public and private insurance coverage for medications and supplies for those managing their diabetes. "People with diabetes need access to [appropriate and evidenced-based] medications, devices, supplies, diabetes education and care to effectively self-manage their condition. Without these, complications will increase and further strain our healthcare system. While all Canadians with diabetes should have comparable access to supports regardless of where they live, disparities continue to exist across the country."³⁶

In addition to barriers accessing care, many Indigenous individuals have poor access to screening programs for diabetes and related complications. High rates of undiagnosed diabetes and complications have been described.^{12, 14, 27} Oster et al. (2009)²⁷ reported that 23% of First Nations individuals living on-reserve had undiagnosed kidney damage or proteinuria, 22% had high cholesterol, 11% had undiagnosed foot complications, 9% had hypertension, and 7% had undiagnosed retinopathy. Another study also found that 8% of First Nations with newly diagnosed diabetes in Manitoba had evidence of neuropathy at diagnosis.¹²

1.3.3. Mortality

Diabetes-related mortality is also disproportionately higher in Indigenous populations.^{11, 23, 24, 35, 37} In Saskatchewan, two recent studies found that the risk of mortality was between two and three times higher for Indigenous people.^{23, 24} Similarly, in British Columbia, the risk of mortality was estimated to be between 1.5 times higher for Indigenous males (standardized mortality ratio [SMR]=1.5, 95%CI: 1.0-2.6), and 2.2 times higher for Indigenous females (SMR=2.2, 95%CI: 1.5-4.5), with Indigenous people also experiencing higher mortality from cardiovascular and renal disease.³⁸

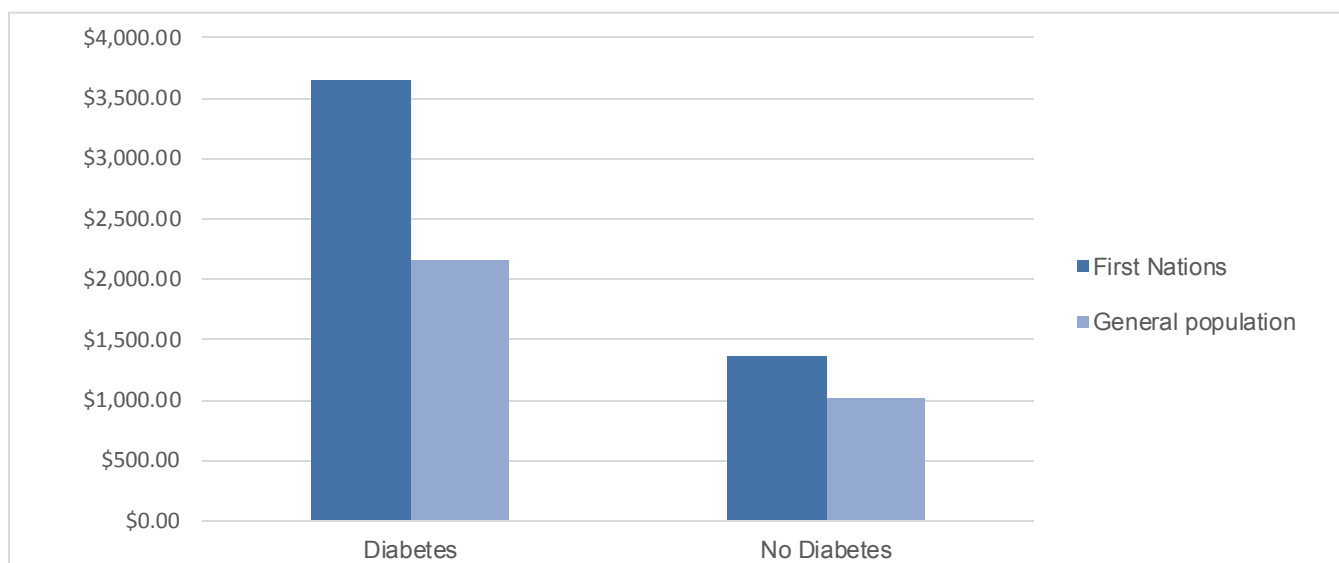
In Alberta, a longitudinal study examined annual changes in diabetes mortality and found similar decreases in mortality between Indigenous and non-Indigenous people.¹¹ While the annual rate of decrease in mortality was similar between the groups, diabetes mortality remained higher in Indigenous people at the end of the study, and, unlike non-Indigenous populations where there was a clear downward trend in mortality, an overall trend was not readily apparent in Indigenous populations.¹¹

