Diabetes prevalence and complication rates

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

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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.

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.

Points de repère du rédacteur

▸ La prévalence du diabète et les taux de complications dues à cette maladie sont élevés dans les communautés des Premières Nations au Canada. Cette étude portant sur la région de Sioux Lookout, en Ontario, avait pour but de tester la faisabilité de la production de rapports sur les indicateurs du diabète sur les plans de la région et de la collectivité à l'aide de données administratives.

▸ Les auteurs ont démontré qu'il est possible de produire des rapports sur la prévalence du diabète dans les collectivités des réserves des Premières Nations dont la population est de 250 habitants ou plus, au moyen de données administratives. Il est aussi possible de surveiller les améliorations majeures à long terme (5 ans) des complications du diabète lorsque l'examen des données porte sur des groupes de collectivités dont la population compte de 1200 à 2000 personnes.

▸ Les dirigeants de ces collectivités peuvent se servir de ces renseignements pour prévoir les besoins en ressources pour lutter contre le diabète et mobiliser les membres de la communauté dans des stratégies locales.

▸ Ces constatations procurent un référentiel pouvant servir à répondre aux critiques antérieures du vérificateur général concernant la capacité de surveillance du diabète au Canada.

La prévalence du diabète et les taux de complications

Dans des collectivités individuelles des Premières Nations de la région de Sioux Lookout, en Ontario

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Résumé

Objectif Tester la faisabilité de la production de rapports sur les indicateurs du diabète à l'échelle de la région et de la collectivité dans le but de fournir des données aux dirigeants locaux sur le rendement du système de santé.

Type d'étude Une analyse des données administratives tirées des rapports de congés de l'hôpital et de la facturation par les médecins.

Contexte La région de Sioux Lookout, en Ontario.

Participants Les résidents de 30 collectivités éloignées desservies par les autorités sanitaires des Premières Nations de Sioux Lookout.

Principaux paramètres à l'étude La faisabilité de l'estimation de l'incidence et de la prévalence du diabète, de même que de l'incidence des complications du diabète, notamment les infarctus, les AVC, la rétinopathie, les amputations, les néphropathies au stade terminal, les hospitalisations liées au diabète et les décès.

Résultats Des données étaient accessibles sur 18 542 résidents des 30 collectivités éloignées. Les résidents étaient presque tous d'origine autochtone. La prévalence du diabète se situait à 12,9 %, l'incidence annuelle était de 1,0 % et le taux annuel de complications s'élevait à 5,4 % en 2015-2016. La prévalence a augmenté légèrement avec le temps. Nous avions des données suffisantes pour faire rapport de la prévalence dans 25 des 30 collectivités (population moyenne de 738; variant entre 234 et 2626). Nous avons signalé des différences statistiquement significatives dans la prévalence selon la collectivité; 8 collectivités étaient au-dessus de la moyenne et 2 étaient sous la moyenne. En ce qui a trait aux complications du diabète, les données sur 5 ans ont été regroupées et, bien qu'il eut été possible de rapporter les résultats à l'échelle de la collectivité, la variance était trop élevée pour permettre la détection de différences significatives. Au moyen de tests *t* bilatéraux pour établir la différence dans les proportions, nous avons déterminé qu'en regroupant les collectivités en sous-régions d'environ 2000 personnes, il serait possible de détecter des différences de 30 % par rapport au taux de complications moyen sur 5 ans.

Conclusion Cette étude démontre la possibilité de produire des rapports sur la prévalence du diabète par collectivité individuelle dans les réserves des Premières Nations. Les taux de complications peuvent être signalés par collectivité individuelle, mais les estimations sont plus utiles aux fins de comparaison lorsque les collectivités moins populeuses sont regroupées. De telles études pourraient être répliquées dans toutes les régions du Canada dans le but de promouvoir l'utilisation locale de ces données pour planifier les ressources et surveiller les progrès à long terme des programmes et des services liés au diabète.

