Editor's key points

- Canada's First Nations communities have an elevated prevalence of diabetes and rate of diabetes complications. This study from Ontario's Sioux Lookout region aimed to test the feasibility of reporting diabetes indicators at a regional and community level using administrative data.
- The authors demonstrate that it is possible to report diabetes prevalence for First Nations reserve communities with populations of 250 and above, using administrative data. When examining groupings of communities with populations of 1200 to 2000, it is feasible to monitor major improvements in diabetes complications over a long-term period (5 years).
- Community leaders can use this information to anticipate resource requirements to address diabetes and engage community members on local strategies.
- These findings provide a framework for addressing the Auditor General's past criticisms of Canada's surveillance capability for diabetes.

Diabetes prevalence and complication rates

In individual First Nations communities in the Sioux Lookout region of Ontario

Benjamin T.B. Chan MD MPH MPA Sumeet K. Sodhi MD MPH Graham C. Mecredy MSc Terri Farrell MB ChB DCH CCFP Janet Gordon

Abstract

Objective To test the feasibility of reporting diabetes indicators at a regional and community level in order to provide feedback to local leaders on health system performance.

Design Analysis of administrative data from hospital discharges and physician billings.

Setting Sioux Lookout region of Ontario.

Participants Residents from 30 remote communities served by the Sioux Lookout First Nations Health Authority.

Main outcome measures Incidence and prevalence of diabetes and incidence of diabetes complications, including heart attack, stroke, retinopathy, amputations, end-stage kidney disease, diabetes-related hospitalizations, and death.

Results Data were available for 18 542 residents from the 30 remote communities. Residents were almost entirely of First Nations descent. The prevalence of diabetes was 12.9%, the annual incidence was 1.0%, and the annual rate of complications was 5.4% in 2015-2016. Prevalence increased slightly over time. We had sufficient data to report prevalence in 25 of 30 communities (average population 738; range 234 to 2626). We reported statistically significant differences in prevalence by community; 8 were above average and 2 were below average. For diabetes complications, data were pooled over 5 years, and while community-level results could be reported, the variance was too high to allow detection of significant differences. Using 2-tailed *t* tests for difference of proportions, we determined that grouping communities into subregions of approximately 2000 persons would permit the detection of differences of 30% from the average 5-year complication rate.

Conclusion This study demonstrates the possibility of reporting diabetes prevalence by individual First Nations reserve communities. Complication rates can be reported by individual community, but estimates are more useful for comparison if the smallest communities are grouped together. Such studies could be replicated across Canada to promote local use of these data for resource planning and monitoring long-term progress of diabetes programs and services.

First Nations people in Canada have a prevalence of diabetes that is twice that of the general population.[1] Those living on First Nations reserves are at even higher risk[1]; one recent Ontario study measured an age-sex standardized prevalence of 18.7%, compared with 15.7% for First Nations persons off reserve and 8.1% for the remaining population.[2] A Saskatchewan study found that First Nations women had higher prevalence than First Nations men, and the median age of onset was earlier, at 40 to 49 years for First Nations persons compared with 60 to 69 years for non–First Nations persons.[3] Earlier onset results in a longer period of living with diabetes, which in turn leads to higher rates of diabetes complications.[4] First Nations persons have higher rates of heart attack, stroke, retinopathy,[5] end-stage kidney disease, and amputations due to foot ulcers.[2]

There are multiple root causes for this heavy disease burden. Canada's residential school system was characterized by widespread physical and sexual abuse, resulting in serious mental health and addictions challenges.[6] Low self-esteem and self-neglect increases the risk of unhealthy lifestyles,[7] and studies demonstrate that depression is associated with poor diet, physical inactivity,[8,9] and obesity.[10] Furthermore, the process of assimilation in residential schools resulted in devaluation of traditional lifestyles, which emphasized vigorous physical outdoor activity and traditional foods.[5] A diagnosis of diabetes is linked to subsequent depression,[11] likely owing to the psychological burden of living with the disease.[2] Hence, a positive feedback loop might exist that exploits the bidirectional relationship between psychological distress and diabetes.