SECTION 2: Economic Impact of Diabetes in Indigenous Populations

2.1. Economic impact

Despite the high prevalence and increased risk of diabetes, related complications, and mortality in Indigenous populations in Canada, few studies have examined the economic costs of diabetes in these populations. In one study conducted in Manitoba, the authors found that the excess prevalence of diabetes in Indigenous populations added 15.9% to total healthcare costs (\$7.4 million), and excess costs due to increased utilization added 14.6% to total costs (\$6.8 million).³ In their study, the rate of hospitalization was a key driver of costs related to excess utilization. First Nations people were 2.74 times more likely to be admitted to hospital than the non-Indigenous population, had higher rates of admission for complications, and had higher rates of procedures including amputations, dialysis, cardiovascular procedures, and eye procedures.³

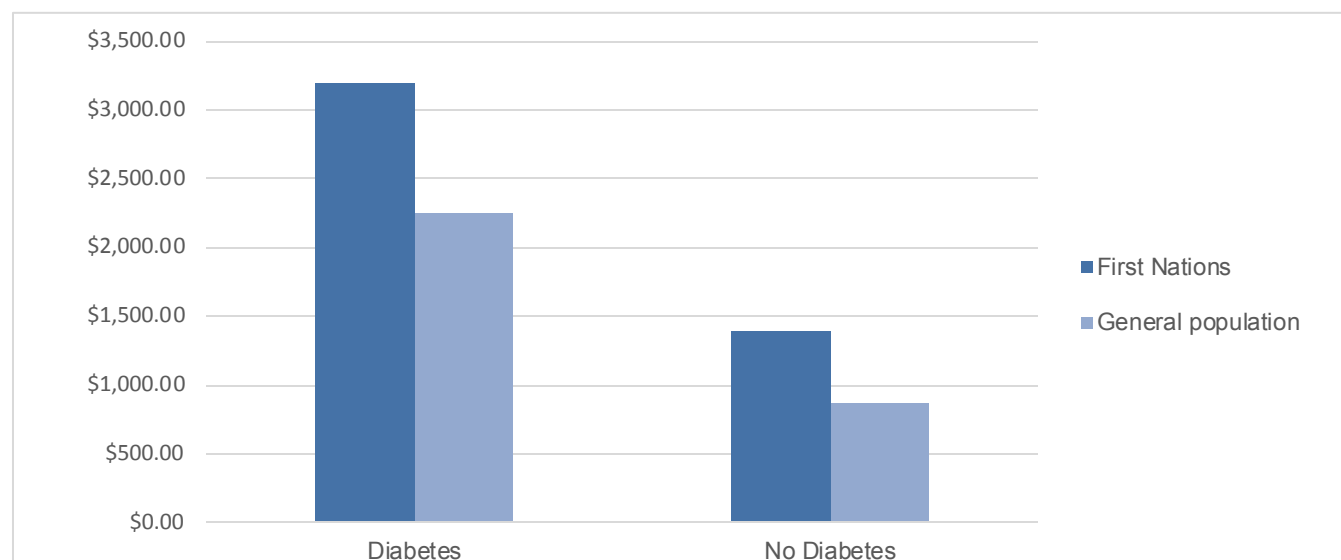
Figure 2: Estimated total per capita healthcare costs for First Nations and non-First Nations individuals with and without diabetes



Source: Jacobs (2000)³

Similarly, in a study of First Nations individuals in Saskatchewan, the authors found that the odds of hospitalization for First Nations patients with diabetes were 1.8 times higher in comparison to non-Indigenous diabetes patients, and 2.0 times higher than healthy, non-Indigenous controls.⁴ In addition, they found that per capita healthcare costs were 40% higher for First Nations individuals with diabetes in comparison to non-Indigenous diabetes patients (\$3,204 [95%CI: \$3,201-3,206] vs. \$2,257 [95%CI: \$2,256-2,258]), and expenditures were 266% higher in First Nations patients with diabetes than in non-Indigenous, healthy controls (\$3,204 [95%CI: \$3,201-3,206] vs. \$875 [95%CI: \$875-875]).⁴ Further, in First Nations populations, diabetes was associated with 2.3 times higher healthcare costs (\$3,204 [95%CI: \$3,201-3,206] vs. \$1,395 [95%CI: \$1,394-1,397]).⁴ The increased costs were attributed to high rates of physician visits, hospitalization, and dialysis.⁴

