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# **Original quantitative research**

# Mental health indicators among pregnant Aboriginal women in Canada: results from the Maternity Experiences Survey

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### Abstract

Introduction: There is little research done on mental health among pregnant Aboriginal women. Therefore, the purpose of the study was to examine the prevalence of postpartum depression (PPD) and its determinants, including pre-existing depression among non-Aboriginal and Aboriginal women in Canada.

Methods: The Maternity Experiences Survey (MES) is a national survey of Canadian women's experiences and practices before conception, up to the early months of parenthood. Predictors of PPD were calculated using the Mantel-Haenszel correction method relative to the risk estimates based on the odds ratio from adjusted regression analysis. The analysis was conducted among women who self-identified as Aboriginal (Inuit, Métis or First Nations living off-reserve) and those who identified as non-Aboriginal.

Results: The prevalence of pre-existing depression was higher among self-reported First Nations off-reserve and Métis women than non-Aboriginal women. Inuit women had the lowest prevalence of self-reported pre-existing depression, and Aboriginal women reported a higher prevalence of PPD than non-Aboriginal women. Pre-existing depression was not a predictor for PPD for Inuit or Métis women in this study but was a positive predictor among First Nations off-reserve and non-Aboriginal women. A disproportionally higher number of Aboriginal women reported experiencing abuse, as compared to non-Aboriginal women.

**Conclusion:** Our study demonstrated that common predictors of PPD including anxiety, experiencing stressful life events during pregnancy, having low levels of social support, and a previous history of depression were consistent among non-Aboriginal women. However, with the exception of the number of stressful events among First Nations offreserve, these were not associated with PPD among Aboriginal women. This information can be used to further increase awareness of mental health indicators among Aboriginal women.

**Keywords:** postpartum depression, Aboriginal, pregnant, mental health

### Introduction

The Canadian Mental Health Association estimates that up to 20% of new mothers experience postpartum depression (PPD).1 Antenatal depression is the strongest predictor for PPD.2 Antenatal depression has been associated with poor maternal functioning and poorer birth outcomes such as higher preterm birth rates and increased rates of caesarean deliveries.3-5 Further, predictors for PPD include: anxiety, marital stress, stressful life events during pregnancy, lack of prenatal care, partner

### Highlights

- Métis and First Nations women reported a higher prevalence of pre-existing depression than non-Aboriginal women while Inuit women reported the lowest prevalence.
- Overall, Inuit, Métis and First Nations women had a higher prevalence of postpartum depression than non-Aboriginal women.
- A disproportionally higher number of Aboriginal women reported experiencing abuse, as compared to non-Aboriginal women.

instability, and low levels of social support, to name but a few.4 Given the potential negative effects of PPD on a woman and child, knowledge of the prevalence and the predictors of PPD are necessary to implement preventative measures and to help health practitioners ensure that appropriate supports are in place for those most likely to experience PPD.2

In Canada, Aboriginal peoples are a collective name for the original peoples of North America and their descendants and are comprised of three groups: First Nations, Métis and Inuit.6 Aboriginal women's health status, when compared to that of non-Aboriginal Canadian women, can only be understood in the context of a range of health determinants that arise from the history of colonization and the legacy of Indian Residential Schools, including socioeconomic status, education and employment conditions, social support networks, physical environment, and

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access to health services.7 The social determinants of health make Aboriginal women more vulnerable than other Canadian women in terms of their health status. At the same time, it is important to acknowledge the resilience of Aboriginal peoples and in particular, the promising practices arising across the country to reduce disparities in maternal and child health outcomes.8 Unfortunately, accurate descriptions of the health disparities experienced by Aboriginal women have been limited by a lack of standardized First Nations, Métis, and Inuit identifiers in vital registration, health care utilization, and surveillance databases.

While some research has demonstrated that Aboriginal women have higher levels of PPD symptoms compared to non-Aboriginal women,<sup>2,8</sup> the prevalence of predictors of PPD have not previously been well described. To address this research gap with respect to the perinatal mental health of Aboriginal women, this study examines the prevalence of PPD and its determinants along with other mental health indicators (including pre-existing depression) in First Nations living off-reserves, Métis, and Inuit women in Canada.

### Methods

The Maternity Experiences Survey (MES), which was developed by the Public Health Agency of Canada (PHAC), is a national survey of Canadian women's experiences and practices prior to conception and up to the early months of parenthood. The primary objective of the survey was to provide data on Canadian women's experiences during pregnancy, birth, and the postpartum period.

Mothers 15 years of age and older who had given birth to a live, singleton baby in Canada between November 1, 2005 and May 15, 2006 and who lived with their infant at the time of data collection were eligible to participate in the survey. Mothers under 15 years of age at the time of giving birth, First Nations' mothers living on reserves or women living in institutions, and any woman who had a multiple birth (e.g., twins), stillbirth, suffered an infant death, or was no longer living with her baby were excluded.9 A stratified, random sample of 8542 women was selected without replacement, using recent births drawn from a Census-based sampling frame. In total, 6421 completed enough of

the questionnaire to be considered respondents for the MES study cohort.9 Sampling weights and additional post-strata, based on the mother's first language and Aboriginal status, were used.9 The 6421 respondents were thus weighted to represent 76 508 women, which are considered a nationally represented sample. Interviews were conducted primarily by telephone between October 23, 2006 and January 31, 2007. Most (96.9%) women were interviewed between five and nine months postpartum, with the timing ranging from five to 14 months. Interviews were conducted in English, French, and 13 non-official languages.9

The analysis included women (excluding those that did not report their ethnicity) who self-identified as First Nations off-reserve (2.5%, n = 1435), Métis (2.5%, n = 1456), or Inuit (0.5%, n = 239), and women who did not identify as Aboriginal, that is, they self-defined as non-Aboriginal (94.5%, n = 55405).

Mental health variables included Edinburgh Postnatal Depression Scale (EPDS) scores, pre-existing depression, perceived stress, number of stressful events, history of abuse, levels of social support, and substance use in pregnancy (drugs and alcohol). Women were considered to have symptoms of PPD if their EPDS score was ≥ 13. If women answered yes to the following question, "Before your pregnancy, had you ever been prescribed anti-depressants or been diagnosed with depression?" they were considered to have a history of depression. Women were also asked a series of questions relating to stress. Women were asked to think about the amount of stress in their lives during the 12 months before their baby was born and responded with "not stressful", "somewhat stressful" and "very stressful." Similar to definitions reported by Dzakpasu et al.10 and Kingston et al.,11 high stress was defined as experiencing three or more stressful events (death in family/friend, moved, change in employment/housing status, divorce, relationship issues, financial stress, physical altercations, jail, and substance abuse) in the past 12 months before the baby was born. Women were asked a series of ten questions, which included questions about physical and/or sexual violence and threats of violence to determine if they had suffered abuse. A "yes" response to any of these items was categorized as abuse, in accordance with the Daoud et al. study.12 Social support

was determined by the following question "during your pregnancy, how often was support available to you when you needed it?" If women responded "none of the time", they were considered to have no social support; if they responded "a little of the time" or "some of the time" they were considered to have low social support, and if they responded "most of the time" or "all of the time" they were considered to have social support. If women responded anything other than "was not drinking at the time/stopped drinking" to the following question, "After you realized you were pregnant, how often did you drink alcoholic beverages?" they were considered to have consumed alcohol while pregnant. If women responded yes to the following question "After you realized you were pregnant, did you use street drugs?" they were considered to have used drugs while pregnant.

Sociodemographic characteristics included self-reported age (in years), marital status, education, and employment status. A variable labeled low-income cut-off (LICO) was derived using a set of criteria used by Statistics Canada to identify an income threshold below which a family will likely devote a larger share of its income on the necessities of food, shelter, and clothing than the average family in Canada. This was dichotomized as "at/ below LICO" and "above LICO." Marital status categories included: single/never married, married, living common-law, divorced, separated, widowed, and refused. Education was based on the highest level of formal education completed and were grouped as: less than high school, completed high school and some post-secondary, post-secondary, and university degree.

Pregnancy-related characteristics included parity (primiparous/multiparous), time to first prenatal care visit (first trimester/ after first trimester), pregnancy planning status (planned/unplanned), and smoking status. Planned and unplanned pregnancy was determined by a proxy question "Thinking back to just before you became pregnant, would you say that you wanted to be pregnant ...?" If women answered "later" or "not at all" they were considered an unplanned pregnancy and if women responded "sooner" or "then" they were considered a planned pregnancy. Lastly, if women responded "daily" or "occasionally" to the following question "During the last three months of your pregnancy, did you smoke daily, occasionally or not at all?" they were considered to have smoked during pregnancy.

Data were analyzed using SPSS, version 21.0. Using the Mantel-Haenszel correction method proposed by Zhang and Yu,13 relative risk estimates were calculated based on the odds ratio from adjusted regression analysis. This correction method has shown to be a valid method to yield an estimate that represents the true relative risk. All analyses used sampling weights, and variance and 95% confidence intervals (CI) were also calculated. Univariate analysis was used to estimate unadjusted odds ratios and any variables showing an association at p < 0.05 with the outcome were included in the Mantel-Haenszel model to calculate adjusted relative risk (ARR). The models were adjusted for significant pregnancy, mental health, and sociodemographic variables, which included: age, marital status, education, employment, LICO, parity, time to prenatal care, planned pregnancy status, smoking status during pregnancy, a history of pre-existing depression, abuse, stress, and social support. ARR were calculated for all Aboriginal groups for all mental health and psychosocial variables (non-Aboriginal women were the reference group). We then stratified our analysis into four groups: non-Aboriginal, First Nations offreserve, Métis, and Inuit to compare women with PPD to those without PPD (reference group).

### **Results**

### Sample characteristics

Differences between Aboriginal and non-Aboriginal women were noted in terms of sociodemographic characteristics. Overall, First Nations off-reserve, Métis, and Inuit women were younger, more likely to be single, had fewer years of formal education, and were more likely to report being at or below the low-income cut-off (LICO) than non-Aboriginal women (see Table 1).

### Pre-existing and postpartum depression

First Nations off-reserve and Métis women reported a higher prevalence of pre-existing depression than non-Aboriginal women (22.1%, 28.8%, versus 17.8%), while Inuit women reported the lowest prevalence with 9.4%. When compared to non-Aboriginal women, after controlling for potential confounding variables, Inuit women were more likely to have pre-existing depression (ARR 1.9; 95% CI: 1.5–2.5), while Métis women were less likely to have pre-existing depression (ARR 0.8; 95% CI: 0.7–0.9). No differences were found among First Nations off-reserve women (ARR 1.0; 95% CI: 0.9–1.2).

Overall, First Nations off-reserve, Métis, and Inuit women had a higher prevalence of PPD than non-Aboriginal women (Table 1), with 12.9%, 9.1%, 10.6% reporting symptoms of depression as indicated by the EPDS compared to 5.6%. However, after adjusting for confounders, there were no statistically significant differences found for PPD between First Nations off-reserve, Métis and Inuit women compared to non-Aboriginal women (Table 2).

When comparing women with no PPD to those who experienced symptoms of PPD

TABLE 1
Sociodemographic and selected mental health characteristics among the total Maternity Experiences Survey (MES) sample stratified by Aboriginal and non-Aboriginal status

Variable	Non-Aboriginal (%, 95% CI)	Inuit (%, 95% CI)	Métis (%, 95% CI)	First Nations off-reserve (%, 95% CI)	<i>p</i> -value				
	n = 55 405	n = 239	n = 1456	n = 1435	•				
Sociodemographic variables									
Age group					< 0.01				
15–19	1.9 (1.7–2.0)	13.4 (9.2–18.9)	7.3 (6.0–8.9)	11.7 (10.1–13.7)					
20–24	12.0 (11.7–12.3)	38.1 (30.7–46.7)	26.3 (23.7–29.1)	25.2 (22.9–28.2)					
25–29	32.1 (31.7–32.6)	30.5 (23.9–38.4)	30.7 (28.0–33.7)	31.8 (29.3–35.2)					
30–34	35.0 (34.6–35.5)	13.0 (8.8–18.4)	25.3 (22.7–28.0)	21.1 (18.1–22.8)					
35–39	15.7 (15.4–16.0)	5.0 (2.6-8.8)	8.0 (6.6–9.5)	8.7 (7.3–10.5)					
40–44	3.1 (2.9–3.2)	0	1.4 (0.9–2.2)	1.5 (1.0–2.3)					
45–49	< 1	0	1.0 (0.5–1.6)	0					
Marital status					< 0.01				
Single, never married	6.6 (6.4–6.9)	_	15.5 (13.6–17.7)	25.7 (23.2–28.5)					
Married	62.5 (61.8–63.1)	-	51.3 (47.7–55.2)	27.0 (24.3–29.8)					
Common-law	29.1 (28.6–29.5)	-	30.5 (27.7–33.4)	40.9 (37.7–44.4)					
Divorced/separated	1.7 (1.6–1.8)	_	1.7 (1.1–2.5)	6.5 (5.2–7.9)					
Highest level of education completed					< 0.01				
< high school	6.7 (6.5–6.9)	51.9 (43.2–61.9)	13.5 (11.6–15.5)	28.4 (25.7–31.3)					
High school and/or some post-secondary	19.4 (19.0–19.7)	27.2 (21.0–34.7)	39.4 (36.2–42.7)	34.9 (31.9–38.1)					
Post-secondary	39.6 (39.0–40.1)	14.2 (9.9–19.9)	33.1 (30.2–36.2)	30.2 (27.5–33.2)					
University degree	34.2 (33.7–34.7)	4.2 (2.0–7.7)	14.1 (12.2–16.1)	6.3 (5.0–7.7)					
Employment status					< 0.01				
Employed	83.6 (82.8–84.3)	51.5 (42.8–61.4)	76.5 (72.1–81.2)	59.2 (54.9–62.9)					

Continued on the following page

TABLE 1 (continued)
Sociodemographic and selected mental health characteristics among the total Maternity Experiences Survey (MES)
sample stratified by Aboriginal and non-Aboriginal status

Variable	Non-Aboriginal (%, 95% CI)	Inuit (%, 95% CI)	Métis (%, 95% CI)	First Nations off-reserve (%, 95% CI)	<i>p</i> -value
	n = 55 405	n = 239	n = 1456	n = 1435	•
Parity					< 0.01
Primiparous	45.5 (45.0–46.1)	25.5 (19.5–32.8)	45.3 (41.9–48.9)	47.8 (43.8–51.0)	
Prenatal care					< 0.01
First prenatal care visit in first trimester	96.6 (95.9–97.5)	91.2 (86.9–96.9)	92.9 (86.2–96.1)	93.8 (87.9–96.9)	
Pregnancy planning status					
Planned pregnancy	74.4 (73.2–74.8)	53.9 (42.8–62.8)	53.4 (48.7–56.2)	55.4 (49.9– 58.7)	
Low-income cut-off					< 0.01
At/below LICO	13.9 (13.5–14.2)	36.0 (28.8–44.4)	28.6 (25.9–31.5)	47.0 (43.6–50.7)	
Above LICO	79.5 (78.8–80.3)	36.4 (29.2–44.9)	62.7 (58.7–66.9)	37.4 (34.3–40.7)	
Missing	6.6 (6.4–6.9)	27.6 (21.4–35.1)	8.6 (7.2–10.3)	15.5 (13.6–17.7)	
Mental health variables					
<b>Edinburgh Depression Scale</b>					< 0.01
Symptoms of PPD	5.6 (5.4–5.8)	10.6 (6.8–15.4)	9.1 (7.6–10.8)	12.9 (11.1–14.9)	
History (hx) of depression					< 0.01
Hx of depression	17.8 (17.4–18.1)	9.4 (5.9–14.2)	28.8 (25.9–31.4)	22.1 (19.7–24.7)	
Perceived stress					< 0.01
Somewhat stressful	45.3 (44.7–45.9)	45.6 (37.4–55.0)	44.0 (40.6–47.5)	47.1 (44.0–51.2)	
Very stressful	12.2 (11.9–12.4)	13.4 (9.2–18.9)	16.0 (14.1–18.3)	16.0 (14.0–18.2)	
Number of stressful events					< 0.01
High (≥ 3 events)	8.5 (8.3–8.7)	24.3 (18.4–31.4)	24.6 (22.1–27.3)	25.3 (22.8–28.0)	
Abuse					< 0.01
Experienced abuse	5.5 (5.2–5.6)	26.4 (20.3–33.7)	12.0 (10.2–13.8)	19.6 (17.4–22.0)	
Frequency of abuse					< 0.01
Once	42.9 (29.9–32.9)	55.6 (42.4–71.5)	35.4 (29.6–42.1)	40.3 (34.8–46.4)	
More than once	57.1 (55.3–59.0)	44.4 (32.8–58.9)	64.6 (56.6–73.4)	59.7 (53.0–67.0)	
Social support					< 0.01
No social support	< 1	4.2 (2.0–7.7)	2.1 (1.4–2.9)	0	
Low social support	8.9 (8.6–9.1)	15.3 (11.1–21.6)	7.4 (6.0–8.8)	13.0 (11.3–15.1)	
Alcohol use					< 0.01
Consumed alcohol in pregnancy	12.0 (11.7–12.3)	4.2 (2.0–7.7)	6.1 (4.9–7.5)	3.9 (2.9–5.1)	
Drug use					< 0.01
Used drugs in pregnancy	1.0 (0.9–1.1)	6.8 (3.8–10.9)	6.9 (5.6–8.3)	1.9 (1.3–2.8)	
Smoking					< 0.01
Smoked during pregnancy	8.2 (7.9–8.4)	44.4 (36.3–53.6)	16.6 (14.5–18.8)	12.1 (10.5–14.2)	

Abbreviations: CI, confidence interval; hx, history; LICO, low-income cut-off; PPD, postpartum depression.