While First Nations data on diabetes exist at provincial or regional levels, little is known about burden of disease within individual communities. This study addresses this data gap by testing the feasibility of a monitoring system for diabetes incidence, prevalence, and complication rates among residents in each of 30 remote on-reserve communities serviced by the Sioux Lookout First Nations Health Authority in Ontario. These communities are inhabited almost entirely by First Nations persons, and most are accessible only by airplane or ice road in the winter.

We believe that such information might be useful to community leaders to monitor the long-term effects of local programs. Multiple initiatives have taken place over the years in First Nations communities to address the root causes of poor diabetes control, such as mental health and addictions programs; nutrition counseling; physical activity programs; "living off the land" programs, which aim to reintroduce traditional lifestyles; and self-management support.[12-14] Such programs have been organized at provincial, regional, and community levels.[12,15,16] For example, the Aboriginal Diabetes Initiative provided federal funding for many such programs from 1999 to 2015.[14] Despite these activities, there is little evidence on the effectiveness of these interventions,[17] as noted by Canada's Auditor General,[18] and filling this gap is essential.

Methods

This project received ethics approval from the Research Ethics Board of the Meno-Ya-Win Health Centre in Sioux Lookout.

A list of target communities was prepared by the Sioux Lookout First Nations Health Authority (**Table 1**). The small urban community of Sioux Lookout was excluded, as it has a substantial non–First Nations population. Researchers at ICES in Toronto, Ont, identified the 4-digit residence code and postal code for each community, based on lists from the Ministry of Health and Statistics Canada, respectively. The former was considered the most accurate record of a patient's residence, as it is recorded at each hospital or emergency department visit. When residence code was not available, the postal code was used to determine a person's location.

Administrative data housed at ICES were used for this study to identify individuals with diabetes and the services provided to them. The Ontario Diabetes Database combines information from the Discharge Abstract Database for hospitalizations and day surgery; the Ontario Health Insurance Plan database of physician billings; and the Registered Persons Database for postal code and vital statistics. A patient was deemed to have diabetes if there was 1 hospitalization or 2 physician billings with a diagnosis of diabetes in a year. An incident case was defined as a patient who met these criteria in 1 year but not the preceding years. Once a patient is identified as having diabetes, this status remains for subsequent years.

In addition to death, we examined the incidence of 6 types of diabetes complications: acute myocardial infarction, stroke, retinopathy, end-stage renal failure, lower-limb amputations, and diabetes-related hospitalizations. A full list of diagnosis, procedure, and billing codes used to define complications is available on request. Stroke included both ischemic and hemorrhagic strokes; end-stage renal failure included patients receiving outpatient hemodialysis or peritoneal dialysis (ie, excludes hospital patients receiving dialysis temporarily); amputations included any amputations of the toes, feet, or below the knee; hospitalizations for diabetes included, for example, cases with diabetes, ketoacidosis, or hypoglycemia as the main diagnosis; and retinopathy included cases requiring a surgical procedure (typically day surgery) such as photocoagulation or vitreous injection, or aspiration with a diagnosis of diabetes or diabetic retinopathy.

The time frame for the analysis was 2006-2007 to 2015-2016.

To complement this empirical evaluation of the feasibility of reporting on small communities, we applied the

Table 1. List of rural communities in Ontario's Sioux Lookout region

COMMUNITY	POPULATION IN 2015-2016
Bearskin	407
Cat Lake	591
Deer Lake	924
Eabametoong	1126
Eagle Lake	241
Fort Severn	390
Kasabonika	1018
Keewaywin	402
Kingfisher Lake	489
Kitchenuhmaykoosib Inninuwug	1086
Lac Seul	1054
McDowell Lake	NR
Mishkeegogamang	803
Muskrat Dam	279
Neskatanga	249
Nibinamik	356
North Spirit Lake	333
Pikangikum	2626
Poplar Hill	574
Sachigo	513
Sandy Lake/Koocheching	2403
Saugeen	39
Slate Falls	234
Wabauskang	NR
Wabigoon Lake	35
Wapekeka	270
Wawakapewin	NR
Weagamow	850
Webequie	671
Wunnumin	570
Total	18 542†