Figure 3: Estimated total per capita healthcare costs for First Nations and non-First Nations individuals with and without diabetes



Source: Pohar (2007)⁴

Table 3: Estimated total per capita healthcare costs for First Nations and non-First Nations individuals with and without diabetes

	First Nations, diabetes	First Nations, no diabetes	General population, diabetes	General population, no diabetes
Jacobs et al.³ (2000, Manitoba)				
Total per capita costs	\$3,656	\$1,359	\$2,169	\$1,011
Cost ratio*	1.00 (reference)	0.37	0.59	0.28
Pohar et al.⁴ (2007, Saskatchewan)				
Total per capita costs	\$3,204	\$1,395	\$2,257	\$875
Cost ratio*	1.00 (reference)	0.44	0.70	0.27

*Ratio compared per capita costs for First Nations without diabetes, General population with diabetes, General population without diabetes to: First Nations with diabetes

In another study from Saskatchewan, registered First Nations patients with diabetes had higher per-person mean costs for hospitalizations, physician services, and dialysis, compared to non-Indigenous diabetes patients.⁵ The authors also estimated the costs of diabetes complications and found that, in 1996, 54.9% (\$73.7 million) was attributable to hospitalization, and 36.4% (\$48.9 million) of healthcare expenditures for people with diabetes was attributable to major comorbidity.⁵

**1.3x**

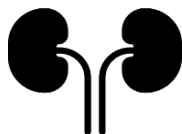
Average per person costs for hospitalizations were **1.3 times higher** in Indigenous patients

**1.1x**

Average per person costs for physician services were **1.1 times higher** in Indigenous patients

**0.7x**

Average per person costs for day surgery were **0.7 times lower** in Indigenous patients

**4.0x**

Average per person costs for dialysis were **4.0 times higher** in Indigenous patients

Data from Simpson et al. (2003)⁵

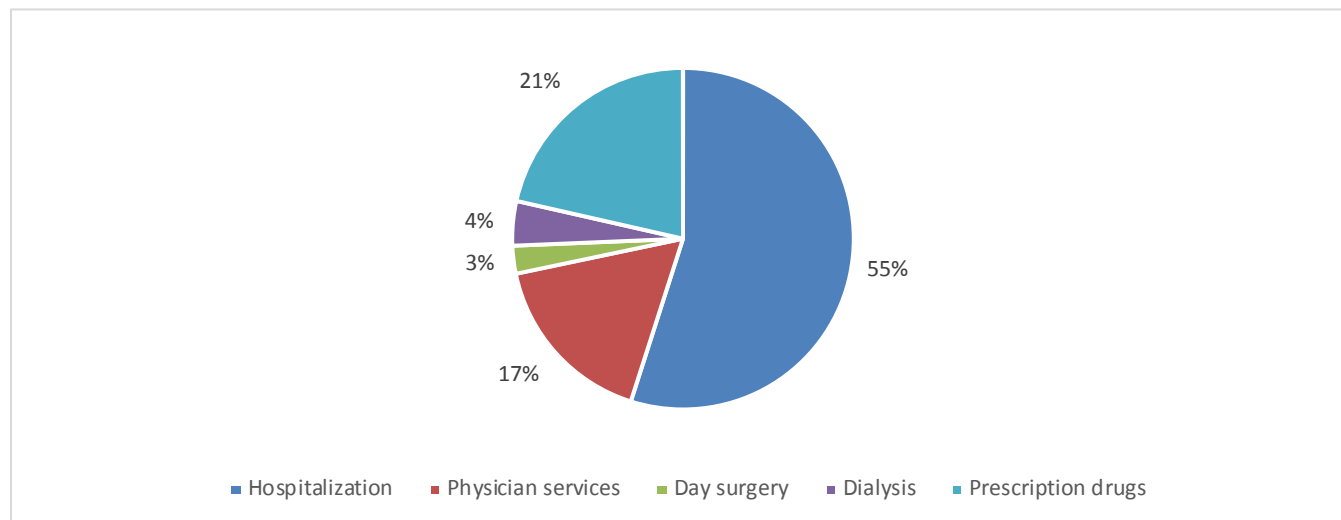
Lastly, in a study in Alberta, McBrien et al. (2013)³⁹ examined the impact of diabetes-related complications and glycemic control on the costs of care for diabetes. They found that costs increased with kidney dysfunction, proteinuria, and poor glycemic control.³⁹ Costs for patients with proteinuria were double the costs of patients without, and patients with inadequate glycemic control (HbA1c > 9%) had 20% higher costs compared with patients with good control (HbA1c < 7%). Costs were also associated with Indigenous status.³⁹

