

# Chronic Diseases and Injuries in Canada

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# Cyclist head and facial injury risk in relation to helmet fit: a case-control study

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This article has been peer reviewed.

## Abstract

**Introduction:** We examined the effect of bicycle helmet fit and position on head and facial injuries.

**Methods:** Cases were helmeted cyclists with a head ( $n = 297$ ) or facial ( $n = 289$ ) injury. Controls were helmeted cyclists with other injuries, excluding the neck. Participants were interviewed in seven Alberta emergency departments or by telephone; injury data were collected from charts. Missing values were imputed using chained equations and custom prediction imputation models.

**Results:** Compared with excellent helmet fit, those with poor fit had increased odds of head injury (odds ratio [OR] = 3.38, 95% confidence interval [CI]: 1.06–10.74). Compared with a helmet that stayed centred, those whose helmet tilted back (OR = 2.90, 95% CI: 1.54–5.47), shifted (OR = 1.91, 95% CI: 1.01–3.63) or came off (OR = 6.72, 95% CI: 2.86–15.82) had higher odds of head injury. A helmet that tilted back (OR = 4.81, 95% CI: 2.74–8.46), shifted (OR = 1.83, 95% CI: 1.04–3.19) or came off (OR = 3.31, 95% CI: 1.24–8.85) also increased the odds of facial injury.

**Conclusion:** Our findings have implications for consumer and retail education programs.

**Keywords:** head protective devices, bicycling, injuries

## Introduction

Helmets reduce the risk of head and facial injury in cycling crashes.<sup>1</sup> However, many cyclists do not wear their helmets correctly.<sup>2</sup> Bicycle helmet design and certification have changed during the past two decades.<sup>3</sup> While mandated use of bicycle helmets is increasing worldwide, a variety of types of legislation exist; some are restricted to youth, others apply to all ages.<sup>4,5</sup> Comparative studies in regions that have implemented helmet legislation have shown an overall decrease in reported

traumatic brain injuries.<sup>4,6,7</sup> While this lends strength to arguments supporting helmet legislation, efforts to increase helmet use could fail to achieve the expected benefits to health outcomes if helmets are worn incorrectly.

Safety certification testing is typically based on drop tests, ensuring that the impact is delivered centred on the top of the helmet. In this setting, helmet effectiveness is based on ideal conditions, and a helmet's maximum protection is achieved when the helmet is correctly positioned. Proper fit is important in cases

where the rider receives multiple hits to the head. Ensuring the helmet remains in place after the first blow protects against subsequent blows.<sup>8</sup>

Most of the literature on correct bicycle helmet use refers to the prevalence of correct use,<sup>9</sup> but reports vary largely due to the inconsistent criteria used to assess helmet fit. A 2010 study found that 20% of children aged under 13 years and 16.7% of 13- to 17-year-olds wore their helmets incorrectly.<sup>10</sup> The most frequently observed error was the helmet sitting too far back on the head. The upper rim of the helmet has been shown to protect the upper face from injury in a frontal collision,<sup>1,11</sup> and helmeted cyclists have a significantly lower risk of facial injury,<sup>1,12</sup> though it seems necessary that their helmets stay in place to do this. Only one study has investigated the relationship between bicycle helmet fit and the risk of head injury.<sup>13</sup> The authors found double the risk of head injury with a poorly fitting helmet compared with an excellently fitting helmet, triple the risk of head injury with a helmet that came off during the incident compared with one that stayed centred, and a 52% increase in risk of head injury in those with a helmet that tipped back compared with a helmet that stayed centred.<sup>13</sup> Though methodologically sound, this study used data captured nearly two decades ago, making it necessary to re-examine this issue with newer helmet designs. In addition, no studies have reported how proper helmet use and correct fit affect facial injuries among cyclists.

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The purpose of our study was to determine the relation between the risk of head or facial injury and self-reported bicycle helmet fit and position.

## Methods

### Data collection

Injured cyclists were recruited from seven emergency departments (EDs) in Calgary (Alberta Children's Hospital, Foothills Medical Centre, Rockyview General Hospital, Peter Lougheed Centre) and Edmonton (Stollery Children's Hospital, University of Alberta Hospital, Northeast Community Health Centre), Alberta, over three years (May 2008 to October 2010). We identified the cyclists by scanning the Regional Emergency Department Information System and reviewing ED charts daily, with the co-operation of the ED staff. Eligible injured cyclists (or parents of those aged less than 14 years) were approached and asked to participate by research staff or, in some cases, the ED physician or nurse.

After giving consent, patients were interviewed in the ED or, if they did not wish to complete the interview immediately, by telephone. If an eligible patient was missed in the ED, they were mailed a study information package including a consent form and were contacted by telephone and asked to participate. If a patient was admitted to the hospital after their ED visit, the research staff made arrangements to inform the patient about the study and interview them in hospital if they were willing. If the patient was too young to answer the questions, research staff interviewed the patient's parent or guardian. If the parent did not know the details of the event or could not respond to a question, responses were filled out as "don't know" or "missing," as appropriate. For telephone interviews, we requested the participation of the child; however, if the parent did not allow the child to respond on their own, responses from the parent were accepted instead.