NR—not reported, as population was < 6.
†Includes the 3 communities for which data are not reported.

formula for calculating statistically significant differences between proportions (assuming 2-tailed test, $\alpha = .05$) to find out under what conditions of community size and number of diabetes patients per community it would be possible to observe a 20%, 30%, and 40% difference from the Sioux Lookout area average for incidence of complications. We consider these relative differences clinically significant, as they would represent a considerable step toward reducing the observed difference in diabetes complications between First Nations and non–First Nations persons.[2] We performed these calculations for both 1-year and 5-year observation periods.

Results

In 2015-2016, information was available from 18 542 residents. Men slightly outnumbered women (51.4% vs 48.6%), and 41.1% were aged 18 or younger. Among the 30 communities, 2 had more than 2000 residents, 5 had populations between 1000 and 2000, and 3 had populations too small to report (ie, fewer than 6).

Diabetes prevalence was 12.9% in 2015-2016, representing a modest increase from 11.9% in 2006-2007 ($P = .005$). The incidence was 1.0%, with no significant change between the start and end of the study period. For both incidence and prevalence, there was a slight decrease in the middle of the study period (**Figure 1**).

In 2015-2016, 5.4% of patients with diabetes (or 1 out of every 18 persons) developed a major complication such as heart attack, stroke, surgery for diabetic retinopathy, diabetes-related hospitalization, or surgery for poor leg circulation (eg, amputation) (**Table 2**). About 1 in 140 patients were receiving dialysis at any given moment, and 1 in 75 patients died in a given year. There were not enough events to identify statistically significant changes over time.

Data on diabetes prevalence and incidence of major complications were analyzed by individual community. In order to obtain a reasonable sample size for community-specific rates, data were aggregated across 5 years, with the most recent period being from 2011-2012 to 2015-2016. We excluded communities where the numerator was less than 6 or denominator less than 50. We had sufficient data to report prevalence in 25 of 30 communities (average population 738; range 234 to 2626). Eight communities had prevalence that was statistically significantly above average and 2 were significantly below average (**Figure 2**).

The incidence of major complications over a 5-year period was 16.8%. Many individuals experienced more than 1 complication within this 5-year period. The incidence rate of major complications could be reported in 22 of 30 communities. It was not possible to detect any statistically significant differences from the average, owing to small sample sizes (**Figure 3**).

Table 3 lists the results of calculations for minimum community size needed to observe a significant difference from the Sioux Lookout average for incidence of complications. If communities grouped themselves into subregions of 1200 to 2000, then it would be possible to detect differences from the average of around 30% or 40% over a 5-year span. The Sioux Lookout region would be able to detect differences from other regions of comparable size in the range of 20% to 30% with data from a single year.

Figure 1. Prevalence and incidence of diabetes and incidence of diabetes complications among First Nations communities in the Sioux Lookout region of Ontario