In First Nations populations, high rates of hospitalization, poor disease management, and subsequent high rates of complications are major drivers of excess costs, pointing to a need for improvements in primary, secondary, and tertiary prevention in these populations. Of the few studies of economics costs of diabetes in Indigenous populations, health services utilization (including hospitalization and procedures to treat comorbid complications) are key drivers of costs,^{3, 4} and efforts to not only prevent diabetes but also to support access to care and management programs that reduce the incidence of complications and inpatient medical services are likely to yield significant cost savings.

Notably, mobile screening clinics and telemedicine care programs have emerged as strategies to improve access to specialists and other care providers to support ongoing care and diabetes prevention for Indigenous communities in rural and remote areas. These strategies not only reduce costs for travel to urban centres for care,^{40, 41} but are also cost-effective alternatives to

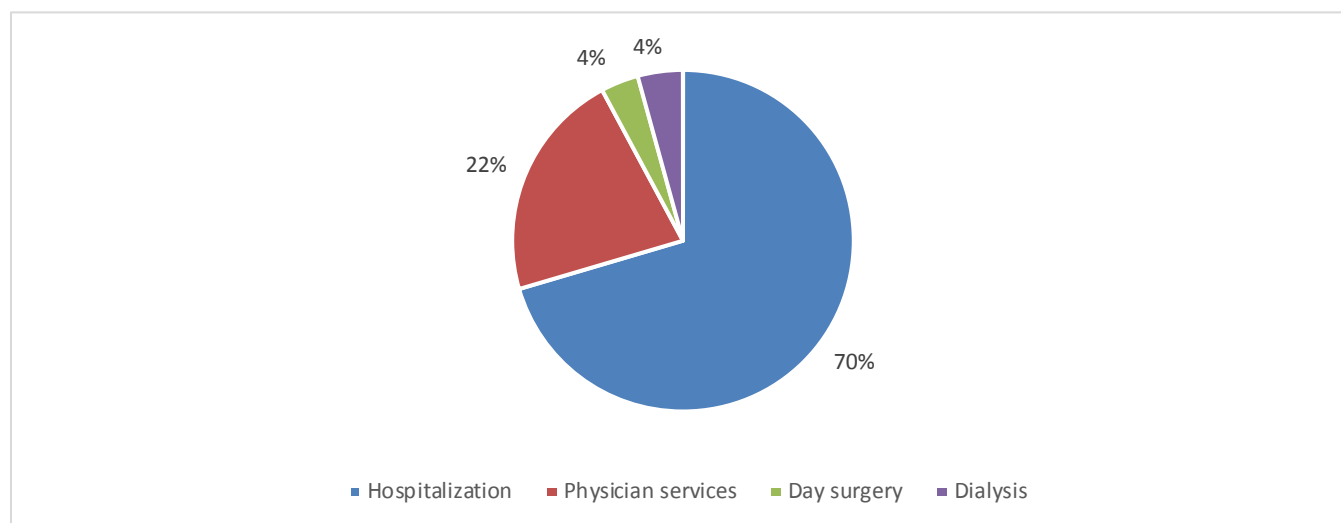
care that have resulted in reduced rates of complications and supported improvements in the quality of life for Indigenous diabetes patients.⁴²