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	18542*

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 18542 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
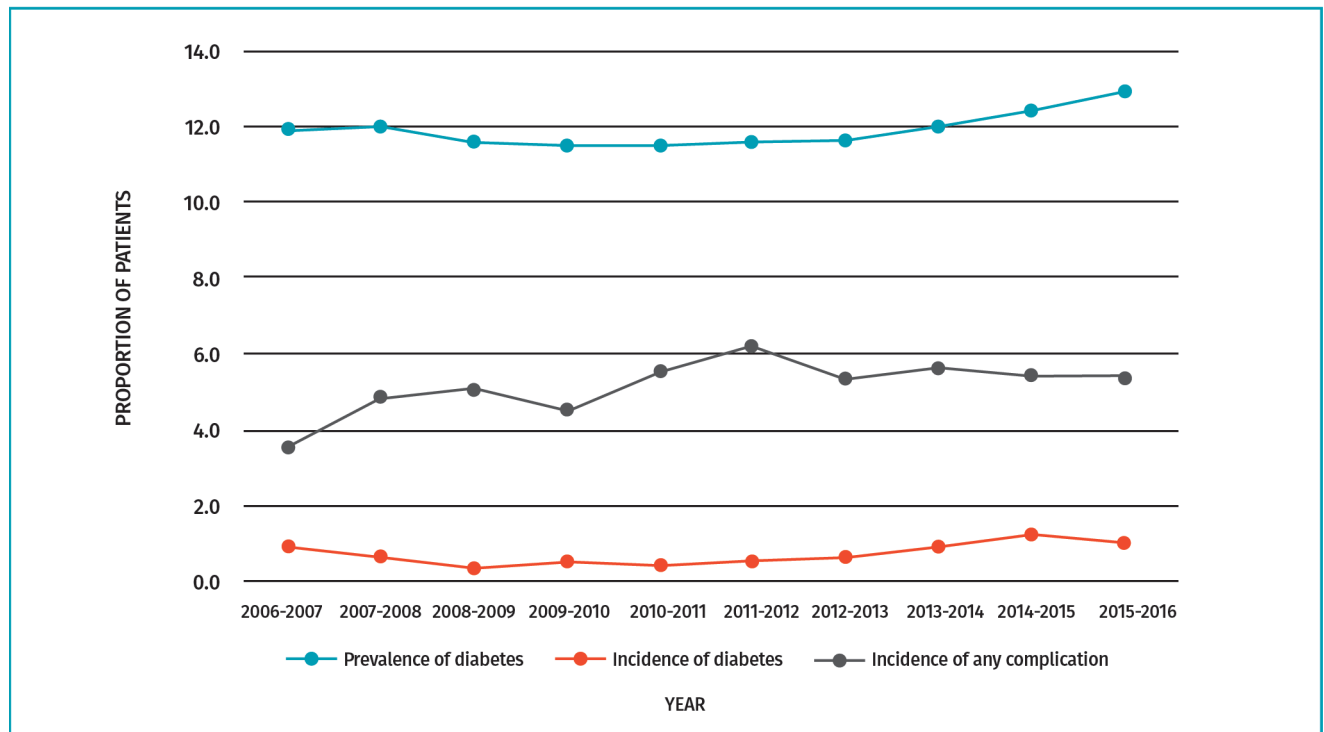
Table 2. Incidence and prevalence of diabetes and complications, 2015-2016