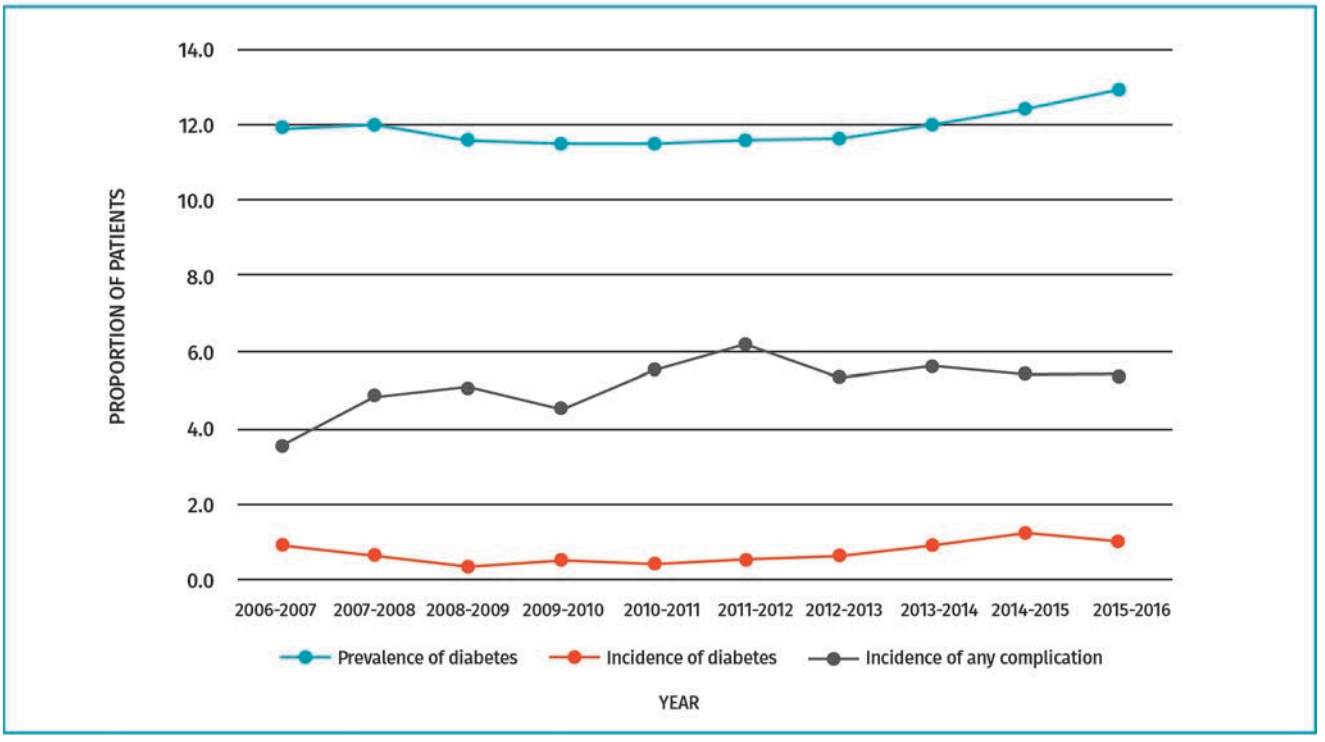


Table 2. Incidence and prevalence of diabetes and complications, 2015-2016

INDICATOR	VALUE (95% CI), %
Prevalence of diabetes	12.9 (12.4-13.4)
Incidence of diabetes	1.0 (0.9-1.1)
Prevalence of dialysis among patients with diabetes	0.7 (0.4-1.0)
Death rate among patients with diabetes	1.3 (0.8-1.8)
Incidence of complications among patients with diabetes	
• Surgery for leg circulation problem (eg, amputation)	0.8 (0.4-1.2)
• Heart attack	1.4 (0.9-1.9)
• Stroke	1.6 (1.1-2.1)
• Diabetic retinopathy requiring surgery	1.5 (1.0-2.0)
• Hospital admission for diabetes	0.6 (0.3-0.9)
• Any incident complication	5.4 (4.5-6.3)

Discussion

Our study found that the prevalence of diabetes among rural First Nations communities in the Sioux Lookout region is 12.9%, which is comparable to the overall prevalence of diabetes among First Nations persons in Ontario (14.1%).[2] The incidence rate was 1.0%. In other words, about 1 in 8 persons has diabetes and, in any given year, 1 in every 100 residents will develop diabetes. Diabetes complications were common, affecting about 1 in 6 patients over 5 years. These findings are comparable to rates in other studies of First Nations populations and confirm that rates are higher than those in the general population.[4] Clearly, there is room for improvement.