Figure 4a: Diabetes healthcare expenditures in Canada, total population



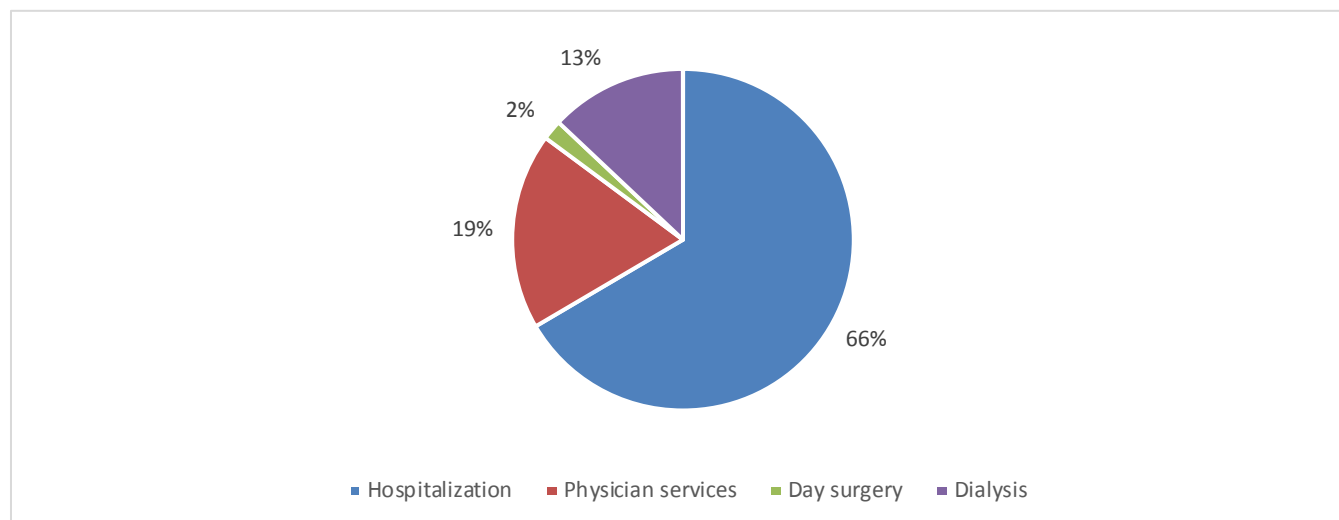
Source: Simpson (2003)⁵

Figure 4b: Diabetes healthcare expenditures in Canada, non-Indigenous population, excluding prescription drugs



Source: Simpson (2003)⁵

Figure 4c: Diabetes healthcare expenditures in Canada, Indigenous population, excluding prescription drugs



Source: Simpson (2003)⁵

SECTION 3: Diabetes Prevention and Management in Canada

Diabetes is a growing concern for many Canadians, but has had an especially pronounced impact on Indigenous populations over the last 70 years.¹ Indigenous populations have disproportionately high rates of diabetes, and debilitating complications and mortality associated with the disease.

The issue is incredibly complex, and heavily influenced by a mix of socioeconomic deficits, complicated by historical and ongoing cultural, social, political, and economic factors and processes that perpetuate social and health inequalities for Indigenous peoples.⁴³⁻⁴⁷ Not only do these factors predispose many Indigenous peoples to a multitude of inferior health outcomes, but they also impede access to effective treatment, support, and wellbeing.

Table 4: Determinants of health in Indigenous populations

Conventional DoH	Indigenous DoH	Other DoH with Indigenous-specific impact
Income	Colonization	Globalization
Social status	Connectivity to land	Racism
Poverty	Self-determination	Gender
Education	Historical trauma	Worldview
Employment		
Social supports		
Genetics		

Adapted from: King and McGavock (2017),⁴⁸ King et al. (2009),⁴³ Jacklin (2017)⁴⁵

DoH: determinants of health

Many of these factors are highly prevalent and influence care for Indigenous patients with diabetes.^{44, 45} For many patients, geographic isolation, physician shortages, high rates of healthcare worker turnover, and limited access to necessary supplies due to complex government funding impedes access to timely care.⁴⁵ Furthermore, these issues may exacerbate other Indigenous-specific determinants of health and perpetuate ongoing negative experiences with care that is perceived as inferior and not aligned with cultural beliefs.⁴⁵ Altogether, these factors may lead to avoidance of healthcare providers, increased mistrust of physicians, and resistance to other service providers which may limit the effectiveness of many health interventions and programs.⁴⁵