Notes: Not all groups add to 100% due to rounding and missing information.

(stratified by ethnicity), non-Aboriginal women and First Nations off-reserve women who developed PPD were more likely to have a history of pre-existing depression. This observation was not found in Métis women and data could not be presented for Inuit women due to small cell counts (Table 3).

### Abuse/violence

A disproportionally higher number of Aboriginal women reported experiencing abuse compared to non-Aboriginal women. The prevalence of self-reported abuse was 19.6% for First Nations off-reserve women, 12.0% for Métis women, 26.4% for Inuit

women, and 5.5% among non-Aboriginal women.

When adjusting for confounding factors, First Nations off-reserve and Inuit women were more likely to experience abuse than non-Aboriginal women (ARR 2.8; 95% CI: 1.7–4.8 and ARR 4.3; 95% CI: 1.9–7.3).

<sup>-:</sup> suppressed due to small cell count (< 5).

TABLE 2
Unadjusted associations of mental health indicators among Aboriginal and non-Aboriginal women

	In	uit	Mé	étis	First Nations off-reserve			
-	Unadjusted RR (95% CI)	ARR <sup>a</sup> (95% CI)	Unadjusted RR (95% CI)	ARR <sup>a</sup> (95% CI)	Unadjusted RR (95% CI)	ARR <sup>a</sup> (95% CI)		
Edinburgh Depression Scale								
No PPD	1	1	1	1	1	1		
Symptoms of PPD	0.8 (0.5–1.4)	0.7 (0.2–1.6)	1.3 (1.0–1.8)	0.9 (0.4–1.8)	2.1 (1.7–2.8)	1.8 (1.0–3.2)		
Hx of depression								
No hx of depression	1	1	1	1	1	1		
Hx of depression	1.8 (1.2–1.6)	1.9 (1.5–2.5)	1.4 (1.1–1.8)	0.8 (0.7-0.9)	0.8 (0.6–1.0)	1.0 (0.9–1.2)		
Perceived stress								
Not stressful	1	1	1	1	1	1		
Somewhat stressful	0.5 (0.3–0.9)	0.8 (0.3–1.9)	0.9 (0.7–1.3)	0.9 (0.4–1.7)	0.6 (0.4–0.8)	0.8 (0.4–1.6)		
Very stressful	1.4 (1.0–1.9)	0.8 (0.4–1.5)	1.0 (0.7–1.3)	0.9 (0.6–1.4)	0.6 (0.4–0.7)	0.9 (0.6–1.4)		
Number of stressful events								
Low (< 3 events)	1	1	1	1	1	1		
High (≥ 3 events)	1.6 (1.4–1.7)	1.8 (0.8–3.1)	1.6 (1.3–1.7)	3.0 (1.7–5.3)	1.9 (1.6–2.4)	2.2 (1.3–3.9)		
Abuse								
No abuse	1	1	1	1	1	1		
Experienced abuse	3.6 (2.4–4.4)	4.3 (1.9–7.3)	0.8 (0.6–1.0)	1.3 (0.7–2.4)	1.2 (1.0–1.5)	2.8 (1.7–4.8)		
Social support								
No social support	1.5 (0.3–6.3)	1.9 (0.3–4.3)	0.4 (0.1–1.8)	1.1 (0.2–2.5)	0.4 (0.1–1.3)	0.7 (0.4–1.3)		
Low social support	5.9 (4.4–8.1)	4.2 (1.6–6.7)	0.7 (0.5–1.0)	0.6 (0.3–1.2)	0.8 (0.6–1.0)	1.2 (0.8–2.1)		
Social support	1	1	1	1	1	1		
Smoking								
No smoking	1	1	1	1	1	1		
Smoked during pregnancy	3.4 (2.4–4.5)	4.8 (4.0–5.8)	0.9 (0.7–1.2)	1.5 (0.8–1.8)	1.5 (1.3–1.6)	1.6 (1.3–1.9)		

Abbreviations: ARR, adjusted relative risk; CI, confidence interval; hx, history; LICO, low-income cut-off; PPD, postpartum depression; RR, relative risk.

Note: Reference group: non-Aboriginal women.

There were no significant differences of self-reported abuse between Métis women and non-Aboriginal women. However, when examining determinants of PPD within the respective ethnicity groups, having experienced abuse was a predictor for PPD among non-Aboriginal women (ARR 2.1; 95% CI: 1.3–3.5) but was not a predictor for Métis or First Nations off-reserve women. Data for Inuit women could not be presented due to unreliable estimates (attributed to small cell counts).

### Social support

Overall, more than half of survey respondents reported having social support available to them (56%). Inuit women reported the least amount of social support among all categories of women whereas the majority of non-Aboriginal women, First Nations off-reserve, and Métis women reported they had social support most or all of the time.

In comparison to non-Aboriginal women, there were no significant differences in social support for First Nations off-reserve or Métis women, but Inuit women were significantly more likely to report low social support (ARR 4.2; 95% CI:1.6–6.7). Having little or no social support was a positive predictor for PPD among non-Aboriginal women, but this was not the case for First Nations off-reserve or Métis women. Data for Inuit not presented due to unreliable estimates (attributed to small cell counts).

### Perceived stress and stressful events

Overall, all women reported that most days in the past year were somewhat stressful (44%) and very stressful (15%). First Nations off-reserve, Métis, and Inuit women reported a higher number of stressful events (more than 3 stressful events) during their pregnancy compared

to non-Aboriginal women 25.3%, 24.6%, 24.3%, compared to 8.5% respectively.

When compared to non-Aboriginal women, no significant differences in perceived levels of stress during pregnancy for all Aboriginal women were found. However, First Nations off-reserve and Métis were more likely to report a high number (more than 3) of stressful events (ARR 2.2 95% CI: 1.3–3.9 and ARR 3.0 95% CI: 1.7–5.3) than non-Aboriginal women. Levels of perceived stress and the number of stressful events were found to be positive predictors for PPD among non-Aboriginal women, however, only the number of stressful events was a predictor for PPD among First Nations women.

### Discussion

In this study, the prevalence of pre-existing depression was higher among selfreported First Nations off-reserve and

a Adjusted for age, marital status, education, employment, LICO, parity, time to prenatal care, planned pregnancy status, alcohol use, drug use and smoking status during pregnancy.

TABLE 3
Determinants of PPD among Aboriginal and non-Aboriginal women

	Non-Abo	original	Mé	étis	First Nations off-reserve			
	Unadjusted RR (95% CI)	ARR <sup>a</sup> (95% CI)	Unadjusted RR (95% CI)	ARR <sup>a</sup> (95% CI)	Unadjusted RR (95% CI)	ARR <sup>a</sup> (95% CI)		
Hx of depression								
No hx of depression	1	1	1	1	1	1		
Hx of depression	2.1 (1.7–2.5)	2.5 (1.8–3.5)	1.8 (1.0–2.6)	0.4 (0.2–0.7)	6.7 (5.2–8.0)	4.4 (1.4–8.6)		
Perceived stress								
Not stressful	1	1	1	1	1	1		
Somewhat stressful	4.1 (3.1–5.4)	7.6 (4.8–12.1)	1.0 (0.8–2.1)	0.7 (0.3-1.4)	b	b		
Very stressful	2.4 (1.9–3.2)	2.9 (1.9-4.3)	0.7 (0.1–1.3)	0.5 (0.3-0.8)	b	b		
Number of stressful events								
Low (< 3 events)	1	1	1	1	1	1		
High (≥ 3 events)	1.4 (1.3–2.1)	1.7 (1.3–2.7)	2. 6 (1.9–3.9)	1.1 (0.7–1.2)	1.3 (1.1–5.3)	2.3 (1.3–3.9)		
Abuse								
No abuse	1	1	1	1	1	1		
Experienced abuse	1.3 (1.1–1.6)	2.1 (1.3–3.5)	4.7 (1.2–6.6)	1.0 (0.5–1.8)	0.6 (0.4-4.3)	0.6 (0.2–2.7)		
Social support								
No social support	6.2 (3.8–9.9)	3.1 (2.3–3.9)	3.6 (1.0-6.4)	1.1 (0.7–1.6)	0.5 (0.4-6.0)	0.6 (0.4–1.1)		
Low social support	1.2 (1.0–1.5)	2.2 (2.0-3.1)	2.2 (0.8–5.1)	1.6 (0.8-4.1)	0.7 (0.1–2.3)	0.5 (0.3–1.1)		
Social support	1	1	1	1	1	1		
Smoking								
No smoking	1	1	1	1	1	1		
Smoked during pregnancy	1.5 (1.2–1.8)	1.3 (0.9–2.1)	1.0 (0.7–2.9)	2.5 (0.4–4.4)	3.7 (2.7–4.2)	2.4 (0.4–7.6)		

Abbreviations: ARR, adjusted relative risk; CI, confidence interval; hx, history; LICO, low-income cut-off; PPD, postpartum depression; RR, relative risk.

Notes: Reference group: women with no PPD stratified by ethnicity.

Inuit data are not available due to small cell counts and large variance.

Métis women than non-Aboriginal women. Inuit women had the lowest prevalence of self-reported pre-existing depression, and Aboriginal women reported a higher prevalence of PPD than non-Aboriginal women.

A meta-analysis revealed the strongest predictors of PPD included depression during pregnancy, anxiety during pregnancy, experiencing stressful life events during pregnancy, low levels of social support, and a previous history of depression.4 These predictors were consistent in our study among the non-Aboriginal population; however, with the exception of the number of stressful events among First Nations off-reserve women, the above stated predictors were not associated with PPD among Aboriginal women. Pre-existing depression was not a predictor for PPD for Inuit or Métis women in this study sample but was a positive predictor among First Nations off-reserve and non-Aboriginal women. Studies have shown there is a lack of culturally appropriate access to pre- and postnatal care for Aboriginal women, 14-19 and that the impact of intergenerational trauma on Aboriginal women, intersecting racism and sexism have an impact on mental health. While we were unable to identify any specific predictors aside from pre-existing depression, these other influences can be contributing to the higher prevalence of PPD among Aboriginal women and cannot be overlooked.

Many studies have found a link between abuse and PPD.<sup>12,17,18</sup> Research suggests that physical abuse during pregnancy is associated with additional predictors for preterm birth, particularly stress and behavioral predictors such as substance abuse.<sup>12</sup> The data in this study suggest that Aboriginal women experience a higher prevalence of abuse/violence and stressful events during the pregnancy period than non-Aboriginal women; however, the link between substance use and abuse was not seen when adjusting for

potential confounding variables (data not shown). In this study, abuse does not appear to be a risk factor for PPD among Aboriginal women but is positively associated with PPD among non-Aboriginal women. Regardless, the high prevalence of abuse self-reported by Aboriginal women is disconcerting and should not be ignored.

Pre- and postnatal screenings are important as they can facilitate the identification of potential predictors for PPD, ensure timely diagnosis, and allow early interventions to be initiated for the benefit of the woman and the baby.<sup>2</sup> While standardized screening tools can be used, our study highlights that known predictors for PPD may not be common in Aboriginal populations. Previous research shows lower levels of social support to be associated with higher rates of PPD in the postpartum period, but this was not found in our study. In our study we noted that First Nations off-reserve, Métis, and Inuit women

<sup>&</sup>lt;sup>a</sup> Adjusted for age, marital status, education, employment, LICO, parity, time to prenatal care, planned pregnancy status, alcohol use, drug use and smoking status during pregnancy.

<sup>&</sup>lt;sup>b</sup> Unable to report due to high variance.

reported higher levels of social support than non-Aboriginal women but having no or low social support was only predictive for PPD among non-Aboriginal women. A study by Leahy-Warren, McCarthy and Corcoran<sup>19</sup> found that differentiating the type of social support was important for predicting postpartum depression. They found that in the general population functional and informal social support was significantly related to postnatal depression whereas women who received informational support, instrumental support, emotional support and/or appraisal support were less likely to experience postnatal depressive symptoms. As this study did not distinguish the types of social support, we cannot further examine if differences in types of social support might help explain the higher social support reported by Aboriginal women or the lack of association with PPD.

A meta-analysis linked anxiety during pregnancy and experiencing stressful life events during pregnancy to the development of PPD.4 A dose-effect relation was found between the numbers of stressful life events experienced in the year prior to pregnancy and mean EPDS score. While we observed higher rates of stressful events among First Nations off-reserve, Métis, and Inuit women, higher rates of stressful events were only associated with a significant increase in the risk of developing PPD among non-Aboriginal and First Nations off-reserve women. A protective factor was observed among Métis women, which could not be examined among Inuit women as the data produced unreliable estimates (due in part to smaller cell counts).

### Limitations

There are limitations to our study. We are limited in our analysis to examine women with PPD/no PPD among Inuit women (Table 3). Indeed, due to the small cell counts, the estimates produced were unreliable. Further, as the Inuit sample size was so small, we did not have adequate power to detect differences in outcomes/ predictors where differences may actually exist. Variables were only included for analysis if they had a coefficient of variation less than 33.3%. Therefore, while the measures are considered good quality, some data in the Aboriginal sub-samples had larger variability than the non-Aboriginal sample. As this survey was conducted off-reserve due to operational reasons, the findings cannot be generalized to women

residing on reserves. The MES is a rich source of maternal data for Canadian women; however, further details on culture and other indicators that are specific to First Nations off-reserve, Métis, and Inuit women were not collected, which would permit further analysis.

### Conclusion

The prevalence of self-reported PPD was highest among Aboriginal women compared to non-Aboriginal women, although no statistical difference was found after adjusting for confounders. The information from this study can be used to further increase awareness of mental health indicators and predictors among Aboriginal women. Public health efforts should continue to include First Nation, Métis, and Inuit specific strategies to promote positive mental health within culturally holistic concepts of health and wellness. Our study highlights the importance of tailored screening and health promotion efforts for different cultures as the evidence indicates common predictors for PPD are not consistent for Inuit, Métis and First Nations off-reserve women.