This study confirms that it is possible to construct community-level profiles of diabetes prevalence, even for communities with a population as low as 250. We successfully reported data in all but 5 communities, and identified significant differences compared with the average in some sites. This information is of potential benefit to local leaders. Data on the number of patients with diabetes, for example, can be used to estimate the number and amount of personnel, consultations, equipment, supplies, and other resources needed to service a population. This information could also be used to engage the community on the best strategies to improve quality, as community members are most interested in data that pertain to their own setting. Prevalence data can also be used as an indicator of the long-term effectiveness of population-based prevention programs, as some researchers suggest.[19] In the future, information comparing sites can provide insight into which communities have the best results. If these results are owing to good management practices, then their success could serve as a model for other communities to emulate.

Figure 2. Diabetes prevalence in Sioux Lookout First Nations communities, 2015-2016

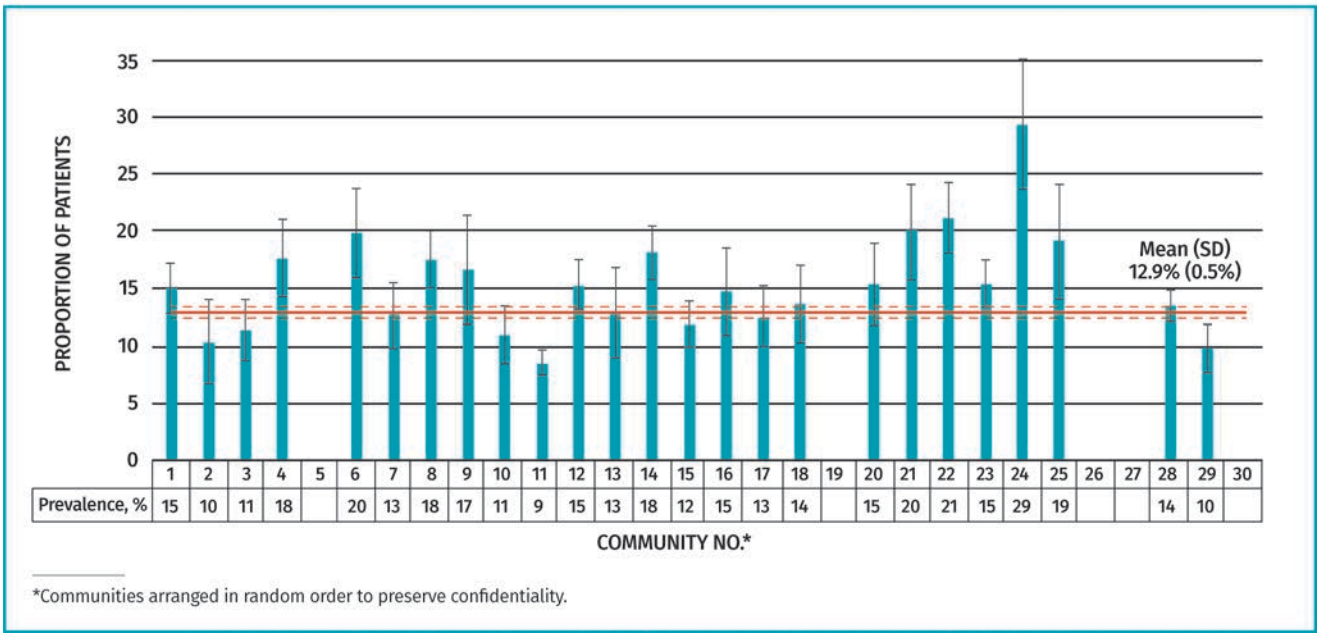
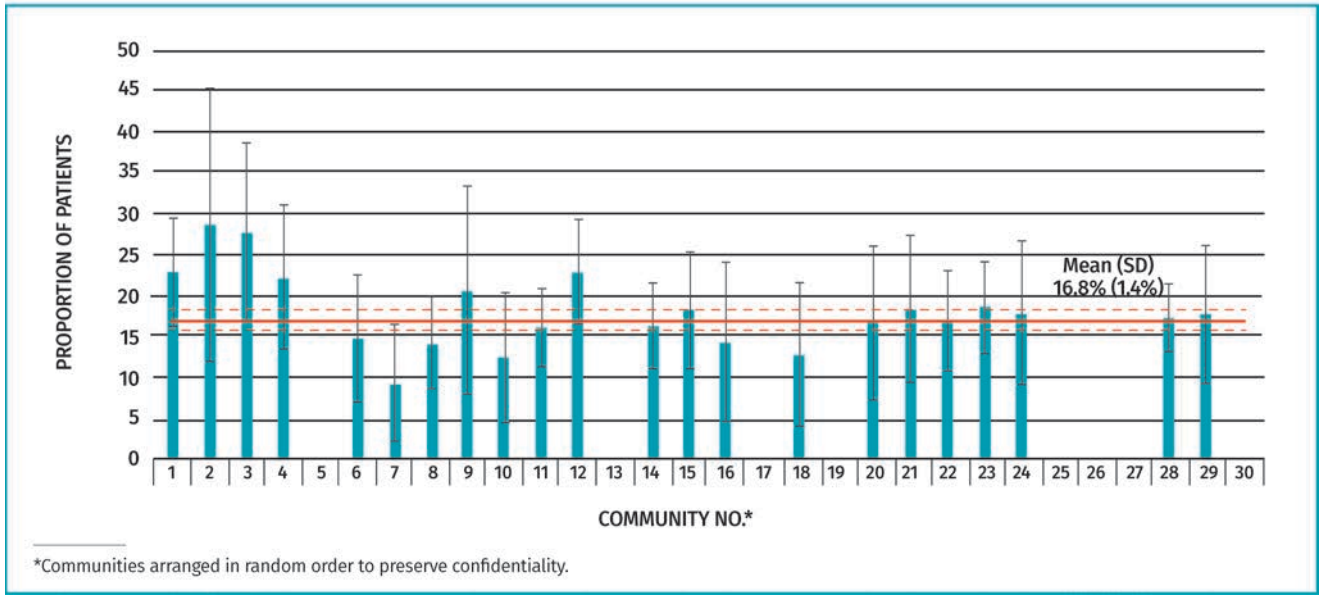