Clearly, the root causes of disparities between Indigenous and non-Indigenous peoples are complex and driven by a number of sociocultural factors. It follows that efforts to remedy these differences must address both the medical and nonmedical needs, and root causes of disease. For Indigenous peoples, the concept of health is defined holistically and much more broadly than just disease and treatment. Health incorporates physical, emotional, mental, and spiritual elements of life, and balance between these elements is essential to support a strong and healthy person.^{43, 49} The concept of balance also extends beyond the individual, to incorporate aspects of community, spirituality, land, and food, as aspects of health and wellbeing.⁴³

"Any effort to address the health disparities between Indigenous peoples and other Canadians must therefore attend to the relationship between colonization, inequality and health. Moreover, such efforts must also attend to the loss of cultural continuity and identity due to active suppression of Indigenous culture and knowledge, including Indigenous concepts of health and wellness as well as severe social and economic disadvantage. Many interventions aimed at Indigenous communities have met limited success in part because they have failed to account for local conceptualizations of wellness."

Rice et al. (2016)⁵⁰

Therefore, health promotion and prevention programs that fail to address these aspects, and the imposition of health services and stand-alone programs that treat individual symptomatic issues separately, are likely to miss their mark.^{43, 50-53}

To avoid these pitfalls and to deliver effective health services to Indigenous populations, there is a need to include communities in all stages of interventions, from design to evaluation.⁵⁰ In the 2013 guidelines for diabetes care in Indigenous populations, it was recommended that prevention programs should be initiated "in and by Aboriginal communities with support from the relevant health system(s) and agencies to assess and mitigate environmental risk factors such as: geographic and cultural barriers, food insecurity, psychological stress, insufficient infrastructure, and settings that are not conducive to physical activity."⁸ Community-developed programs take time, effort, and money, but serve to empower patients in their care journey and

to foster the development of culturally appropriate services and supports that meet the complex needs of patients and communities.^{43, 45, 51}

In Canada, numerous communities are involved in diabetes care programs that have evolved through effective engagement, leadership, and collaboration between Indigenous peoples, researchers, clinical professionals, and other community agencies. Still, not all communities have the resources to plan, develop, and implement these programs, or even the opportunity to influence how care is delivered, and there is an imperative for government, researchers, research-funding bodies, and clinical staff to engage communities in the development of health programming to deliver effective interventions.^{50, 51, 54, 55}

SECTION 4: Examples of Best Practices from Across Canada

This section offers a brief introduction to a number of successful diabetes care and management programs that have been implemented across Canada, where Indigenous communities, government, researchers, and healthcare providers have worked in partnership to develop solutions that improve care for community members with diabetes. We acknowledge that this list is far from exhaustive, and only represents a few select programs that were commonly identified through discussions with clinicians, researchers, and community program leaders as initiatives that have effectively engaged communities to improve diabetes care and outcomes. For a more comprehensive review of initiatives and best practices, please see a recent systematic review of best practices completed by Rice et al. (2015).⁵⁰

4.1. Diabetes and My Nation

Diabetes and My Nation is a community-based health management program that uses E-health and conventional healthcare services to provide culturally appropriate and holistic diabetes awareness, prevention, education, monitored self-management, and treatment programming to First Nations communities in British Columbia. The initiative is guided by an Advisory Group consisting of First Nations Elders, First Nations youth, healthcare professionals, and government officials, as well as extensive community consultation. Diabetes and My Nation has several program components including education, physical activity, nutrition education, awareness and screening, and ongoing monitoring and support for self-management. Programming is available for adults (The Circle of Diabetes Self-Management), youth (Our Spirit Lives), and school-age children (Health Warriors).