### **Conflicts of interest**

The authors have no conflicts of interest to disclose.

# Authors' contributions and statement

CN devised the project, analyzed the data and wrote the first draft with input from all authors. KML and EKD contributed to the design of the project, provided input on data analysis, interpretation of data, and revised the manuscript after providing intellectual content and a critical review. VO provided editorial support and completed a critical review of the data. All authors discussed the results and provided comments on the manuscript.

The content and views expressed in this article are those of the authors and do not necessarily reflect those of the Government of Canada.

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# **Original qualitative research**

# Indicators to guide health equity work in local public health agencies: a locally driven collaborative project in Ontario

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### Abstract

**Introduction:** Funded by a Public Health Ontario 'Locally Driven Collaborative Project' grant, a team led by public health practitioners set out to develop and test a comprehensive set of indicators to guide health equity work in local public health agencies (LPHAs).

**Methods:** The project began with a scoping review, consultation with content experts, and development of a face-validated set of indicators aligned with the four public health roles to address health inequities (NCCDH, 2014), plus a fifth set of indicators related to an organizational and system development role. We report here on the field testing of the indicators for feasibility, face validity (clarity, relevance), reliability, and comparability in four Ontario LPHAs. Data were collected by two separate individuals or groups at each site, during two consecutive periods. These individuals participated in separate focus groups at the end of each test period, which further examined indicator clarity, data source availability and relevance. A third focus group explored anticipated indicator uses.

**Results:** Field testing showed that indicators addressed important issues in all public health roles. Although the capacity for indicator use varied, all test sites found the indicators useful. Suggestions for improved clarity were used to refine the final set of indicators, and to develop a *Health Equity Indicator User Guide* with background information and recommended resources.

**Conclusion:** The process of evaluating health equity-related activity within LPHAs is still in its early stages. This project provides Ontario LPHAs with a tool to guide health equity work that may be adaptable to other Canadian jurisdictions.

Keywords: public health practice, health equity, indicators, Ontario

### Introduction

Reducing health inequities—those differences in health associated with underlying systematic disadvantage (e.g. due to unequal access to power, income) that are

modifiable and considered unfair<sup>1,2,3</sup>—has become a global public health priority.<sup>3</sup> Achieving health equity—where all people have a fair chance to reach their full health potential and are not disadvantaged by social, economic and environmental

### Highlights

- Public health roles for reducing health inequities have been identified, but there is a lack of consensus in practice on the most effective strategies that local public health agencies (LPHAs) in Ontario should use to address health inequities at the local level.
- This study produced a comprehensive set of evidence-based, field-tested indicators that support LPHAs' health equity work as required by the Ontario Ministry of Health and Long-Term Care's public health standards and that align with Canadian public health roles for reducing health inequities across population groups.
- Although developed for the Ontario context, the indicators may be adaptable to other Canadian jurisdictions.

conditions<sup>1</sup>—has been characterized as an ethical imperative and a matter of social justice and human rights.<sup>2,3</sup> The Canadian public health sector, with its foundational values of social justice and equity,<sup>4</sup> and its ethical obligation to assure the conditions of population health,<sup>5</sup> has an important role to play in promoting health equity.<sup>6</sup>

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In the Province of Ontario, Canada, the release of the Ontario Public Health Standards (OPHS)<sup>7</sup> in 2008 signaled changes regarding the way local public health agencies (LPHAs) should assess, plan, implement and evaluate public health programs and services. Changes included an increased emphasis on addressing the determinants of health and reducing health inequities. A key component of the OPHS requirements is to identify and work with "priority populations." Complimentary to the OPHS, the Ontario Public Health Organizational Standards (OPHOS),8 released in 2011, established the management and governance requirements for LPHAs. Boards of health are required to have a strategic plan and ensure that, within it, they describe how equity issues will be addressed in the delivery and evaluation of program and services.

Although addressing social determinants of health (SDOH) to reduce health inequities is fundamental to the work of public health in Ontario, at the time that this research was conducted, there were no program standards that clearly defined the health equity mandate and requirements for local boards of health and their public health agencies. However, addressing the social determinants of health to reduce inequities was recognized as foundational to public health practice.7 While the literature provided consistent definitions of public health roles for addressing social determinants of health to reduce health inequities,6 there was a lack of consensus in practice on the most effective strategies that LPHAs could and should use to address health inequities at the local level.9-11 An informal process in 2013, led by a provincial health equity group in Ontario (that included RS and CW), identified an initial suite of health equity indicators12 derived from the OPHS which garnered some interest and support from the field. However, this approach to indicator development was acknowledged as a starting point requiring further evaluation prior to any wide-scale adoption.

Funded by a Public Health Ontario (PHO) 'Locally Driven Collaborative Project' grant, our objective was to develop a set of evidence-based and rigorously tested indicators to monitor and guide health equity and SDOH-related activity in Ontario LPHAs. Our scope of interest focussed on identifying indicators that would assist in developing and assessing the public health roles specific to addressing the

social determinants of health to reduce health inequities across population groups, identified by the National Collaborating Centre on the Determinants of Health [NCCDH].<sup>6</sup> To our knowledge, these roles (described later) were the first to be articulated that were specific to the Canadian context and were based on empirical evidence.

Our team was led by the last author and five additional public health practitioners (CW, DA, JR, KM, SL) representing six Ontario LPHAs, in partnership with four university-based researchers (AK, BC, KS, MJL) who assisted throughout the project. An earlier phase of the project involved a scoping reviewing of the literature (reported elsewhere<sup>13</sup>) to identify validated indicators that could be used to reflect the health equity activity within local public health agencies and to help guide future activity within each of the identified NCCDH<sup>6</sup> public health roles. The scoping review included obtaining initial feedback on a potential suite of indicators from provincial, national and international health equity and indicator development experts (key informants), and then integrating the results of the key informant interviews to derive a set of indicators for field testing. Both the literature review and key informant steps confirmed that the use of indicators to assess, measure and report health equity work in public health was still in an early developmental stage. The project team used a group consensus method to identify an initial set of indicators in each of the four NCCDH6 health equity roles. In accomplishing this, a fifth role pertaining to internal organizational systems emerged. A workbook containing indicators representing these five public health roles in promoting health equity was prepared for the next phase of the project—the field testing of indicators—as described in this article.

In both phases of the project, we used a definition of health equity (noted in the introduction) that has been widely adopted in the public health community.¹ Some might critique this definition for moving away from the responsibilities of the health care system. However, our position is that a comprehensive understanding of optimal health reflects research linking health and sociopolitical, economic and environmental conditions.

### Methods

To test indicators of health equity work for feasibility (ease of data collection), face

validity (clarity, relevance), reliability and comparability, an exploratory, multiple case study design, as advanced by Yin,14 was adopted as a framework. For the project, the case was defined as the LPHA test site. Four LPHA test sites were used to support the identification of convergent findings and to facilitate exploration of variation in capacity to implement the assessment tool. LPHAs were recruited at the time of study initiation, through team members' professional networks, to participate as test sites. Using maximum variation sample selection,15 preference was given to sites that were representative of a variety of Statistics Canada<sup>16</sup> peer groupings (urban, rural, urban-rural mix) and of different public health governance structures (autonomous public health board, semi-autonomous public health board, regional council acts as public health board). See Table 1 for a description of the test sites. Ethics approval was received as required from the institutions of all participating project team members and LPHA

### Recruitment and orientation

We were not prescriptive about the recruitment of participants, other than to provide eligibility criteria. Individuals were eligible to participate if they had been employed by the LPHA for at least two months and were a member of a 'social determinants of health' or health equity team or related working group in the LPHA. Each test site then determined their own process of identifying which staff would assist with data collection based on what worked best for them in terms of their size and structure. In some sites, data collection was limited to one or two individuals: in others, data collection was divided between members of a team. Interested individuals contacted the project research assistant directly. Consent to participate was obtained from all individuals (n = 14) from all sites prior to the commencement of data collection.

These individuals were invited to participate in an orientation webinar, provided by project team members prior to commencing the first round of data collection. In advance of the webinar, all test sites received a workbook (discussed below) containing a draft of (a) the proposed indicators; (b) background information and definitions; and (c) data collection worksheets. This made it easier for participants to ask questions about the process.

### TABLE 1 Description of test sites

Pilot test site	Governance model	Peer group <sup>a</sup>
Site 1	Regional Council acts as public health board	Urban / rural mix <sup>a</sup> Population centre with high population density and rural mix High percentage of visible minority population Low percentage of Aboriginal population Average employment rate
Site 2	Autonomous public health board	Sparsely populated urban / rural mix <sup>a</sup> Populationcentre and rural mix Average percentage of visible minority population High percentage of Aboriginal population
Site 3	Autonomous public health board	Mainly rural <sup>a</sup> Mainly population centre with moderate population density Average percentage of visible minority population High employment rate
Site 4	Semi-autonomous public health board <sup>b</sup>	Metro centre <sup>a</sup> Large population High percentage of visible minority population Very low Aboriginal population

<sup>&</sup>lt;sup>a</sup> As identified by Statistics Canada.<sup>9</sup>

As well, the provided materials established a common understanding of project goals. The presentation was recorded as a cached webinar for access by any participant unable to attend the orientation meeting.

### Field testing of indicators

All LPHA sites participated in this phase concurrently, over a period of approximately 16 weeks (June-September 2015). The field testing process was conducted in a series of five steps. Although the process of data collection occurred in sequence, it should be noted that analysis, synthesis and indicator development processes were ongoing, emergent and iterative.

Step 1 (Weeks 1 - 4): Test sites were tasked with collecting indicator data using the standard workbook containing specific data collection worksheets, developed by the research team. Worksheets included a series of questions about indicator relevance, clarity, and feasibility (ease of data collection) (examples of worksheets can be found in the *User Guide*, discussed later in the article). Sites were asked to nominate one individual who would assume primary responsibility for data collection in Round 1.

Step 2 (Weeks 5 - 7): The participants who were 'most responsible' for the data collection process in the first round of data collection at each test site were asked to participate in a two-hour telephone focus

group led by the team research assistant (KS). Questions prompted participants to discuss issues of clarity, feasibility and relevance for each indicator item. The discussion (in this, and subsequent focus groups) was audio-recorded and transcribed verbatim. All worksheets completed by each test site were returned to the research assistant by email. Data collected to complete indicators were entered into Microsoft Excel spreadsheets. All focus group transcripts and open-ended responses to worksheet questions were entered into NVIVO (version 10) for preliminary coding and content analysis. In addition, information from the test sites pertaining to ongoing refinement of the indicators or the information to be contained in a possible 'user guide' to accompany the indicators was uploaded to the project team's collaborative site for ongoing development. This approach to data collection and analysis was used throughout the remaining stages of the project.

Step 3 (Weeks 8 - 11): Test sites were asked to complete a second round of data collection, using the worksheets as before. However, each site was asked to nominate a different individual to oversee this task. Data collectors in Round 2 were supplied with a guidance document based on the results of the first focus group discussions (described further in the 'Results' section).

Step 4 (Weeks 12 - 14): A second two-hour telephone focus group was conducted with the four participants most involved

in the second round of data collection at each test site. The focus group used the same questions as prompts as in the first focus group, but was informed by the previous discussion group, the analysis and the production of the guidance document.

Step 5 (Weeks 15 - 16): A third and final telephone focus group was held to discuss relevance and anticipated use of the information collected from the indicators. This group was open to all individuals who had participated in data collection at each site.

### Data analysis

Following the first focus group, all data collected by the test sites in response to the indicator items were compiled in such a way that results by site could be viewed easily. Open-ended responses from test site workbooks were compiled and imported for content analysis into NVivo. Transcripts from the first focus group were likewise imported into NVivo for analysis. Within the NVivo environment, preliminary coding was conducted by the research assistant to identify common concepts associated with clarity, feasibility (barriers and facilitators, ease of data collection) and relevance associated with each indicator. The results of this analysis (of both the workbook and focus group data) were reviewed by several other team members who provided refining comments. Based on these initial procedures, a guidance document was created to provide feedback to the individuals at each test site who would be responsible for conducting Round 2 data collection activities. In addition, concepts identified within the initial analysis that could be used to refine a) the indicator items, and b) the background and definitions that accompanied each item in the indicator workbook were summarized and posted on our collaborative site online. Within the online working space used by the research team, these comments were used to assist with the refinement of the indicators and associated testing materials. The process for refinement began prior to the second focus group and continued until all concepts and comments identified during the content analysis of Round 2 data could be addressed.

Following the second focus group, transcripts were imported into NVivo for analysis, as were the same feasibility responses from the Round 2 test site worksheets as

<sup>&</sup>lt;sup>b</sup> This is a board that has authority for policy setting but not for finances. Budget matters must be approved by municipal council.

above. Worksheets from the second round of data collection were used to enrich cross case comparisons. Content analysis was carried out as described above. Concepts and comments for indicator refinement following Round 2 were compared with Round 1, summarized and added to the online working space where they were used to inform the ongoing refinement process being conducted by the research team. As before, data collected in response to the indicators were entered into the Microsoft Excel spreadsheets. The third and final focus group was recorded and transcribed as for all other interviews and focus groups. Content analysis proceeded as described previously.

### Results

Field testing resulted in refinement of a set of 15 indicators, organized into five categories. Four of these categories are based on the four public health roles for promoting health equity, outlined by the NCCDH: $^6$  (i) Assess/report inequities (n = 4 indicators); (ii) Modify/orient programs/ services (n = 3); (iii) Engage in community and multi-sectoral collaboration in addressing the health needs of these populations through services and programs (n = 2); and (iv) Lead/support/participate with others to address policies (n = 2). The findings from phase 1 of the project led us to add a fifth category of indicators (n = 4) related to an organizational and system development role. Table 2 provides an example of one indicator for each of the five public health roles. Key findings regarding the relevance, clarity, feasibility, reliability, and applicability of these indicators are discussed below.

#### Relevance

Participants from all test sites agreed that the indicators were important and involvement in the assessment process was valuable. They stressed that the information collected should not be used to compare LPHAs for provincial performance expectations but would be better used to help agencies focus their attention to issues of health equity and learn from each other

TABLE 2 Examples of indicators for public health roles

Role	Example of indicator
I. Assess and report	A) Does your public health agency conduct routine data analysis of health outcomes of public health importance stratified by demographic and/or socioeconomic variables? Yes   No  How frequently?
	□ Monthly
	□ Semi-annually
	□ Annually
	□ Other (please specify)
	B) Please check each variable for which information is included and stratified (as appropriate). Please note that the list provided is not exhaustive.
	□ Sex
	□ Gender
	□ Age group
	□ At least two social markers (e.g. education, income, ethnicity, immigrant status, sexual orientation)
	□ At least one geographical marker (e.g. municipality, urban or rural, neighbourhood)
	□ Aboriginal or indigenous identity (where possible)
	□ A summary measure of absolute inequity (e.g. absolute difference slope index of inequality, summary measures of socioeconomic inequalities in health)
	□ A summary measure of relative health inequity (e.g. disparity rate ratio, population attributable fraction, relative index of inequality, concentration index)
	□ Other (please specify)
II. Modify/orient programs and services	A) Does your public health agency employ a mechanism to ensure that operational planning includes a health equity assessment of programs and services provided by the health unit, at least annually (or with any updates)? Yes   B) Does the public health agency provide a standardized health equity assessment tool for staff to use in the assessment of programs and services?
	Yes □ No □ If yes, please provide a list of tools used:
	C) Have any public health agency programs or services been modified as the result of a health equity assessment?  Yes $\square$ No $\square$ If yes, please list and describe:
III. Engage in community	A) Does your public health agency have an organizational level community engagement strategy? Yes $\square$ No $\square$
and multi-sectoral collaboration	B) If yes, does this strategy include or address priority populations experiencing health inequities? Yes $\square$ No $\square$ If yes, please elaborate:
IV. Lead, support and participate with others to address policies	How many position and policy statements, vetted and approved by the board of health (over the past year), reflect advocacy for priority populations experiencing (or at risk for experiencing) health inequities?
V. Organization and system development	A) Does the board of health's strategic plan describe how equity issues will be addressed? Yes   No   If yes, please explain.  B) What time period (in years) does the current strategic plan cover? Please provide dates.  Does the strategic plan include outcome targets? Yes   No
	If yes, please provide.

through informal mechanisms. As two participants noted:

...this is about raising the bar up for everyone, not pointing fingers...everyone is at a different place along the path

good to have as a guideline or primer to encourage health units to look at and use and include in our own performance measurements and data collection and look at the indicators of what we should look at and focus on.