Figure 3. Incidence of diabetes complications by community



Our study identified a modest increase in prevalence with considerable fluctuation during the study period. Other studies also demonstrate rising prevalence of diabetes in both the general and First Nations populations. These studies, however, are also consistent with our findings that the rate of increase has been relatively modest among First Nations communities.[4]

Our empirical observations suggest that it is not feasible to measure differences in complication rates between communities with very small sample sizes. Our analysis of comparisons, however, suggests that grouping smaller communities into units of around 2000 could allow for detection of a 30% difference from average over a 5-year period. Many First Nations communities have already grouped themselves into Regional Tribal Councils, which manage health services. Future analyses might wish to consider reporting at this level.

These findings on feasibility of reporting on small populations might be useful in other settings such as urban clinics serving off-reserve First Nations and Aboriginal persons. Such centres could monitor similar outcomes and voluntarily compare results with similar

Table 3. Minimum size of community needed to detect a statistically significant difference from the Sioux Lookout average for incidence of complications

TIME PERIOD	DIFFERENCE FROM AVERAGE, %	MINIMUM NO. OF PATIENTS WITH DIABETES IN COMMUNITY	ESTIMATED MINIMUM SIZE OF COMMUNITY*
1 y			
	20	4000	31 000
	30	970	7500
	40	470	3700
5 y			
	20	720	5600
	30	280	2200
	40	150	1200

*Based on assumption that diabetes prevalence is 12.9%, as measured in 2015-2016.

facilities for quality improvement purposes.