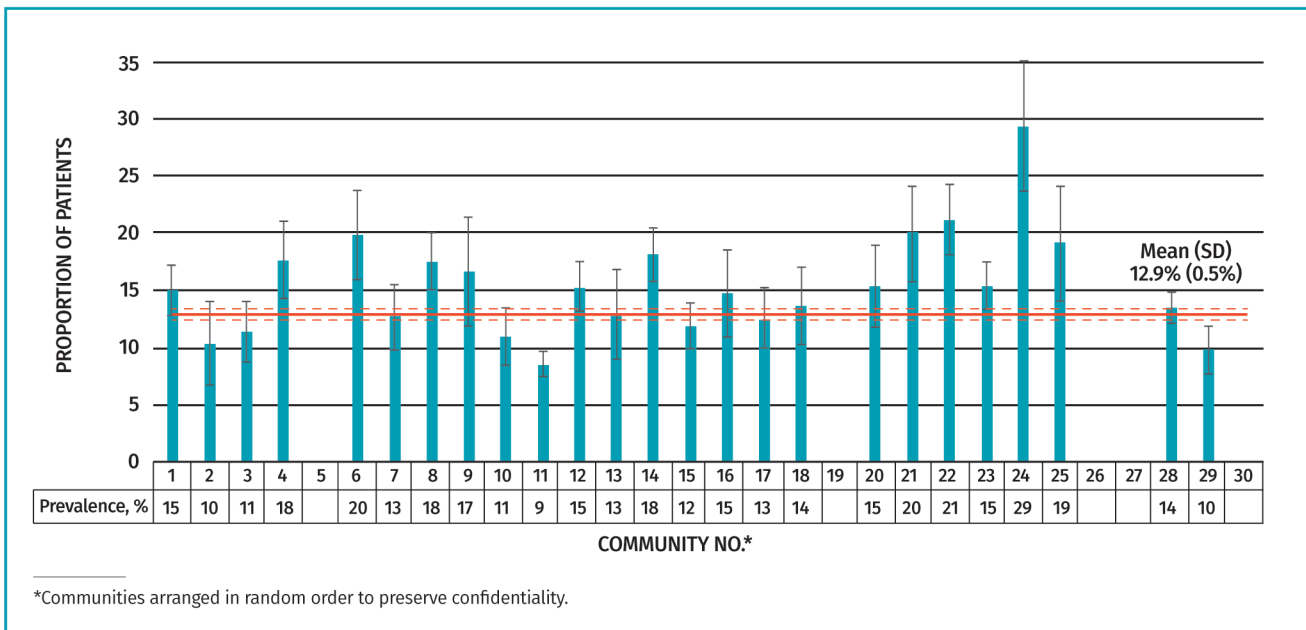| INDICATOR	VALUE (95% CI), %
Prevalence of diabetes	12.9 (12.4-13.4)
Incidence of diabetes	1.0 (0.9-1.1)
Prevalence of dialysis among patients with diabetes	0.7 (0.4-1.0)
Death rate among patients with diabetes	1.3 (0.8-1.8)
Incidence of complications among patients with diabetes	
• Surgery for leg 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.
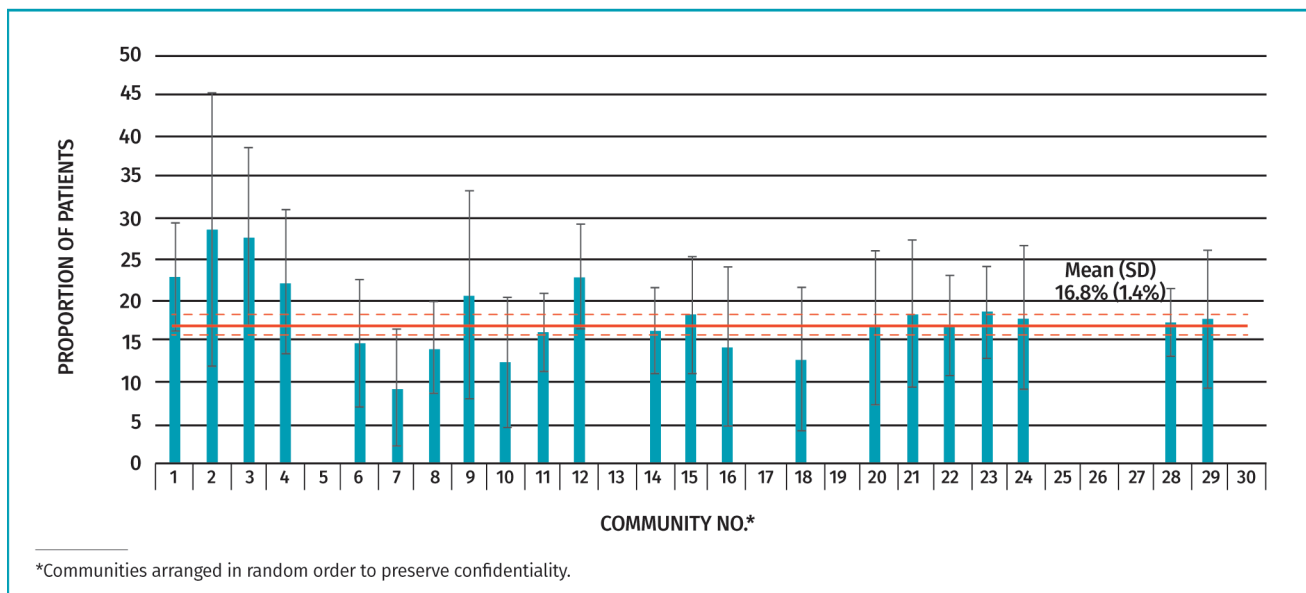
This study confirms that it is possible to construct community-level profiles of diabetes prevalence, even for communities with a population as low as 250. We successfully reported data in all but 5 communities, and identified significant differences compared with the average in some sites. This information 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

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
Prevalence, %	15	10	11	18		20	13	18	17	11	9	15	13	18	12	15	13	14		15	20	21	15	29	19			14	10	

COMMUNITY NO.*

*Communities arranged in random order to preserve confidentiality.

Figure 3. Incidence of diabetes complications by community

COMMUNITY NO.*

*Communities arranged in random order to preserve confidentiality.

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 facilities for quality improvement purposes.

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.

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.

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