### Clarity

While many of the indicators were considered to be understandable, particularly in the role of organizational and system development, participant feedback called for improvements to indicator clarity as well as revisions to the background and definition information that was provided to the sites as part of the testing materials. Following the first focus group, and after the preliminary analysis of the focus group and written workbook responses, it became apparent that several issues related to indicator clarity needed to be addressed in the feedback provided to test sites prior to the second round of data collection. First, there was confusion over the use of "Board of Health" in the indicator language. In response, sites were instructed to interpret "Board of Health" as "local public health agency" for Round 2. In the final version, the indicators have been revised accordingly. Sites also requested clarity over the purpose of the exercise and wished to know against what standard their responses would be judged. All materials accompanying the indicators now strongly emphasize that the information gathered is for the LPHA to reflect on their own practices and areas for improvement. Lastly, respondents provided comments and suggestions for improving the clarity of indicators and background definitions. In some cases, respondents noted that lack of clarity hindered their ability to complete (or evaluate the relevance of) the indicator. We used this feedback to improve the workbook and indicators.

### Feasibility

### **Barriers to completion of the indicators**

For completion of data collection related to indicators in Role 1—those typically related to the reporting of epidemiological or population data—barriers identified in both rounds were mostly related to the availability and quality of data sources. Not "being able to access the right data at the right time" and not having "sources of data that focus specifically on priority and vulnerable populations" were specific barriers noted as was the "cancellation of the long-form census." All test sites noted that there were limitations regarding potential data quality. Concerns were expressed regarding sample size (i.e. "sample size for us is going to be a constraint because it will be very difficult for our populations to be stratified") especially when the data were collected from "public health data sources" and for smaller agencies. For completion of other indicators that did not use traditional epidemiological or population data, the test sites reported that there was often no single, centralized place where information was stored, or a strategy put in place for capturing it at the organizational level. In those cases, it was challenging to know where the data were located and/or whom to approach to find the information needed.

Other barriers to the completion of the indicators included lack of time and limited resource capacity. The process of completing this data collection activity required more time than was originally estimated, partly because of the type of information participants needed to access, and the lack of coordinated data collection, storage and mechanisms for communicating the information within the agency, as mentioned above. Smaller LPHAs noted "we don't have the people or the time to put toward this the way we'd like to." In all focus groups, participants noted that data collection was more difficult if the issue addressed by the indicator had not been made a priority for the agency. As one individual stated, "when it is not visible and it's not a priority, it doesn't get done."

### **Facilitators to completion of the indicators**

All test sites noted that commitment was essential to a successful data collection process—particularly given that, for some indicators, there was no clear mechanism for data storage or communication. Respondents noted that indicator completion was much easier in areas where there was a strategic plan that explicitly addressed health equity within the organization and where there was strong leadership supporting the commitment to equity work.

As one individual noted, "we have leadership, strong leadership support for this work and prioritizing this work and I think that's a real strength." Indicator areas that had been included as a strategic, organizational priority were more likely to be associated with established and accessible mechanisms for data storage or dissemination, such as website pages, or balanced score cards, to which respondents could turn to in their data collection process. Relationships were also noted as an important facilitator to data collection—particularly regarding those indicators that called for engagement with or dissemination to the community. Respondents noted that "there is a lot of collaboration, inter-professional connections and a lot of community members involved," and "we see our strengths in participation...as part of a collaborative partnership."

### Reliability

After the first focus group, the project team chose, based on feedback from test sites, to provide them with some clarification to assist them in their data collection before the second focus group. As a result, a comment cannot be made about the reliability of the indicators. The team felt strongly that supporting the pragmatic application of the workbook outweighed the ability to examine indicator reliability.

### **Applicability**

In the final focus group, participants from both data collection periods at each site discussed what they had learned and how they might apply information gained from the pilot testing of the indicators.

- 1) All participants noted that the process had highlighted the need for a strong, organizational approach to health equity activities. Individuals noted a lack of a "comprehensive approach" across the organization despite doing well in "some areas, in some programs and in some divisions, but not across the whole health unit." One individual suggested that "having a strategy... would really increase our capacity to be engaged."
- 2) Completion of data collection for the indicators served as a **prompt for future planning**. Participants noted that by completing indicators, they

realized that "this is what we should be doing" and "this indicator is giving examples of good practice, better practice." The process "really raised awareness" and "raised the awareness of the importance of the work and, I think, really put some wheels in motion."

- 3) Collecting this data helped participants to think about doing things differently. For example, participants noted that they should plan to be more inclusive in their methods of information dissemination (e.g. "more in plain language," "use more accessible formats"). They talked about mandating activities related to health equity, such as Health Equity Impact Assessments, and improving mechanisms for internal communication around health equity activity within their own organizations.
- 4) For some participants, data collection had **provided an opportunity to discover activities within their own agency**. These participants noted the need to improve internal communication (e.g. "might be a pocket of good work happening somewhere that's just a best kept secret"; "we learn something is happening in a program area or division area that we weren't aware of, it might create better internal partnership opportunities").

### Cross case analysis

The responses to the testing of indicators were examined across all sites to explore the influence of context (i.e., geography and governance structure). A comparison of indicator completion across all four test sites revealed that Sites 2 and 4 seemed to find completion of the indicators easier than the other two sites overall. These two sites (one sparsely populated, urban/ rural mix and the other a large metro site) reported very different data collection methods. The sparsely populated site relied on engagement of key individuals from within the organization through a meeting at which the indicators were addressed collectively. The large metro site had a larger number of data collecting participants who engaged members of various teams who could best address the indicators and assist in data collection.

When comparing completeness of data collection, there was no evidence that

LPHAs with autonomous Board structures had any relative advantage in terms of their ability to collect data. The LPHA with the semi-autonomous Board appeared to have the fewest gaps in indicator data, while the site where the regional council acts as the Board had the most information gaps. The sites with autonomous Board structures fell between the two in terms of data completeness.

There was consensus in responses provided across the four sites for the following indicators:

- 1) All agencies identified and planned for priority populations (although there was a standard and explicit process reported in only two of four sites) (Role 1, Indicator 1).
- 2) All sites involved community members from priority populations in data collection activities other than surveys (Role 1, Indicator 3).
- 3) All sites reported forming active partnerships with most of the non-health partners listed (Role 3, Indicator 2).
- 4) All sites reported having 4-year strategic plans (though they vary in focus regarding health equity) (Role 5, Indicator 1).
- No sites reported having performance appraisals for health unit staff or management that require health equity goals (Role 5, Indicator 4).

Having said this, given the limited scope of testing, we viewed the findings of the cross-case analysis as preliminary signposts for future work rather than definitive conclusions about the study sites.

### Development of a User Guide

Based on feedback received from the test sites, we created a *Health Equity Indicators* for Ontario Public Health Agencies: User Guide. <sup>17</sup> This Guide is presented in sections corresponding to each of the five indicator roles outlined earlier. Within each section, each indicator is accompanied by additional background information. References, resources, a glossary of terms and working/operational definitions, and worksheets for each indicator are provided at the end of the document.

### Discussion

Tackling issues of inequity is a major focus of any public health system and, as

outlined in the Ontario Public Health Standards,<sup>7,8</sup> addressing the determinants of health is fundamental to the design and provision of effective public health programs. However, addressing the determinants of health, particularly as they pertain to issues of inequity in health, can be challenging as inequities are often multi-factorial, values-oriented, and the result of complex relationships between social hierarchy, economic and financial restraint, and political ideology.18 Given the complexities involved in addressing inequities in public health, it has become important to not only evaluate health outcomes as they pertain to inequities but also the processes and related activities of the LPHAs responsible for implementing public health programs. Ziglio19 argues that addressing health inequities is an overall system performance issue and requires a sustained approach to improving capacity. Most public health systems have tools, such as measurement indicators, in place to monitor and evaluate the functioning of the health system on a "routine basis." However, performance indicators, as they relate to how local public health agencies assess addressing issues of inequity, are far less common. The literature review<sup>13</sup> conducted in the first phase of our study revealed that, in spite of some efforts to develop tools, frameworks and indicators to assist public health agencies in equity-related work,21-25 we could not identify any evidence-based indicators that could be used by Ontario LPHAs to monitor and guide health equity and SDOH-related activity within each of the defined NCCDH 6 public health roles. Furthermore, most of the identified indicators represented a connection between public health performance and health status outcomes. We recognize that some of these outcomes are seen as sensitive markers in the path to achieving health equity. Health outcome measures are useful to public health units for helping them identify areas of inequality within their local populations that may be prone to experiencing inequity. However, these indicators do little to assist in assessing the impact or effectiveness of programs and services administered through a public health agency.<sup>26</sup>

This project produced a comprehensive set of evidence-based, field-tested indicators and an accompanying *User Guide* that support LPHAs' work to address health inequity as required by the Ontario Ministry of Health and Long-Term Care and that align with identified Canadian

public health roles6 that are viewed as being fundamental in reducing health inequities across population groups. They are designed for application at the local level where boards and public health agencies are active and accountable. For example, evidence-based indicators could be used as a performance management tool to guide and monitor progress in meeting the public health equity mandate effectively established in Ontario's legislative framework. Boards of health could report their results to demonstrate accountability to their funders and the public, providing information to show that inequities are being addressed at the local level. These indicators could be a first step toward incorporating health equity-related performance measures into future accountability agreements and/or the development of an equity-specific Foundational Standard to include in the OPHS. Accountability agreements, which are used to monitor both compliance and performance, currently do not address this area of public health activity. Holding local boards of health accountable for demonstrating progress towards addressing health inequities in their local communities would potentially make these indicators, and any others that would be developed, useful internal tools. At a minimum, these indicators help boards organize their work into five strategic areas. As a starting point, they can generate a learning conversation that could spread across important partnerships and collaborations that are required to set significant and meaningful health equity targets and to achieve them.

It is important to note that these indicators are not meant to be used in a competitive fashion through provincial comparisons, but rather for developmental purposes. The indicators are most useful as a way of determining, internally, the extent to which LPHAs are working towards health equity-related activity in programs and services, where improvements can be made, and progress made over time. The *User Guide* may start or enhance the discussion within Ontario LPHAs about health equity as a priority, required resources or capacity issues, or help to identify barriers to health equity work.

Participants identified several operational issues that acted as challenges to the completion of the indicators, such as the need for improved data collection and storage, or for an organizational equity plan to be put in place. The introduction and integration

of new organizational practices in LPHAs can face resistance for many reasons, including the often ignored "social determinants of action." For one, each sub-unit has developed its own collective processes around sense-making, coalition building and rhetorical strategies that need to be addressed for successful wide-level change.27 And while there might be little debate over the value of achieving health equity, it is important to acknowledge that there are variable costs (e.g. resources needed to achieve health equity strategies) across the organization.27,28 Identifying where the winning and losing occur will be vital for buy-in across organizational and professional boundaries.29

### Limitations

This was a limited field test of health equity indicators at only four of 36 LPHAs in Ontario; therefore, it is possible that we did not capture all the potential experiences regarding indicator applicationespecially related to feasibility of data collection. Our ability to draw meaningful inferences from the cross-case comparison was also limited. For example, if additional northern/ isolated health units had participated in the study, perhaps we would have learned more about the feasibility of data collection in those contexts. as compared to southern contexts. In addition; the reporting requirements attached to the project, involving deliverables due by certain dates, meant that limitations had to be imposed on the time available for participants to collect data for each indicator. It is possible that, with more time, the feasibility of indicator use may have been different. Further evaluation of the reliability and validity of indicator items would also be ideal.

Lastly, data pertaining to operational issues were revealing in terms of identifying obstacles to addressing health equity. However, since this was a limited test, the *User Guide* would need to be adapted and used much more broadly and repetitively to provide a comprehensive understanding of operational issues. Anecdotal evidence indicated that some Ontario LPHAs were using the indicators to guide their work. More formal study of this use is currently underway.

### Conclusion

Strengthening organizational capacity for health equity action has been identified as a top public health priority in Canada. <sup>6,30</sup> Through a deliberate, systematic and iterative

process that was informed by individuals who are acknowledged experts in the areas of health equity, social determinants of health and indicator development, as well as the practical experience of individuals working within Ontario LPHA contexts, we compiled a set of indicators that might be used to reflect health equity activity at the level of the public health unit organization. These indicators are accompanied by background information and definitions that were also developed by a process of review, testing and consultation with our collaborative partners as well as the individuals engaged in data collection practices at LPHAs.

While we acknowledge that the process of evaluating health equity-related activity within organizations is in the early stages, we view these indicators as one tool that will be available to LPHAs to strengthen organizational capacity for health equity action—a tool that can lead to greater consensus among Ontario's boards of health regarding how to address the social determinants to reduce health inequities in their regions. Although developed for the Ontario context, the indicators may be adaptable to other Canadian jurisdictions.

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### **Conflicts of interest**

The authors have no conflicts of interest to disclose.

# **Authors' contributions and statement**

All authors designed the study and developed the data collection and analysis

protocols. KS completed the data acquisition. All authors contributed to data analysis. BC took the lead in drafting and revising the paper, with input from RS, AK, MJL, KS, SL, KM and CW. All authors read and gave final approval of this version to be published.

The content and views expressed in this article are those of the authors and do not necessarily reflect those of the Government of Canada.

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# **Original quantitative research**

# Effectiveness of the CANRISK tool in the identification of dysglycemia in a Canadian South Asian Population

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### **Abstract**

**Introduction:** South Asians have a higher than average risk of developing type 2 diabetes. We ascertained the effectiveness of CANRISK, an existing diabetes risk assessment tool, examining its sensitivity and specificity at two different predetermined scoring cut-off points comparing those participants under the age of 40 and those 40 and over. We examined the predictive ability of a model based on CANRISK variables, comparing ethno-specific body mass index (BMI) and waist circumference (WC) cut-off points with the original BMI and WC cut-off points to see if predictive ability could be improved for this population.

**Methods:** Canadian South Asians of unknown diabetes status, age 18 to 78, were recruited across seven provinces from various community or health centers. CANRISK variables were collected followed by oral glucose tolerance testing. Descriptive analysis, logistic regression including alternative ethno-specific BMI and WC cut-off points, and sensitivity and specificity analyses were performed.

**Results:** 832 participants were recruited (584 under age 40). Using the entire study sample, logistic regression models including CANRISK variables predicted dysglycemia effectively (AUC of 0.80). However, by using alternative BMI/WC cut-off points with the scoring algorithm, predictive power via AUC was not improved. Sensitivity and specificity of CANRISK using the original pre-determined "high risk" cut-off point of 33 points in individuals age 40 years or over were 93% and 35%, respectively; in individuals under 40, these were 33% and 92%, respectively. Using the lower pre-determined "moderate risk" cut-off point of 21 points improved the sensitivity to 77% and specificity to 53% in the younger age group.