In this study, results are presented on an anonymous bar chart for illustrative purposes. The Assembly of First Nations has promoted the principles of OCAP (Ownership, Control, Access and Possession)[20] for governance of First Nations data.[21] To this end, it is required that consent be obtained from the leaders of each community to make this information publicly available for educational and planning purposes.

Limitations

One limitation of this study is that hospitalizations might be underestimated if patients were sent to hospitals in neighbouring Winnipeg, Man. However, patients were included if they were treated first in Sioux Lookout and then transferred to Winnipeg, or if a Manitoba-based physician billed the Ontario Health Insurance Plan through the reciprocal billing system. Therefore, we believe that this underestimation problem affects mainly the indicator for hospitalizations for a main diagnosis of diabetes.

Conclusion

This study sets a precedent that it is possible to report diabetes prevalence data for individual First Nations communities. Complication rates can be reported for individual communities, and comparisons are more meaningful if communities are grouped into subregions of at least 2000. Such studies could be replicated across Canada, in partnership with First Nation communities, to promote local use of these data to determine what staff and other resources are needed to service the local population, and for monitoring the long-term progress of diabetes programs.

Dr Benjamin Chan a primary care physician and Assistant Professor of global health and quality management at the Institute for Health Policy, Management and Evaluation at the University of Toronto in Ontario. **Dr Sumeet Sodhi** is a family physician with the University Health Network's Toronto Western Hospital Family Health Team and Associate Professor and Academic Lead for the Indigenous Health Partners Program at the University of Toronto. **Graham Mecredy** is a staff scientist for the ICES Indigenous Portfolio in Toronto. **Dr Terri Farrell** is a family physician and Medical Director with the Sioux Lookout First Nations Health Authority. **Janet Gordon** is Chief Operating Officer with the Sioux Lookout First Nations Health Authority and a current member of Lac Seul First Nation.

Acknowledgment

This study was supported by ICES, which is funded by the Ontario Ministry of Health and Long-Term Care. We thank **Susmitha Rallabandi** for assistance in preparing the background literature search and for administrative support, **Erin Graves** for coordinating the research approval process, and **Dr Peter Austin** for a discussion on some statistical methods used in the paper. All content is the responsibility of the authors.

Contributors

All authors contributed to the concept and design of the study; data gathering, analysis, and interpretation; and preparing the manuscript for submission.