Sources

- Background paper: www.diabetesandmynation.com/docs/m_paper.pdf
- Website: www.diabetesandmynation.com/
- Health Warriors: diabetesandmynationfoundation.com/school.html
- Our Spirit Lives: diabetesandmynationfoundation.com/youth.html
- The Circle of Diabetes Self-Management: diabetesandmynationfoundation.com/circle.html

4.2. Kahnawake Schools Diabetes Prevention Project

The Kahnawake Schools Diabetes Prevention Project (KSDPP) began in 1994 as a 3-year National Health and Development Research Program (NHRDP) research project, and is a partnership between the Mohawk community of Kahnawake, represented through a Community Advisory board, and researchers. KSDPP was developed out of community concern for high rates of diabetes, coupled with perceived increases of obesity in children and the Mohawk tradition to care for future generations. Over the years, the program has delivered elementary school-based and community-wide interventions aimed at reducing the incidence of type 2 diabetes in the Kahnawake community by promoting physical activity and healthy eating habits.

KSDPP activities take a holistic approach to diabetes prevention and embed intervention activities in the community. Activities include a health education program, recreational activities, and community-based activities with an overall goal of living in balance.

Sources

- KSDPP website: www.ksdpp.org/
- Aboriginal Ways Tried and True: cbpp-pcpe.phac-aspc.gc.ca/aboriginalwtt/kahnawake-school-diabetes-prevention-project-qb/

4.3. Sandy Lake First Nation Health and Diabetes Project

The Sandy Lake Health and Diabetes Project (SLHDP) began in 1991, when the Chief and Council of Sandy Lake First Nation approached regional health officials due to community concerns of the rising prevalence of diabetes. SLHDP is also built on a partnership between the community and researchers, and the sustainability and success of the program can be attributed to community ownership and participation in programming.

Over the years, SLHDP has implemented a number of interventions to educate community members regarding diabetes prevention and management, and to create environments that support increased physical activity and healthy eating habits. These interventions include the following:

- community survey to describe baseline prevalence and risk factors for diabetes;
- northern food store program to support increased access to low-fat food and sugar-free alternatives, and to develop labels for health food choices in both English and Oji-Cree syllabics;
- home visit program supporting access to care, management, and prevention activities;
- diabetes radio show to provide information on diabetes prevention and management;
- school-based diabetes curriculum;
- ongoing and iterative evaluation;
- community-wide walking trails to create environments that promote physical activity;

- youth diabetes summer camp; and
- diabetes prevention program to promote healthy lifestyles.

Sources

- Background paper:⁵⁵ www.ncbi.nlm.nih.gov/pmc/articles/PMC3824247/
- Aboriginal Ways Tried and True: cbpp-pcpe.phac-aspc.gc.ca/aboriginalwtt/sandy-lake-health-and-diabetes-project/
- Website: sandylake.firstnation.ca/?q=sandy-lake-health-authority

4.4. Reorganizing the Approach to Diabetes through the Application of Registries Study

The Reorganizing the Approach to Diabetes through the Application of Registries (RADAR) Study integrates electronic health records linked with diabetes registries designed for First Nations communities (Community Assessment Response and Empowerment [CARE] platform), and professional care coordinators to organize care in communities to improve diabetes-related outcomes. The CARE platform was built to meet specific requirements of nurse-driven health programs currently delivered in First Nations communities, and integrates information from Home and Community Care, the Aboriginal Diabetes Initiative, and Community Health. The care coordinator provides access to primary care, supports patient and provider education, and acts as a bridge between communities and other service providers.

Sources

- Background paper:² bmchealthservres.biomedcentral.com/articles/10.1186/s12913-017-2049-y
- Website: www.okaki.com/whatwedo.html#rad

4.5. Transformation of Indigenous primary healthcare Delivery Program

The TransFORMation of IndiGENous PrimARy HEALthcare Delivery (FORGE AHEAD) program is a 5-year, participatory research program that aims to develop and evaluate community-driven primary healthcare models to support improvements in chronic disease care for First Nations populations. The FORGE AHEAD team is composed of:

- 11 First Nations communities;
- Indigenous and non-Indigenous healthcare providers;
- 21 co-investigators;
- Diabetes Canada;
- The Heart and Stroke Foundation;
- Assembly of First Nations; and
- First Nations and Inuit Health Branch, Health Canada.