**Conclusions:** The existing CANRISK is an adequate risk assessment tool for dysglycemia in Canadian South Asians for those age 40 years and over; however, the tool does not work as well for individuals under 40. The lower cut-off of 21 points may be warranted for younger individuals to minimize false negatives. Ethno-specific BMI/WC cut-off points did not improve predictive ability of the CANRISK scoring algorithm as measured by AUC.

**Keywords:** CANRISK, Type 2 Diabetes, South Asians, risk-assessment, screening, sensitivity and specificity

### Highlights

- CANRISK data were analyzed from a convenience sample of Canadian South Asians; 70% of participants were under 40 years old, 12.4% had prediabetes and 3.7% had undetected diabetes.
- CANRISK is an adequate risk assessment tool for dysglycemia risk in Canadian South Asians aged 40 and over using the standard "high risk" score cut-off point; the "moderate risk" cut-off point of 21 was shown to be more sensitive for individuals under 40, highlighting how differently CANRISK performs by age.
- Alternative ethnicity-specific body mass index / waist circumference cut-off points did not improve the predictive ability of a logistic regression model using the CANRISK variables.

### Introduction

South Asians (people claiming heredity from India, Pakistan, Bangladesh, Sri Lanka, Nepal, and Bhutan) are at a higher risk of developing type 2 diabetes (T2DM) than the average Canadian. For South Asians in North America, this risk is two to three times higher than the general population, with an earlier mean age at diagnosis. When compared to immigrants from the United States or Western Europe, the prevalence odds ratio for diabetes among South

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Asian immigrants to Canada was 4.01 for men and 3.22 for women.<sup>3</sup> This increased risk may be due to biological factors, a preponderance to be sedentary and certain dietary factors.<sup>4-14</sup>

At 4.8% of the population, people of South Asian origin are the largest visible minority group in Canada.15 Given their population size, growth rate16 and increased risk for T2DM, it is important to validate a diabetes risk assessment tool for the Canadian South Asian population. Additionally, the onset of diabetes for this population may occur earlier, which may require that screening be initiated at an earlier age.2 A validated risk assessment tool has been suggested for younger South Asians, 17 as evidence shows that diabetes detected and treated at an earlier time point can slow the progression or even prevent frank diabetes. 18-20

The Public Health Agency of Canada's diabetes risk assessment tool, CANRISK, was developed based on a Finnish diabetes risk assessment tool.21 It is now widely used across Canada. It was developed for those aged 40 or over, both for use in a primary care setting and by individuals themselves. Furthermore, it is used to assess risk of prediabetes and diabetes (dysglycemia) and to determine which individuals would benefit from further targeted screening. Although recommended,22 it is not feasible to screen everyone aged 40 years and over. The tool consists of a series of questions that form a risk score, resulting in categories based on dysglycemia risk (low = a score below 21, moderate = 21-32, high = 33 +). These existing score cut-off points were determined by modelling data from a large sample of Canadians from seven provinces (n = 6223) where CANRISK was administered in conjunction with the gold standard oral glucose tolerance test.23 It is these score cut-off points that are used in practice for all populations across Canada. It is also important to note that CANRISK was originally validated on a Canadian population aged 40 and over,23 and is, therefore, not validated in a younger general population. However, a recent study using a sample of Indigenous Peoples, similar to the current study, found that CANRISK could be used on those below the age 40 with an adjustment of the score cut-off in order to improve the tool's sensitivity and reduce false negatives for this age group.24

When CANRISK was developed,23 only a small number of Canadian South Asians (n = 323), most of whom were 40 years or older, were included in the sample used to develop the scoring algorithm. Therefore, it has not been specifically validated among Canadian South Asians, over or under 40 years of age. Furthermore, both waist circumference (WC) and body mass index (BMI) have been linked to diabetes in South Asians at lower cut-off points than those in other ethnicities.<sup>25,26</sup> One study showed that Canadian South Asians have a glucose level at a BMI cut-off point of 21.0 kg/m<sup>2</sup> corresponding to that of Caucasian Canadians with a BMI of 30 kg/ m<sup>2</sup> <sup>27</sup>. Higher glucose levels at lower BMI levels may lead to T2DM at lower BMI levels. Therefore, the inclusion of ethnicspecific cut-off points may yield better predictive ability than the original CANRISK WC/BMI cut-off points.

The primary aim of this paper was to evaluate the effectiveness of CANRISK as a risk assessment tool for dysglycemia as measured by a standard oral glucose tolerance test (OGTT) in a population exclusively comprised of South Asians residing in Canada, with emphasis on a younger population aged 18 to 39. The secondary aim was to test whether the predictive ability of a logistic model including the variables from CANRISK would be improved with ethnic-specific BMI and WC cut-off points specific to South Asian populations.

### Methods

As part of the validation of the CANRISK tool, the Public Health Agency of Canada collected data from a large multi-ethnic convenience sample of Canadians from across Canada.<sup>23</sup> They have since collected a second phase of data, focussing on people of higher risk ethnicities aged 20 to 39 years, and the current study analyzed a sub-sample of South Asian participants from this data set, pooled over both phases of data collection. Note that subsample characteristics are described in the results section.

### Participant recruitment

During the periods from 2007 and 2011 (Phase 1), and from 2013 to 2015 (Phase 2), residents aged between 18 and 78, from seven Canadian provinces (British Columbia, Saskatchewan, Manitoba, Ontario, New Brunswick, Nova Scotia and Prince Edward Island), of unknown diabetes

status, were approached to participate in a dysglycemia risk assessment study. Though several large urban sites were deliberately included to ensure a diverse multi-ethnic sample of participants aged 40 and over in Phase 1 (2007-2011), Phase 2 of recruitment in 2013-2015 was specifically aimed at increasing the number of participants mainly aged 20-39 and of specific ethnicities (East Asian, South Asian, First Nations and Métis, and Inuit). In Phase 1, most participants were recruited during opportunistic community health centre visits, although some were recruited through local mail-outs from community health centres and the regional health authority. In Phase 2, social media sites (Facebook and Twitter), posters, brochures and pamphlets advertised study recruitment, and interested participants contacted local public health nurses. Participants were excluded if they already had diabetes, were currently pregnant or were not living within the local study area. Participants in Phase 2 received \$50 in compensation in either cash or as a food voucher.

#### Data collection and risk assessment

After informed consent was provided, individuals were invited for a dysglycemia assessment conducted at a local community centre. The assessment consisted of a self-administration of CANRISK, anthropometric measurements and two venous blood samples as part of an oral glucose tolerance test (OGTT). Study participants were weighed dressed in indoor clothing without shoes, using a digital standing scale. Height was determined using a standardised tape measure attached to the wall. WC was measured as the minimum circumference between the umbilicus and xiphoid process. Nurses and health centre staff were able to help study participants in English and other languages as needed and received training on how to conduct the anthropometric measurements to ensure the standardisation of the measurements.

The CANRISK questionnaire includes questions on gender, age, self-reported physical activity (such as brisk walking for at least 30 minutes each day), self-reported fruit and vegetable consumption (consumption every day/not every day), history of high blood pressure, history of high blood glucose, family history of diabetes, ethnicity (both mother's and father's), and education.<sup>23</sup> The time it

typically took to complete CANRISK was approximately less than 5 minutes. Since WC, weight and height were collected as continuous variables, it was possible to create categories based on different referenced cut-off points. The CANRISK used World Health Organisation (WHO) and Canadian Diabetes Association (CDA) standard cut-off points for BMI: < 25 kg/m<sup>2</sup> (underweight and normal weight), 25-29.9 kg/m<sup>2</sup> (overweight), 30-34.9 kg/  $m^2$  (obesity class 1) and 35 + kg/ $m^2$  (obesity class 2+);<sup>28</sup> and for WC: small (male < 94 cm and female < 80 cm), medium (male 94-102 cm and female 80-88 cm) and large (male > 102 cm and female > 88 cm).<sup>29</sup> In the current analysis, alternative South Asian specific cut-off points for BMI<sup>26</sup> were: < 23.5 kg/m<sup>2</sup> (underweight/normal weight); 23.5-27.5 kg/m<sup>2</sup> (overweight) and greater than 27.5 kg/m<sup>2</sup> (obese). Additionally, alternative South Asian specific cut-off points for WC (25) were: male < 90 cm, female < 80 cm (small); male 90–100 cm, female 80–90 cm (medium); male > 100 cm, female > 90 cm (large).

Participants had their glycemic status confirmed with an OGTT, i.e., testing their fasting plasma glucose (FPG), administering a 75 g glucose challenge, and a further plasma glucose test taken two hours later, as recommended by WHO and CDA guidelines. <sup>22,30</sup> An individual was classified as having prediabetes if they had an FPG level of 6.1 to < 7.0 mmol/L and/or a 2-hour serum glucose of 7.8–11.0 mmol/L, or having diabetes if they had an FPG level of 7.0 mmol/L or higher and/or a 2-hour serum glucose level of 11.1 mmol/L or higher. <sup>22,30</sup>

### Data analysis

Descriptive analyses were undertaken to characterize study participants. A series of logistic regressions were performed using SAS 9.3, with the presence or absence of dysglycemia as the outcome variable. These analyses were conducted to determine if the predictive ability of the original CANRISK model could be improved with alternative WC and BMI cut-off points for a Canadian South Asian population. Specifically, Model A used the original CANRISK variables, Model B used CANRISK variables with alternative WC cut-off points, Model C used CANRISK variables with alternative BMI cut-off points, and Model D used CANRISK variables with both alternative WC and BMI

cut-off points. The Hosmer-Lemeshow Goodness of Fit test<sup>31</sup> and a Receiver Operating Characteristic (ROC) Curve, measured by the area under the curve (AUC), were used to assess model fit and predictive ability.

CANRISK was originally developed for use by those 40 and over, and a score of 0 for age was accorded to participants aged 40 to 44.23 In the present analyses those who were under the age of 40 were also accorded an age score of 0. Points assigned to each variable are weighted based on the original CANRISK model, which only included data from individuals aged 40 and over, and by disregarding the variability in the age variable we reduced the maximum points a young individual can be assigned. To compensate for the loss of this variable in our younger participants, an alternative CANRISK cut-off was proposed. This cut-off was similar to a previous study using a sample of young Indigenous Peoples.<sup>24</sup> We investigated the predictive ability of CANRISK for this younger population by comparing an alternative CANRISK cut-off point of 21 points "moderate risk" to the original cutoff point of 33 points "high risk". A score equal to or above the cut-off point was classified as positive for dysglycemia risk while a score below the cut-off point was classified as negative.

Sensitivity and specificity were calculated to evaluate the effectiveness of CANRISK in the detection of dysglycemia risk by comparing both CANRISK cut-off points among older adults (≥ 40 years) and younger adults (< 40 years) using the original and alternative CANRISK score cut-offs. Sensitivity was defined as the proportion of people with a positive CANRISK score among those with a positive OGTT test. Specificity was defined as the proportion of people who had a negative CANRISK risk score among those with a negative OGTT test. The positive predictive value (PPV) was the proportion of subjects with a positive OGTT among those with a positive CANRISK score test. The negative predictive value (NPV) was defined as the proportion of subjects without dysglycemia as determined by OGTT among those with a negative CANRISK score. The accuracy rate was the proportion of the laboratory test confirmed positive or negative CANRISK scores out of the entire study population. The PPV, NPV and accuracy were calculated to be able to allow a comparison with the CANRISK results in the original validation population.<sup>23</sup>

### **Results**

The sub-sample used in this analysis consisted of 832 Canadian South Asian individuals pooled from both Phase 1 (n = 323) and Phase 2 (n = 509). The majority were from the 18-39 age group (70%) and female (62%) (Table 1). Nearly half had obtained college or higher education. Using CANRISK BMI cut-off points, 50% were considered overweight or obese, but using the alternative cut-off points specific for Asian populations,<sup>26</sup> 66% were overweight or obese. Using CANRISK and alternative WC cut-off points, 42% and 39%, respectively, of our sample were identified as having a large waist circumference. Eighty percent reported consuming fruits and vegetables daily and 63% self-reported regular physical activity. Based on the results of FPG and/or OGTT, dysglycemic status (Table 2) was noted in 16% of participants; 12% were classified as having prediabetes and 4% were classified as having diabetes.

Odds ratios derived from adjusted logistic regression for all four models are presented in Table 3. All four logistic regression models passed the Hosmer-Lemeshow goodness of fit test<sup>31</sup> with *p*-values ranging from 0.53 to 0.98 (Table 3). Regardless of the model, the odds of dysglycemia increased with age, with significantly higher odds in the 55 to 64 and 65 + age groups as compared to those aged 40 to 44. Using CANRISK cut-off points, individuals with class 2 obesity had significantly greater odds of dysglycemia than those in the normal or underweight group (Models A and B); using ethnic-specific BMI cut-off points, those who were considered obese had significantly higher odds than those who were normal/underweight (Models C and D). Men and women with medium or large waist circumference using CANRISK cut-off points had no significantly higher odds of dysglycemia (Model A and C); while those with medium waist circumference using alternative cut-off points had significantly higher odds of dysglycemia (Model B and D). All four logistic regression models show good predictive ability for dysglycemia, with similar AUCs of ranging from 0.80 to 0.81. In other words, alternative BMI and/or WC cut-off points did not alter the AUC much, nor did it improve the model fit. The sensitivity and specificity

TABLE 1
Demographics of the study population according to CANRISK variables

Sample characteristics	Pooled total sample (N = 832)	% of pooled total sample
Gender		
Female	518	62.26
Male	314	37.74
Age		
18–29	230	27.64
30–39	354	42.55
40–44	40	4.81
45–54	68	8.17
55–64	79	9.5
65+	61	7.33
BMI (kg/m²) – CANRISK cut-off points		
Normal/underweight (< 25)	420	50.48
Overweight (25–29.9)	281	33.77
Obese, class 1 (30–34.9)	107	12.86
Obese, class 2+ (≥ 35)	24	2.88
BMI (kg/m²) – Alternative cut-off points		
Normal/underweight (< 23.5)	279	33.53
Overweight (23.5–27.5)	326	39.18
Obese (> 27.5)	227	27.28
Waist circumference – CANRISK cut-off points		
Male < 94, Female < 80	292	36.14
Male 94–102, Female 80–88	174	21.53
Male > 102, Female > 88	342	42.33
Waist circumference – Alternative cut-off points		
Male < 90, Female < 80	221	27.35
Male 90–100, Female 80–90	268	33.17
Male > 100, Female > 90	319	39.48
Daily brisk physical activity (No)	311	37.42
Daily consumption of fruit/vegetable (No)	165	19.86
High blood pressure (Yes)	99	11.93
High blood sugar (Yes)	68	8.19
Positive family history of diabetes		
No relatives with DM (all relatives = No)	367	44.11
Secondary relative has DM (sibling or other = Yes)	139	16.71
Primary relative has DM (mother, father, or child $=$ Yes)	293	35.22
No confirmed cases, but suspected cases (no relatives marked as yes, but some relatives marked "unsure")	33	3.97
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observed using the whole sample of Canadian South Asians at the original CANRISK score cut-off of 33 points were 69% and 78%, respectively. The PPV was 38% and the total accuracy rate was 77%.

However, despite adequate model fit and predictive ability, as measured by AUC, across the entire study sample, the tool functions differently across age groups. Sensitivity and specificity analysis by age group (Table 4) showed that by using the original CANRISK cut-off of 33 points, in those aged 40 years and over, the sensitivity was 93%, specificity 35%, PPV 41% and accuracy rate 54%. In those aged under 40 years, sensitivity was 33%, specificity was 92%, PPV was 28% and accuracy was 87%. When using the alternative lower CANRISK cut-off of 21 points, sensitivity was 100% in those 40 years and over, specificity was 10%, and accuracy was 40%. However, in those aged under 40 years, the sensitivity was improved to 77%, specificity was 53%, and accuracy was 56%. The ROC curves for each age group depicting the sensitivity and specificity at different CANRISK score cut-offs can be seen in Figure 1.