Competing interests

None declared

Correspondence

Dr Benjamin T.B. Chan; e-mail **drben.chan@utoronto.ca**

References

1. *Diabetes in Canada: facts and figures from a public health perspective.* Ottawa, ON: Public Health Agency of Canada; 2011.
2. Green ME, Jones CR, Walker JD, Shah BR, Jacklin K, Slater M, et al, editors. *First Nations and diabetes in Ontario.* Toronto, ON: ICES; 2019.
3. Dyck R, Osgood N, Lin TH, Gao A, Stang MR. Epidemiology of diabetes mellitus among First Nations and non-First Nations adults. *CMAJ* 2010;182(3):249-56.
4. Jiang Y, Osgood N, Lim HJ, Stang MR, Dyck R. Differential mortality and the excess burden of end-stage renal disease among First Nations people with diabetes mellitus: a competing-risks analysis. *CMAJ* 2014;186(2):103-9. Epub 2013 Dec 2.
5. Campbell RJ, Sutherland R, Khan S, Doliszny KM, Hooper PL, Slater M, et al. Diabetes-induced eye disease among First Nations people in Ontario: a longitudinal, population-based cohort study. *CMAJ Open* 2020;8(2):E282-8.
6. *Honouring the truth, reconciling for the future. Summary of the final report of the Truth and Reconciliation Commission of Canada.* Winnipeg, MB: Truth and Reconciliation Commission of Canada; 2015.
7. Moulton CD, Pickup JC, Ismail K. The link between depression and diabetes: the search for shared mechanisms. *Lancet Diabetes Endocrinol* 2015;3(6):461-71. Epub 2015 May 17.
8. Frederick T, Frerichs RR, Clark VA. Personal health habits and symptoms of depression at the community level. *Prev Med* 1988;17(2):173-82.
9. Schuch F, Vancampfort D, Firth J, Rosenbaum S, Ward P, Reichert T, et al. Physical activity and sedentary behavior in people with major depressive disorder: a systematic review and meta-analysis. *J Affect Disord* 2017;210:139-50. Epub 2016 Nov 29. Erratum in: *J Affect Disord* 2018;225:79. Epub 2017 Aug 9.
10. Goodman E, Whitaker RC. A prospective study of the role of depression in the development and persistence of adolescent obesity. *Pediatrics* 2002;110(3):497-504.
11. Nouwen A, Winkley K, Twisk J, Lloyd CE, Peyrot M, Ismail K, et al. Type 2 diabetes mellitus as a risk factor for the onset of depression: a systematic review and meta-analysis. *Diabetologia* 2010;53(12):2480-6. Epub 2010 Aug 14.
12. Dawson KG. Diabetes care in First Nations populations in British Columbia. *B C Med J* 2018;60(9):451-4.
13. Kakekagumick KE, Naqshbandi Hayward M, Harris SB, Saksvig B, Gittelsohn J, Manokeesic G, et al. Sandy Lake Health and Diabetes Project: a community-based intervention targeting type 2 diabetes and its risk factors in a First Nations community. *Front Endocrinol* (Lausanne) 2013;4:170. Epub 2013 Sep 2.
14. *Kahnawake Schools Diabetes Prevention Program* [website]. Kahnawake, QC: Kahnawake Schools Diabetes Prevention Program; 2020. Available from: **https://www.ksdpp.org/about-ksdpp.html**. Accessed 2021 Jun 29.
15. Indigenous Services Canada. *Aboriginal Diabetes Initiative* [website]. Ottawa, ON: Government of Canada; 2021. Available from: **https://www.sac-isc.gc.ca/eng/1569960595332/1569960634063**. Accessed 2020 Jun 2.
16. *Aboriginal Diabetes Initiative resources. Traditional wellness resources, nutrition & physical activity.* Vancouver, BC: First Nations Health Council; 2020. Available from: **https://www.fnha.ca/Documents/ADI_Resources.pdf**. Accessed 2021 Jun 29.
17. Halseth R. *The prevalence of type 2 diabetes among First Nations and considerations for prevention.* Prince George, BC: National Collaborating Centre for Aboriginal Health; 2019. Available from: **https://www.nccih.ca/495/The_prevalence_of_Type_2_diabetes_among_First_Nations_and_considerations_for_prevention.nccih?id=250**. Accessed 2020 Jun 2.
18. Chapter 5—promoting diabetes prevention and control. In: *2013 spring report of the Auditor General of Canada.* Ottawa, ON: Auditor General of Canada; 2013. Available from: **https://www.oag-bvg.gc.ca/internet/English/parl_oag_201304_05_e_38190.html#hd5j**. Accessed 2020 Jun 2.
19. Gregg EW, Boyle JP, Thompson TJ, Barker LE, Albright AL, Williamson DF. Modeling the impact of prevention policies on future diabetes prevalence in the United States: 2010-2030. *Popul Health Metr* 2013;11(1):18.
20. *The First Nations principles of OCAP.* Akwesasne, ON: First Nations Information Governance Centre. Available from: **https://www.afn.ca/uploads/files/nihbforum/info_and_privacy_doc-ocap.pdf**. Accessed 2021 Jun 29.
21. *Ownership, control, access & possession. First Nations inherent right to govern First Nations data.* Ottawa, ON: Assembly of First Nations; 2007.

This article has been peer reviewed.
Cet article a fait l'objet d'une révision par des pairs.
Can Fam Physician 2021;67:000-0. DOI: 10.46747/cfp.6708xxx