The research project consists of three stages, with a number of elements in each stage. The first stage (preparatory activities) including a community profile survey, best practices and policy

literature review, and community readiness tools development. The second stage (intervention activities) includes community and clinical readiness consultations, development of a diabetes registry and surveillance system, and community-led quality improvement activities. The third stage (program wrap-up) includes community readiness tool validation, cost-analysis, and process evaluation. Scale-up toolkits will also be developed to support the spread of successful innovations and to support program sustainability.

Sources

- Background paper:⁵⁶ health-policy-systems.biomedcentral.com/articles/10.1186/s12961-016-0127-y
- Website: www.tndms.ca/forgahead/

4.6. First Nations Health Authority Mobile Screening Program

The Mobile Screening Program provides screening for diabetes and long-term complications, as well as care and education for patients and communities to improve the quality of life for on-reserve First Nations people. The mobile care teams (consisting of nurse educators, community diabetes educators, vision technicians, and nutrition and fitness educators, with remote access to physicians and specialists) travel to communities to provide primary care to patients with diabetes.

Sources

- Seabird Island website: www.seabirdisland.ca/index.php/service/mobile-diabetes-program/
- Carrier Sekani website: www.csfs.org/services/mobile-diabetes

Appendix A: Overview of Economic Literature

Table A.1: Costs of diabetes in Indigenous populations

Author	Findings
Jacobs et al. ³ 2000	<p>Purpose: To determine excess costs of diabetes in Indigenous populations attributable to diabetes, prevalence rates, and per person utilization of health services.</p> <p>Findings: Prevalence and utilization were considerably higher in the First Nations population. Excess costs due to disease prevalence added 15.9% to total costs, while excess costs due to utilization added 14.6% (need for primary preventive measures, high utilization indicates complications and suggests a need for secondary prevention).</p>
Pohar et al. ⁴ 2007	<p>Purpose: To compare health care utilization and per capita expenditures according to Registered Indian and diabetes status in the province of Saskatchewan.</p> <p>Findings: Diabetes cases were younger in Indigenous people. Indigenous people were more likely to visit a physician, be hospitalized, or receive dialysis regardless of diabetes status. Per capita healthcare costs were 40-60% higher for Registered Indians than the general population regardless of diabetes status.</p>
Simpson et al. ⁵ 2003	<p>Purpose: To estimate healthcare expenditures for diabetes and its major complications.</p> <p>Findings: In 1996, 36.4% of healthcare expenditures for people with diabetes was attributable to major comorbidity. Actions to prevent or control such comorbidity will yield significant cost savings.</p>
McBrien et al. ³⁹ 2013	<p>Purpose: To determine the association between laboratory-derived measures of glycemic control and the presence of renal complications with 5-year costs for caring for people with diabetes.</p> <p>Findings: Cost increased with worsening kidney function, presence of proteinuria, and suboptimal glycemic control (HbA1c > 7.9%). Increasing age, Aboriginal status, socioeconomic status, duration of diabetes, and comorbid illness were also associated with increasing cost.</p>

Table A.2: Cost-effectiveness of interventions

Author	Findings
Jin et al. ⁴⁰ 2004	<p>Purpose: To evaluate the cost-effectiveness of a telemedicine program.</p> <p>Findings: Mean cost per client was less than for the alternative, transporting clients to care in the nearest cities (cost-effective strategy to improve access to care).</p>
Kim et al. ⁴¹ 2015	<p>Purpose: To evaluate a service delivery model for teleophthalmology screening and follow-up for at-risk and diabetic First Nations clients.</p> <p>Findings: The average cost savings per client, taking project costs into consideration, was calculated to be \$28.16 due to the elimination of travel costs (cost-effective strategy to improve access to care).</p>
Maberley et al. ⁴² 2003	<p>Purpose: To explore the cost-effectiveness of retinopathy screening by travelling retina specialists versus retinal photography with a portable digital camera in an isolated First Nations cohort with diabetes.</p> <p>Findings: The camera was preferable to the specialist program. Over 10 years, 67 vs. 56 sight years were saved, compared with no screening at costs of \$3,900 vs. \$9,800 per sight year and \$15,000 vs. \$37,000 per quality-life adjusted year (QALY). Generalizing these results to the province of Ontario, the camera system could allow most isolated First Nations people with diabetes to be screened for 5 years for approximately \$1.2 million.</p>

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