### Discussion

The original CANRISK model demonstrated good predictive ability via AUC for dysglycemia in this Canadian South Asian sample, including younger participants under the age of 40 years; an age group not originally included in the sample upon which CANRISK was validated. The sensitivity and specificity observed using the whole sample of Canadian South Asians at the original CANRISK score cut-off of 33 points were marginally better than those reported in original validation study for the general population sample;<sup>23</sup> respectively, sensitivity of 69% vs 66%; specificity of 78% vs 70%; and PPV of 38% vs 36% and a total accuracy rate of 77% vs 64%.

When looking at the age group under 40 separately, adjustments to the cut-off point may have to be made; this high-lights that the CANRISK tool performs differently across these two age groups. In the age 40 group or over, the relatively high sensitivity of 93% and low specificity of 35% would be acceptable when the tool is used as the first step of a screening process to triage those at high risk for further clinical testing. However, in the age group under 40, it may be more appropriate

TABLE 1 (continued)
Demographics of the study population according to CANRISK variables

Sample characteristics	Pooled total sample (N = 832)	% of pooled total sample
Education		
Some high school or less	106	12.74
High school diploma	123	14.78
Some college or university	233	28
College or university degree	370	44.47
History of macrosomia (% of female)	32	6.18

Abbreviations: BMI, body mass index; DM, diabetes mellitus.

Note: Sample is those from the CANRISK study Phase 1 (n = 323), Phase 2 (n = 509) who identified South Asian as their mother's or father's ethnicity.

TABLE 2
Dysglycemic status of the South Asian study sample

	Total	sample
	% of total sample	Cases detected (N)
Prediabetes		
A) FPG only or 2hPG only	10.5	87
B) Both FPG and 2hPG	1.9	16
C) Total prediabetes (A + B)	12.4	103
Diabetes		
D) FPG only or 2hPG only	2.4	20
E) Both FPG and 2hPG	1.3	11
F) Total diabetes (D + E)	3.7	31
Total cases of dysglycemia (C + F)	16.1	134

Abbreviations: 2hPG, plasma glucose after 2-hour glucose challenge; FPG, fasting plasma glucose.

to use the lower "moderate risk" CANRISK cut-off of 21 points as the first step in the screening process to increase sensitivity from 33% using the "high risk" cut-off to 77%. The lower cut-off point would also result in a decrease in specificity and a resulting increase in false positives. However, favouring the reduction of false negatives is more desirable in this context than reducing false positives, while still maintaining a balance, as it would minimize the number of young individuals mistakenly identified as lower diabetesrisk and encourage a greater number of younger individuals at risk to seek further screening and to consider important lifestyle changes. This is most important for this age group considering diabetes incidence rates are increasing at younger ages, especially among South Asians.2 If this approach were adopted, the tool administration instructions would need to be altered for the Canadian South Asian population below 40 years of age utilising the CANRISK. This recommendation was made in another study finding similar results for a young Indigenous Peoples population.24 It is important to note that this recommendation has not yet been tested on a younger group of the general Canadian population, i.e., it has thus far only been tested on a sample entirely made of individuals below the age of 40 from Indigenous Peoples<sup>24</sup> as well as Canadian South Asian (in the current study) populations.

TABLE 3
Logistic regression models with different ways of categorizing BMI and waist circumference, using CANRISK variables

Variable	Model A: original CANRISK cut-off points		Model B: alternative WC cut-off points		Model C: alternative BMI cut-off points			Model D: alternative WC and BMI cut-off points				
	OR	95% CI		OR	R 95% CI		OR	95% CI		OR 95		% CI
Age												
18–29	0.65	0.16	2.64	0.69	0.17	2.78	0.67	0.17	2.74	0.70	0.17	2.86
30–39	1.39	0.39	4.93	1.39	0.39	4.94	1.41	0.40	5.04	1.43	0.40	5.09
40–44	Ref			Ref			Ref			Ref		
45–54	3.13	0.80	12.20	3.21	0.82	12.49	3.19	0.82	12.45	3.25	0.83	12.68
55–64	5.94	1.58	22.30	5.88	1.57	22.02	6.19	1.65	23.23	6.13	1.64	22.98
65+	4.93	1.26	19.36	4.69	1.20	18.31	5.46	1.38	21.53	5.19	1.32	20.41
BMI (kg/m²) CANRISK cut-off points												
Normal/underweight (< 25)	Ref			Ref								
Overweight (25–29.9)	1.57	0.93	2.67	1.53	0.90	2.62						
Obese, class I (30–34.9)	1.87	0.95	3.69	1.82	0.91	3.65						
Obese, class II and above (> 35)	4.02	1.31	12.34	3.83	1.23	11.90						
BMI (kg/m²) Alternative cut-off points	BMI (kg/m²) Alternative cut-off points											
Normal/underweight (< 23.5)							Ref			Ref		
Overweight (23.5–27.5)							1.39	0.73	2.66	1.28	0.66	2.46
Obese (> 27.5)							2.90	1.43	5.91	2.74	1.32	5.67

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TABLE 3 (continued)
Logistic regression models with different ways of categorizing BMI and waist circumference, using CANRISK variables

Variable	Model A: original CANRISK cut-off points			Model B: alternative WC cut-off points			Model C: alternative BMI cut-off points			Model D: alternative WC and BMI cut-off points		
	OR	95%	· CI	OR	95%	CI	OR	95%	CI	OR	95%	CI
WC (cm) – CANRISK cut-off points												
Male < 94, Female < 80	Ref						Ref					
Male 94–102, Female 80–88	1.94	0.97	3.90				1.84	0.91	3.68			
Male > 102, Female > 88	1.94	0.91	4.14				1.54	0.70	3.37			
WC (cm) – Alternative cut-off points												
Male < 90, Female < 80				Ref						Ref		
Male 90–100, Female 80–90				2.67	1.17	6.10				2.55	1.11	5.87
Male > 100, Female > 90				2.80	1.12	6.99				2.24	0.87	5.72
Daily brisk physical activity												
Yes	Ref			Ref			Ref			Ref		
No	1.07	0.68	1.67	1.07	0.68	1.67	1.05	0.67	1.65	1.06	0.68	1.66
Daily consumption of fruit/vegetable												
Yes	Ref			Ref			Ref			Ref		
No	0.68	0.36	1.28	0.69	0.37	1.30	0.71	0.38	1.33	0.72	0.39	1.35
High blood pressure												
Yes	0.94	0.52	1.70	0.95	0.53	1.71	0.94	0.52	1.71	0.96	0.53	1.73
No	Ref			Ref			Ref			Ref		
High blood sugar												
Yes	2.08	1.07	4.03	2.10	1.09	4.05	2.03	1.06	3.89	2.05	1.07	3.92
No	Ref			Ref			Ref			Ref		
Positive family history of diabetes												
None	Ref			Ref			Ref			Ref		
DM relatives <sup>a</sup>	1.24	0.93	1.65	1.24	0.93	1.65	1.22	0.92	1.63	1.22	0.92	1.63
Gender												
Female	Ref			Ref			Ref			Ref		
Male	2.19	1.27	3.77	1.97	1.21	3.22	1.94	1.12	3.38	1.84	1.12	3.03
Education												
Some high school or less	1.66	0.92	2.97	1.62	0.91	2.91	1.63	0.92	2.92	1.62	0.91	2.90
High school diploma	1.13	0.62	2.07	1.13	0.62	2.07	1.12	0.61	2.06	1.12	0.60	2.06
Some/graduated college or university	Ref			Ref			Ref			Ref		
History of macrosomia												
No/NA	Ref			Ref			Ref			Ref		
Yes	1.32	0.45	3.86	1.31	0.45	3.86	1.25	0.43	3.69	1.26	0.43	3.73
AUC		0.80			0.80			0.80			0.81	
Hosmer-Lemeshow goodness of fit		p = 0.62 (DF = 8)			p = 0.53 (DF = 8)			p = 0.98 (DF = 8)			p = 0.94 (DF = 8)	

Abbreviations: AUC, area under the curve; BMI, body mass index; CI, confidence interval; DF, degrees of freedom; kg, kilogram; m, metre; NA, not applicable; OR, odds ratio; Ref, reference group; WC, waist circumference.

For South Asians, finding a solution to help young individuals assess their diabetes risk is important as the onset of diabetes is occurring at younger ages than before.<sup>2</sup> A formal risk assessment approach for South Asians has been suggested<sup>17</sup> to help individuals reduce or prevent their risk of diabetes by allowing them the opportunity to make lifestyle changes

such as increase in exercise and changes in diet.<sup>18-20</sup> For instance, South Asians have been shown to be less physically active than their Western European counterparts. In one study, South Asians in the UK reported 50–75% lower physical activity levels than those of European descent.<sup>7</sup> Overall calories and carbohydrate content are higher in the South Asian diet

compared to standard European meals.<sup>14</sup> Furthermore, many South Asians have transitioned from a traditional diet to a non-traditional diet higher in animal proteins, sugar, and fats including trans-fats.<sup>14</sup> With the knowledge from CANRISK that their health may be at risk, individuals of all ages may be more likely to initiate these lifestyle changes.

<sup>&</sup>lt;sup>a</sup> DM relatives: this group counts the number of categories of father, mother, children and siblings affected.

TABLE 4
Sensitivity and specificity statistics for CANRISK scores by age group

Cut-off points	Age group			
Cut-on points	Under 40 (n = 584)	40 and over (n = 248)		
Cut-off point of 33				
Sensitivity	32.7	92.7		
Specificity	91.9	34.9		
Positive predictive value	28.3	41.3		
Negative predictive value	93.3	90.6		
Accuracy <sup>a</sup>	86.6	54.0		
Cut-off point of 21				
Sensitivity	76.9	100.0		
Specificity	53.4	9.6		
Positive predictive value	13.9	35.3		
Negative predictive value	96.0	100.0		
Accuracya	55.5	39.5		

Notes: Total N is 832. See Figure 1 for associated ROC curves.

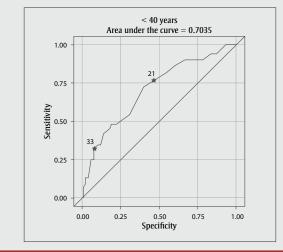
We hypothesized that the predictive ability of the model using CANRISK variables as predictors could be enhanced for Canadian South Asians by the addition of ethnic-specific cut-off points for WC and BMI. However, our results show that the model fit and AUC were not significantly improved when using South Asian-specific cut-off points for either WC or BMI. In other words, changing the CANRISK WC and/or BMI cut-off points to South Asian specific cut-off points did not improve the predictive ability of the CANRISK model beyond what the original CANRISK WC and BMI cut-off points could predict within a sample of Canadian South Asians. We can, therefore, conclude that there is no indication to modify the original CANRISK WC and/or BMI cut-off points in the tool for this population. Ethnic-specific WC and BMI cut-off points were also found to not improve CANRISK predictive ability in a sample of individuals from First Nations and Métis communities.<sup>24</sup>

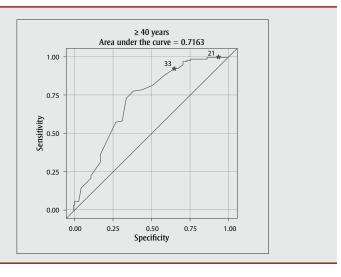
The Indian Diabetes Risk Score (IDRS) tool identifies people with undiagnosed diabetes using four simple parameters, requiring minimal time and effort, with the potential to considerably reduce the costs of screening.<sup>32</sup> It is shorter than CANRISK, consisting of four questions on age, waist circumference, family history

and physical activity. In an Indian population, it was found to have an AUC of 0.70, sensitivity of 73% and specificity of 60% for determining undiagnosed diabetes, with a PPV of 17%, and accuracy of 61 %.32 Our current results on our sample of Canadian South Asians using the original CANRISK cut-off points with all ages show the CANRISK to outperform the predictive ability of IDRS with an AUC of 0.80. Using all ages and the original CANRISK cut-off point of 33 points, our results demonstrate similar sensitivity and specificity, higher PPV from 17% with the IDRS to 38% on the CANRISK, and higher total accuracy from 61% with the IDRS to 77% with the CANRISK. The improved predictive ability may be because the CANRISK collects more information (12 questions) compared to the IDRS (4 questions) allowing for a more specific predictive model. The IDRS has not been tested among Canadian South Asians and further work is needed to assess whether a tool developed specifically for a South Asian population would be preferable to CANRISK.

Potential limitations of this work include a sampling bias resulting from an over-representation of the "worried well" – that is, the recruited population was made up of self-selected volunteers who were more likely to be worried about diabetes, and therefore more likely to respond to recruitment efforts. This is in addition to a sampling bias created by only recruiting individuals from community health centres who may already have an invested interest in their health compared to the

FIGURE 1
CANRISK predicts dysglycemia: ROC with CANRISK cut-off points and AUC by age group





Abbreviations: AUC, area under the curve; ROC, Receiver Operating Characteristic.

Note: Stars on ROC curves indicate the sensitivity and specificity at predetermined CANRISK cut-off points: 21 represents "moderate risk" and 33 represents "high risk".

<sup>&</sup>lt;sup>a</sup> Percentage of confirmed positive and negative CANRISK scores out of the total number of participants.

general Canadian South Asian population. The smoking rates in this group were almost half (2.6%) of that described in the literature for Canadian South Asians 5.0%.<sup>33</sup> Since recruitment materials and CANRISK were only provided in English and French, it is possible that some of the South Asian population would not have been able to participate due to language restrictions. Although, statistics show that most Canadian South Asians can speak either English or French.<sup>34</sup>

In addition, differences in recruitment methods between Phase 1 and Phase 2 may have created a bias given the purposeful sampling of younger adults in Phase 2. Considering the age distribution in our sample does not represent the general Canadian South Asian population, as it includes a very large proportion of individuals below the age of 40, the results from this study need to be interpreted with this in mind. That is, due to this agerelated sampling bias, all models presented should be interpreted with caution as reliability among older adults is weakened (as can be seen with the larger CI among these age categories in the logistic model). It is also important to note that our sample is generally small, especially when comparing between age categories, as the older age category only consisted of 248 individuals. In addition, recruitment during Phase 2 emphasized social media and included incentives, while Phase 1 mostly focussed on public health outreach. These differences in recruitment between phases of data collection could have resulted in somewhat different populations of Canadian South Asian individuals participating in each phase in addition to age differences. Furthermore, participation rates could not be calculated due to the nature of the study sample mentioned above. As a result, the generalizability of the current data to the general Canadian South Asian population cannot be confirmed and should, therefore, be interpreted with caution.

It is also important to note that WC measurement was conducted by trained staff according to the WHO protocol. While this is ideal in the context of research, it is not consistent with the application of CANRISK when used for self-assessment. This poses a problem with ecological validity as there may be discrepancies in the variability of WC measurement when comparing the measurements from self-assessment to those from trained health staff.

### Conclusion

This study has shown that CANRISK is effective at detecting individuals at high risk for dysglycemia in Canadian South Asians aged 40 years and older. An adjustment of the CANRISK score cut-off point to the "moderate risk" category of 21 points for individuals under age 40 is recommended to increase tool sensitivity and avoid false negatives, which is important for this increasingly at-risk population. In addition, using different ethno-specific WC and BMI cut-off points in the CANRISK logistic regression model did not improve predictive ability as measured by AUC. It is important to note that the generalizability of the results from the current sample to the general Canadian South Asian population cannot be confirmed and should, therefore, be interpreted with caution.

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We gratefully acknowledge Health PEI (Charlottetown, Summerside and O'Leary sites), the Diabetes Care Program of Nova Scotia (Kentville and Antigonish sites), New Brunswick Health and Wellness (Fredericton and Lameque sites), Ontario Health and Wellness (the Mississauga site at Credit Valley Hospital), Manitoba Health and Wellness (Brandon and Winnipeg sites), the Saskatoon Regional Health Authority, and particularly the Vancouver Coastal Health Authority, for their support on data collection and community engagement.

### **Ethical review**

Research ethics board review was obtained in writing from each of the regions in which data were collected and from the Health Canada/Public Health Agency of Canada Research Ethics Board.

### **Conflicts of interest**

Dr. Gina Agarwal was commissioned to lead this project by the Applied Research Division of the Health Promotion and Chronic Disease Prevention Branch of the Public Health Agency of Canada.

# **Authors' contributions and statement**

GA, YJ, HM and YM contributed substantially to the study design and drafted the paper. HO provided methodological advice

for data analysis. SRVK and CL analysed the data. MF developed site collection protocols and completed data acquisition. GA, YJ, CL and HO reviewed and revised the paper. All authors read and gave final approval of this version to be published and agreed to be guarantors of the work.

The content and views expressed in this article are those of the authors and do not necessarily reflect those of the Government of Canada.

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# **Original qualitative research**

# Individual, programmatic and systemic indicators of the quality of mental health care using a large health administrative database: an avenue for preventing suicide mortality

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### **Abstract**

Suicide is a major public health issue in Canada. The quality of health care services, in addition to other individual and population factors, has been shown to affect suicide rates. In publicly managed care systems, such as systems in Canada and the United Kingdom, the quality of health care is manifested at the individual, program and system levels. Suicide audits are used to assess health care services in relation to the deaths by suicide at individual level and when aggregated at the program and system levels.

Large health administrative databases comprise another data source used to inform population-based decisions at the system, program and individual levels regarding mental health services that may affect the risk of suicide. This status report paper describes a project we are conducting at the Institut national de santé publique du Québec (INSPQ) with the Quebec Integrated Chronic Disease Surveillance System (QICDSS) in collaboration with colleagues from Wales (United Kingdom) and the Norwegian Institute of Public Health.

This study describes the development of quality of care indicators at three levels and the corresponding statistical analysis strategies designed. We propose 13 quality of care indicators, including system-level and several population-level determinants, primary care treatment, specialist care, the balance between care sectors, emergency room utilization, and mental health and addiction budgets, that may be drawn from a chronic disease surveillance system.

Keywords: suicide, services, mental health care, large health administrative databases

### Highlights

- The quality of health care services affects suicide rates.
- Health administrative databases may inform population-based decisions at three levels (individual, program, and system) by indicating service gaps. Addressing these gaps may improve strategies for suicide prevention.
- Thirteen quality of mental health care indicators are proposed based on data from health administrative databases in Quebec; these data are available from the Quebec Integrated Chronic Disease Surveillance System.
- The proposed indicators and determinants encompass primary care and specialist care, emergency room utilization, mental health and addiction budgets, unemployment rates and socioeconomic deprivation, among other factors.
- Our approach is reproducible in other Canadian provinces.

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### Introduction

Suicide mortality is a major public health issue. Several studies show that this phenomenon is associated with the quality of health care services,1 as well as mental disorders, particularly depression.<sup>1,2</sup> Surveillance plays an essential role in containing the burden of chronic diseases;3 however, prevention strategies to reduce suicide risk remain a challenge.4 To contribute to the prevention and potential reduction of suicide mortality, this status report paper establishes and delineates the development of quality of mental health care indicators using large health administrative databases. We describe how the use of these databases may be maximized in the Canadian context using the Quebec Integrated Chronic Disease Surveillance System (QICDSS) as a case study.

# Conceptual framework of the untapped potential of linked health administrative databases for identifying suicide prevention avenues

From a public health perspective, there are four primary determinants of health status: i) genetics; ii) the environment; iii) lifestyle; and iv) healthcare services. These determinants also apply to suicide risk. The relevant information required to analyze mental health care in relation to suicide mortality is available from suicide audits and health administrative databases.

Tansella and Thornicroft<sup>8</sup> first proposed this type of conceptual framework using the latter, which included service data and patient-based information. These investigators applied the classic Donabedian's medical services quality model9 to create a two-dimensional matrix: a temporal axis of the input-processes-outcomes and a geographical axis of the system-programindividual levels. In their model, suicide rates are outcomes at the system and program levels, and the suicide risk at the individual level. Budgets represent input at the system and program levels; the balance between primary and specialist services is a process indicator at the system and program levels; and the quality of follow-up after the detection of depression in primary care or after an admission for a suicide attempt is a process indicator at all levels. Other terminology has been used to refer to the program level, such as the Meso-level by Contandriopoulos, et al.,10 who also drew their approach from the seminal work of Donabedian.9

Table 1 presents our adaptation of the Tansella and Thornicroft<sup>8</sup> model using the untapped potential of the large linked health administrative databases of the QICDSS to investigate quality of mental health care as a determinant of suicide.

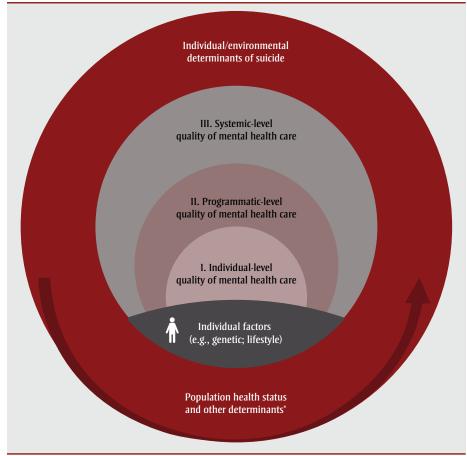
Each level presented in Table 1 refers to a representation of our conceptual framework of a three-level mental health care system, as shown in Figure 1. This system includes the individual, programmatic and systemic levels embedded within environmental determinants of suicide, population health status and other determinants.

Risk factors at the individual level indicated in Table 1 may be used to conduct analyses that would produce algorithms of trajectories associated with a higher risk of suicide. These algorithms, thus, become indicators of the quality of care at the individual level within the available databases. The algorithms are complex to interpret, as demonstrated with the same databases as recent QICDSS trials in cardiovascular diseases. 11,12 A set of largely used indicators of quality of care, such as those presented in the literature or Table 2, is considered in establishing the validity of the individual level-defined algorithms, such as audits that informed at the individual level or aggregated for the validity at the program and system levels. Established indicators of the quality of mental health care may be obtained from the literature at the programmatic and system levels, with potential candidates from the QICDSS proposed in Table 2. At the programmatic level, a casecontrol design between individuals who died by suicide and individuals who did not may be explored. These indicator outcomes should be worse among suicide cases in the year preceding their death than in non-cases with similar mental

TABLE 1
The three levels of the quality of mental health care services model

Level	Input	Process	Outcomes	Examples of comput- ing and innovating methodologies	Information for disease management / information for policy making
1. Individual	Age Gender Socioeconomic status Diagnoses	Types of treatments Settings of encounters Types of programs Intensity of contacts Coordination of referrals	Individual risk of suicide at last contact with services considering all previous information available in database	Computer-learning artificial intelligence algorithms (Kessler et al. <sup>11</sup> )	Individual clinicians in health, social and addiction service settings
2. Program	Hospitalization Emergency department Specialist outpatient General practitioner (GP)	Average number of visits Proportion of individuals readmitted within 30 days after hospital discharge Type of diagnosis Follow-up after emergency visit or hospital admission for intentional self-harm Follow-up after primary care diagnosis of depression	Increased risk of suicide in type of setting (i.e., emergency room)	Electronic case-control studies based on the Secure Anonymized Information Linkage (SAIL) (John et al. <sup>13</sup> )	Regional/local mental health and addiction programs
3. System	Regional mental health or addiction budgets	Regional balance of specialist and primary care Quality of follow-up after hospi- talized suicide attempts	Regional suicide rates	Ecological study (Tondo et al. <sup>21</sup> )	Country/state/provincial

FIGURE 1
Conceptual framework linking health care and determinants of suicide



Source: Adapted from Anctil, et al.<sup>60</sup>, Ferlie and Shortell<sup>61</sup> and the National Academy of Engineering (US) and Institute of Medicine (US) Committee on Engineering and the Health Care System.<sup>62</sup>

disorder diagnoses after controlling for other covariates. <sup>13</sup> Finally, the system-level analysis suggested in Table 1 may employ identified risk factors from the two previous levels as indicators of the quality of mental health care, considering other risk factors as co-variates, if available, in the various linked health databases, and applicable at this level for the dependent variable of regional or provincial/state suicide rates.

Furthermore, suicide is believed to result from the interaction of different factors, including genetics<sup>14</sup> and lifestyle/social factors,<sup>15,16</sup> as illustrated in the other risk factors in Figure 1; several mental illnesses have genetic influences.<sup>17</sup> However, there is no possibility, at this time, to measure genetic risk factors with linked health administrative databases. To accomplish this task, in the future, a reliable test may be discovered and recorded in the electronic medical records available for research.<sup>18,19</sup>

### A brief history of the major initiatives

Previous courses of action have provided important information at each level identified in Figure 1. For example, aggregated individual suicide audits have demonstrated that acting on services may help prevent suicide, as reported by regions following the recommendations outlined in the National Confidential Inquiry into Suicide and Homicide by People with Mental Illness in England and Wales.<sup>20</sup>

Large health administrative databases may provide information relatively promptly for decisions at the system and program levels, whereas the value at the individual level remains experimental. There are reports regarding the examples identified in Table 1. For example, Kessler, et al. addressed individual-level factors and developed an actuarial risk algorithm to predict suicide in the 12 months following inpatient treatment of US Army soldiers for psychiatric disorders using data from

the Historical Administrative Data System (HADS) of the Army Study to Assess Risk and Resilience in Service members (Army STARRS). Furthermore, this study relied on machine learning. The findings suggested that the strongest predictors included sociodemographic factors, criminal offenses, prior suicidality, aspects of prior psychiatric inpatient and outpatient treatment, and disorders diagnosed during the focal hospitalization. Similar experimental endeavors have been undertaken with Quebec's linked health administrative databases by Najjar<sup>12</sup> and a project underway in Wales, UK by co-authors John, et al.

At the program level, John, et al.<sup>13</sup> developed a general population-based study of suicide mortality and mental health using routinely collected administrative databases and proposed a case-control design. The services provided were shown to determine the quality of care and define the program determinants of suicide mortality (i.e., general hospital admission; emergency department contact for self-harm and other indications including psychiatric admission and primary care contact in the year prior to probable suicide).

Finally, a system-level ecological study of suicide rates and assessment of mental health services was conducted by Tondo, et al.21 in the 50 US states. Their study indicated that a higher population density of psychiatrists and physicians and increased levels of federal aid for mental health were associated with lower suicide rates.22 Leff, et al.23 demonstrated that efficient mental health services predicted suicide reduction in a sample of publicly managed US facilities. The conceptualization and findings of these studies further substantiated the richness of the information available in administrative health databases used internationally. As suggested by While, et al.,20 the provision of mental health services may affect suicide rates in clinical populations, and investigations of these services in relation to suicide may help inform future suicide prevention efforts and improve safety for patients receiving mental health care.

Among the environmental and social determinants of suicide, in international and Canadian studies, the unemployment rate has been associated with suicide mortality.<sup>24-28</sup> Seminal work by Durkheim, the

TABLE 2
List of the candidate indicators at the programmatic and system levels supported by the health services and public health literature or practices

Candidate indicators	Aim	Literature support	Description	Measure	Data sources
1. Quality of anxiety	Determine	Based on number of	Denominator: Individuals aged	Prevalence of individuals 15+	QICDSS
or depressive disorders mental health services follow-up in primary care	adequate care for patient diagnosed with anxiety and depressive disorders in primary care	physician visits by Wang, et al. <sup>44</sup> and other studies <sup>47,48</sup>	15+ years with an anxiety or depressive disorder diagnosis by a General Practitioner (GP) in a given year	years who received an anxiety or depressive disorder diagnosis with ≥ 4 visits for mental health	
			Numerator: Received ≥ 4 visits for mental health in that year		
2. Quality of depression disorder mental health services follow-up in primary care	Determine adequate care for patient diagnosed with depression in primary care	Based on number of physician visits by Wang, et al. <sup>44</sup> and other studies <sup>47,48</sup>	Denominator: Individuals aged 15+ years with a diagnosis of depression by a General Practitioner (GP) in a given year Numerator: Received ≥ 4 visits for	Prevalence of individuals 15+ years who received a depression diagnosis with ≥ 4 visits for mental health	QICDSS
3. Quality of substance use disorder mental health services follow-up in primary care	Determine adequate care for patient diagnosed with substance use disorder in primary care	Based on 4 visits with a family physician for counseling as recommended by NICE <sup>58</sup> and the guidelines for American primary care clinicians <sup>58</sup>	mental health in that year  Denominator: Individuals aged 15+ years with a diagnosis of substance use disorder by a General Practitioner (GP) in a given year  Numerator: Received ≥ 4 visits for mental health in that year	Prevalence of individuals 15+ years who received a substance use disorder diagnosis with ≥ 4 visits for mental health	QICDSS
4. Quality of mental health care services follow-up after hospitalization: readmission within 30 days	Determine the quality of mental specialist health care and in- hospital care	Based on the work of the Canadian Institute for Health Information (CIHI) <sup>45,47,48</sup>	Denominator: Individuals aged 15+ years admitted in a hospital with a mental health diagnosis in a given year Numerator: Individual readmitted for mental health within 30 days of initial discharge	Prevalence of individuals 15+ years who were readmitted to a hospital for a mental health diagnosis within 30 days of initial discharge	QICDSS
5. Quality of mental health services follow- up in primary care after suicide attempt	Determine the quality of mental health care of readmission rates in the region compared to others	Based on the work of the Canadian Institute for Health Information (CIHI) <sup>45,47,48</sup>	Denominator: Individuals aged 15+ years admitted to a hospital for suicide attempt in a given year Numerator: Received ≥ 1 visit to a physician for mental health within 30 days of hospital discharge for suicide attempt	Prevalence of individuals 15+ years who received ≥ 1 visit from a physician within 30 days of initial discharge for suicide attempt	QICDSS (linked to MedEcho for suicide attempt) <sup>40,41,50</sup>
6. Quality of community mental health services	Determine the balance of the community-oriented mental health care system	Based on the typologies of primary and specialist (including in-hospital care) mental health care <sup>a,45,46,54</sup> used in the study of suicide attempts <sup>55</sup>	Denominator: Individuals aged 15+ years with a mental health diagnosis in a given year Numerator: Individuals with exclusively outpatient services – psychiatric or general practitioner (GP)	Prevalence of individuals 15+ years who received a mental health disorder diagnosis with exclusively outpatient services (psychiatric or GP)	QICDSS
7. Quality of community mental health services of patients with severe mental illness	Determine the balance of psychiatric outpatient and primary outpatient care depending on the profiles used <sup>a,55</sup>	Based on the associations found for the balance between primary and specialist mental health care and suicide rates <sup>2,46,60,61</sup>	Denominator: Individuals aged 15+ years with exclusively a GP or a psychiatric outpatient visit for psychotic disorder Numerator: Number of individuals with exclusively a GP or psychiatrist outpatient visits	Prevalence of individuals 15+ years who received a severe mental illness disorder diagnosis and used exclusively outpatient services by a GP	QICDSS
8. Quality of community mental health services of patients with common mental disorders	Determine the balance of psychiatric outpatient and primary outpatient care depending on the profiles used <sup>a,55</sup>	Based on the associations found for the balance between primary and specialist mental health care and suicide rates <sup>2,46,60,61</sup>	Denominator: Individuals aged 15+ years with a psychiatric or a GP outpatient visit for depression Numerator: Number of individuals with exclusively GP outpatient visits	Prevalence of individuals 15+ years who received a common mental disorder diagnosis and used exclusively outpatient services by a GP	QICDSS

Continued on the following page

# TABLE 2 (continued) List of the candidate indicators at the programmatic and system levels supported by the health services and public health literature or practices

<b>Candidate indicators</b>	Aim	Literature support	Description	Measure	Data sources
9. Quality of community mental health services of patients with substance use disorders	Determine the balance of psychiatric outpatient and primary outpatient care depending on the profiles used <sup>a,55</sup>	Based on the associations found for the balance between primary and specialist mental health care and suicide rates <sup>2,46,60,61</sup>	Denominator: Individuals aged 15+ years with a psychiatric or a GP outpatient visit for substance use disorder Numerator: Number of individuals with exclusively GP outpatient visits	Prevalence of individuals 15+ years who received a substance use disorder diagnosis and used exclusively outpatient services by a GP	QICDSS
10. Quality of community mental health services of patients with personality disorders	Determine the balance of psychiatric outpatient and primary outpatient care depending on the profiles used <sup>a,55</sup>	Based on the associations found for the balance between primary and specialist mental health care and suicide rates <sup>2,46,60,61</sup>	Denominator: Individuals aged 15+ years with exclusively a GP or a psychiatric outpatient visit for personality disorder Numerator: Number of individuals with exclusively a GP or psychiatric outpatient visits	Prevalence of individuals 15+ years who received a personality disorder diagnosis and used exclusively outpatient services by a GP	QICDSS
11. Adequate use of emergency room for mental health services	Determine the balance of utilization of emergency room (ER) for mental health reasons <sup>a,55</sup>	Based on the associations found for the balance between primary and specialist mental health care and suicide rates <sup>46,60,61</sup>	Denominator: Individuals aged 15+ years with a diagnosis of a mental health disorder Numerator: Number of individuals with ER visits without being admitted	Prevalence of individuals 15+ years who received a diagnosis of mental health disorder with exclusively ER visits without being admitted	QICDSS
12. Program expenditures for mental health services	Determine the strength of the relationship between changes in suicide rates and expenditures for mental health (regional and provincial)	Based on associations found between mental health budget and suicide rates <sup>21,23</sup>	Refer to the Gouvernement du Québec <sup>43</sup>	Dollars per capita spent on mental health programs (provincial and regional)	Annual financial reports from the Ministère de la santé et des services sociaux (MSSS) <sup>43</sup>
13. Program expenditures for addiction services	Determine the strength of the relationship between changes in suicide rates and expenditures for addiction services (regional and provincial)	Based on associations found between mental health budget and suicide rates <sup>21,23</sup>	Refer to the Gouvernement du Québec <sup>43</sup>	Dollars per capita spent on health programs for addiction services (provincial and regional)	Annual financial reports from the MSSS <sup>43</sup>

Abbreviations: CIHI, Canadian Institute for Health Information; ER, emergency room; GP, general practitioner; MSSS, Ministère de la santé et des services sociaux; QICDSS, Quebec Integrated Chronic Disease Surveillance System.

founder of modern sociology, at the end of the 19<sup>th</sup> century demonstrated that suicide rates are higher in socially and materially deprived areas, where the social capital for support and opportunities is lower.<sup>6</sup>

Large health administrative databases are available in Canada; however, there are few national and provincial studies that utilize them. Research in Alberta<sup>29</sup> using a health services administrative database indicated that approximately 90% of individuals who die by suicide utilized a health service in the year prior to their death, and the majority visited a general

practitioner (GP). Moreover, approximately 60% of these individuals had an emergency room (ER) visit, whereas only 39% of their peers had ER visit in the UK and Wales, as reported by Gairin, et al.<sup>30</sup> At the national level, the Canadian Medical Association Journal (CMAJ) recently supported the value of large linked health administrative databases for suicide studies. However, it acknowledged the methodological and analytical challenges noted by Patrick,<sup>31</sup> Quan and Williamson<sup>32</sup> and the international research groups of Benchimol, et al.<sup>33</sup> and Nicholls, et al.<sup>34</sup> The main challenges raised were missing

data and, for non-random missing data, variables that created incomplete or inadequate reporting of research based on routinely collected data.<sup>33</sup>

### Delimitation of a conceptual framework in the Canadian context: health care services and suicide risk using big data

The creation and growth of national surveillance systems in Canada and their impact on chronic disease and injury prevention have been reviewed,<sup>35</sup> with a primary focus on chronic physical conditions. Our conceptual framework considers health

<sup>&</sup>lt;sup>a</sup> Profile 1: psychiatric inpatient care; profile 2: hospital emergency room (ER); profile 3: psychiatric outpatient care; profile 4: general practitioner (GP) clinics; and profile 5: other medical specialist.

care services, particularly mental illness care to analyze suicide mortality and the possibility of obtaining a better understanding and prevention. Based on this conceptual framework, we will independently test each quality of care indicator (13 indicators). Our general hypothesis is that programs and systems that follow literature guidelines in terms of the quality of mental health care are less likely to present higher suicide rates than programs that do not follow guidelines (Table 2).

In Canada, one example of using mental health care service records from large linked health administrative databases is the QICDSS, from the province of Quebec. Our study was produced in collaboration with colleagues from Wales, UK<sup>13</sup> and the Norwegian Institute of Public Health, and it may accelerate and validate gaps in the publicly managed care system regarding suicide.

### **QICDSS**

The QICDSS was created by the Institut national de santé publique du Québec (INSPQ), which is a public health expertise and reference center that extracts data from five linked health administrative databases. The QICDSS includes all data from all individuals who suffer from one or more chronic diseases, including mental disorders. All mental disorder ICD codes are included, except for dementia. All cases of suicide reported by the coroner in the province of Quebec, whether individuals received a mental disorder diagnosis in the previous year or years, will be investigated.

The QICDSS includes, for all cases, the utilization of all services (hospitalization; emergency room; outpatient specialist; and general practitioners). The QICDSS

has been updated annually since 1996.<sup>3</sup> Blais, et al.<sup>3</sup> assessed the essential features and strengths of the QICDSS and determined that it meets all basic requirements of a public health surveillance system.

Underreporting of mental health problems is often called into question; thus, databases and case definitions require validation before being used for epidemiological purposes<sup>36-39</sup>. Therefore, regarding the data quality of the QICDSS, it has been determined that psychiatrists and pediatricians entered the ICD-9 code in billing files in 95% of cases, and an internal medicine diagnosis code was indicated in 94% of claims.37,40 The literature indicates that diagnoses from recorded medical records fully correspond to the entries in administrative databases for other diseases in Quebec, as well as for other provinces. 37,40 In addition, Dodds, et al.41 reported that administrative health databases can clearly identify children with autism. In this context, the official data are considered largely reliable. To complement the data in the QICDSS, the determinants listed in Table 3 are provided by a provincial-level statistics organization42 and a government ministry.43

### Candidate indicators

Table 2 summarizes each of the 13 quality of mental health care candidate indicators produced using the QICDSS and other data sources to specifically cover the determinants presented in our conceptual framework (Figure 1) and at the programmatic and system levels (Table 1).

Our 13 quality of care indicators are based on a literature review of health services research and practices from epidemiological studies. The indicators of receiving four or more visits for mental health in one year<sup>44</sup> following a primary care physician first diagnosis of depression or substance abuse are drawn from US epidemiological studies that defined the quality of depression care or from guidelines for US family physicians for substance-abuse care at the primary care level. The 30-day readmission rate indicator of the quality of specialist care is based on the Canadian Institute of Health Information (CIHI),<sup>45</sup> whereas the balance of specialist and primary care is based on countries with similar socioeconomic profiles and a publicly funded managed care system as Canada.<sup>46</sup>

Interpretation of the indicators proposed in Table 2 all point to a positive relationship with decreased suicide rates, excluding indicator 4, which is the 30-day readmission rate indicator from the CIHI original definition.45 For example, more expenditures on mental health and addiction services per capita would represent an indicator of the capacity to provide effective and timely services, whereas the two environmental determinants of a lower unemployment rate and a better social and material deprivation index would be expected to be associated with lower programmatic- and regional/provincial/statelevel suicide rates and variations. Other variables may be selected,\* since the variables retained are the primary control variables included in analyses in the literature. Overall, by testing the 13 candidate indicators previously described, our aim is to determine the strength of the relationship between the changes in suicide rates and the program or system-level indicators of increased quality of mental health care at the provincial level and in each regional health territory, with consideration of the timeframe allowed for observation by the available linked health administrative databases.

TABLE 3
List of environmental determinants

Determinants	Aims	Literature support	Measure	Data Sources
System determinant of suicide, unemployment rates	Determine the impact of annual regional and provincial unemployment rates	Based on international and Canadian studies that reported a relationship between suicide mortality and unemployment rate <sup>24-28</sup>	Unemployment rates (provincial and regional)	Institut de la statistique du Québec (ISQ) <sup>42</sup>
Individual socioeconomic determinant of suicide	Determine the impact of social deprivation on suicide	Based on the Pampalon index of material and social deprivation of the census that tracts areas of residence for each individual patient in the database <sup>49,59</sup>	Index constructed in two stages by INSPQ <sup>3,49</sup>	File linking between Canadian Census and INSPQ <sup>3</sup>

Abbreviations: INSPQ, Institut national de santé publique du Québec; ISQ, Institut de la statistique du Québec.

<sup>\*</sup>For example, population levels of alcohol consumption or access to firearms.

Our work includes patient-centered information to capture the quality of primary care; however, some data are not recorded. such as family history and child abuse, specific treatments, and non-profit organization activities. In particular, the application of specific evidence-based treatments, such as anti-depressant medication and psychotherapy, are not currently available in the QICDSS; however, this information may be available in the future in Quebec or other jurisdictions. Nevertheless, as previously indicated, linking new health databases, such as medication or electronic medical records, may increase the potential determinants considered; however, these databases suffer from missing data or incomplete coverage of the population of interest.<sup>47</sup> Moreover, primary care improvements in the late 1990s may have reduced suicide rates, and thus, it is difficult to estimate their effect. However, this remains important to note.48

# Next steps: empirical testing of our theoretical framework

The next phase of the project focusses on conducting an empirical analysis to test our theoretical framework. Several statistical models will be tested to explore the relationship between changes in suicide rates and each individual, program and system level indicators of the 13 candidate indicators. The analyses will be performed at the provincial and regional levels. Two models will be considered: 1) a proportional hazard regression model (Cox regression) to investigate the associations between each of the 13 indicators and suicide; and 2) an ecological analysis to assess the association between the two environmental determinants, presented in Table 3, and suicide rates. There will be one model for each indicator - separately. The dependent variables for each Cox regression model will be suicide outcomes, and the exposure variables will be the 13 indicators. Because the indicators may change in value over the course of observation, the Cox regression is an appropriate model to account for timedependent variables.

The individual-level candidate indicators, covariates such as gender, age, comorbidity, and deprivation index,<sup>49</sup> are available and will be integrated into the Cox regression models. Comorbidity will be adjusted at the individual level. Comorbidity refers to the physical conditions described in the Elixhauser comorbidity index.<sup>50</sup> However,

mental conditions, such as mood disorders, depression, substance abuse, personality disorders, psychoses and anxiety, will not be included because they are included in the proposed indicators. Furthermore, the Elixhauser index covers more diseases than the QICDSS. The latter covers chronic conditions that have a validated case definition using health administrative data. Some diseases, such as cancer and liver diseases, that are part of the Elixhauser Index, do not have a validated case definition using linked health administrative databases.

For candidate indicators at the regional level, mental health expenditures and the unemployment rate will also be included in the models. The ecological models will be linear models adjusted at the regional level for the unemployment rate and at the dissemination area-level for the socioeconomic deprivation index.

# Ethics in the Canadian context: respecting access to documents held by public bodies and the protection of personal information

Ethical and legal issues in suicide research and the legal status of suicide have been reviewed in the literature, 51,52 which highlights concerns regarding the context of common ethical perspectives, the acceptability of suicidal behaviors, and the obligations and limitations in intervening to prevent suicides. Specifically, in this study on suicide and mental health services, legitimate issues of confidentiality arise from the use of administrative databases.

The preliminary work of recording the various chronic diseases in a large database was completed by the INSPQ following authorization from the Commission d'accès à l'information du Québec (CAI). The INSPQ operates with strict access procedures and within secured zones. Only authorized programmers can directly access and extract data from the anonymized OICDSS databases. Other analysts and experts can access the unit for specific projects, and only aggregate results may be reported.3 Greater access and collaboration with academic institutes may help accelerate the use of and resolve the difficulty in computing the information. The QICDSS sends aggregate data to the Canadian Chronic Disease Surveillance System (CCDSS) of the Public Health Agency of Canada (PHAC), which has produced two interactive reports on overall mental disorders and anxio-depressive disorders by province.<sup>53,54</sup>

# National chronic disease surveillance: actions for suicide and issues for public health

Suicide is a complex phenomenon. The use of a large public health administrative database may provide further opportunities to identify gaps in care and promotion that may be integrated to inform decisionmakers as they develop population-based programs. The quality of care indicators defined in this paper support the national, regional and local activities of health advocates throughout Quebec using a web public health portal (InfoCentre). A substantial advantage of our approach is that it may be reproduced in other provinces and may be examined at the national level in Canada because the indicators may be readily obtained from provincial/territorial health administrative databases. All cases of an individual citizen dying by suicide are recorded by a coroner or the medical examiner system. This is the responsibility of each individual Canadian province and territory, and there is no overarching federal authority.55 Other countries with similar health care systems and access to large health administrative databases, such as the United Kingdom,13 have begun to examine the associations of mental health care services with suicide and how the innovative use of these data sources may improve prevention strategies. Moreover, a national registry database in Norway has been incorporated by the Norwegian Public Health Institute as part of the effort to monitor mental health and suicidal behaviour.56

Therefore, health administrative databases represent a substantive complement to suicide audits and other data sources by identifying opportunities for intervention services that may improve the prevention of suicide. With approximately 4000 deaths by suicide<sup>57</sup> each year in Canada, our study will likely provide useful information for PHAC, Quebec (INSPQ) and other provinces.

### **Conflicts of interest**

The authors have no conflicts of interest to disclose.

# **Authors' contributions and statement**

AL, ER, and LT designed and conceptualized the work. LT, AL, ER, JL, EP, LR, AJ,

AR, and KL, contributed to the analytical plan, and LR, LT, ER, and JL assessed the suggested statistical modeling for empirical testing. LT drafted the manuscript, and LT, ER, AL, JL EP, LR, AJ, AR, and KL edited and critically reviewed the manuscript. All authors approved the final manuscript for submission.

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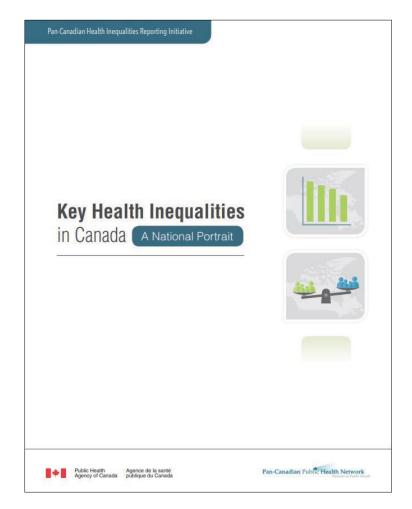
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