We collected injury information from the patient's medical chart. Excluded from the study were injured cyclists who did not speak English, those missed in the ED who

did not have a telephone or who could not be reached after a maximum of six call attempts, and those who were injured while riding indoors or while using a stationary bicycle. We also did not include cyclists who received a neck injury as the relationship between helmet use and neck injury risk is less clear or well-accepted.<sup>7</sup>

From within this arm of the study focusing on helmet fit, we identified two separate case groups. The first consisted of helmeted cyclists who had received a head injury, regardless of the severity of any other injuries. A head injury was defined as any injury to the scalp, skull or brain and did not include injuries to the cervical vertebrae or spinal cord, injuries to the point where the skull meets the spine or injuries to the neck regions or the face. The boundaries of the skull were defined as an imaginary line from normal eyebrow position laterally to the normal hairline, descending posterior to and not including the ears, and to and around the base of the occipital bone.

Since there is some evidence that bicycle helmets prevent facial injuries,<sup>1</sup> our second case group consisted of helmeted cyclists who had received any injury to the face, regardless of the severity of any other injuries. A facial injury was defined as any injury below the normal hairline, anterior to and including the ears, and superior to and including the mandible. Cyclists with both head and facial injuries were included in both case groups. Controls, obtained from the same EDs as the cases, were helmeted cyclists who had received injuries below the neck and had no head, brain or face injuries.

We interviewed bicyclists in the ED using a structured questionnaire (available on request) based on previous work<sup>14,15</sup> that was pilot tested with a convenience sample of respondents. Survey information was captured on the cyclist and the circumstances of the crash. For this analysis, we focused on information that related to helmet use and helmet fit. The two main variables of interest, helmet fit and helmet position/movement during the crash, were self-reported using fixed-response choices. For helmet fit, the response choices were (1) excellent, (2)

good, (3) fair and (4) poor. Helmet position response choices were (1) stayed centred, (2) tilted back, (3) shifted to the side and (4) came off. For both variables participants could also respond "don't know" or "refuse to answer," both of which were treated as missing values for the primary analysis.

Follow-up interviews were conducted with a subsample of participants to measure the reliability of the initial interview. The same questionnaire was used and the initial respondent was asked to complete the follow-up interview (e.g. the parent if they responded initially). The results of the two time-separated interviews were compared using kappa ( $\kappa$ ) statistics<sup>16</sup> with 95% confidence intervals (CIs). The follow-up interviews were conducted at least two weeks after the initial interview with those patients who had agreed to be contacted for follow-up during the initial interview.

The study was approved by the Conjoint Health Research Ethics Board at the University of Calgary and the Health Research Ethics Board at the University of Alberta.

### Data analysis

We calculated crude odds ratios (ORs, with 95% CIs) for the association between helmet fit and head or facial injury. We also examined the relation between helmet position during the crash and head or facial injury. Multiple logistic regression analyses were conducted to adjust for potential confounders (i.e. variables potentially related to helmet fit/position and independent risk factors for head or facial injury) including age, sex, body mass index (BMI), cycling frequency, presence of a cycling companion and cyclist self-reported estimated speed. Age was categorized as less than 13 years, 13 to 17 years, 18 to 39 years or 40 years and older. BMI categories were based on the World Health Organization classifications for underweight ( $< 18.50 \text{ kg/m}^2$ ), normal weight ( $18.50\text{--}24.99 \text{ kg/m}^2$ ), overweight ( $25.00\text{--}29.99 \text{ kg/m}^2$ ) and obese ( $\geq 30 \text{ kg/m}^2$ ).<sup>17</sup> Cycling frequency was classified as at least once per week, at least once per month or at least once per year.<sup>18</sup> Cyclists

were grouped as cycling alone, with children, with adults or with others (e.g. camp leaders). Cyclist speed was dichotomized into less than 25 km/h and greater than or equal to 25 km/h. A forward selection modelling strategy was used where each co-variate was added to the model containing outcome (head or facial injury) and exposure (helmet fit or helmet position) individually. Separate models were developed for helmet fit and helmet position to avoid potential collinearity of the two variables. If a co-variate produced a change in helmet fit or position estimates of greater than or equal to 10%, it was retained in the model. This process was repeated until no more changes were observed or until the number of variables in the model reached 10% of the number of cases.<sup>19</sup>

### **Multiple imputation analysis**

We imputed missing values for exposure variables and potential confounders using chained equations and custom prediction imputation models.<sup>20</sup> In the imputation model, variables were imputed in order of least missing to most missing using predictive mean matching for continuous variables and multinomial logistic or ordered logistic regression for categorical variables as appropriate. Non-missing predictors were also included. Logistic regression models including all co-variates (age, sex, BMI, cyclist speed, cycling frequency and cycling companions) were used to calculate OR estimates and 95% CIs from the imputed data. All data analyses were conducted using STATA version 11.0 (StataCorp LP, College Station, TX, US).

## **Results**

### **Characteristics of the study sample**

In total, 4960 injured cyclists were screened for eligibility and 3111 (63%) agreed to participate and were enrolled into the study. Of these, 2336 (75%) were wearing a helmet at the time of the crash. For this analysis, there were 297 cyclists with a head injury, 289 facial injury cases and 1694 controls. There were 64 participants who had both head and facial injuries; these were included in both case groups.

Table 1 shows the characteristics of the groups of cyclists with head and facial injuries. Compared with controls, the cyclists with head injuries tended to be biking faster and were more likely to be biking alone, while those with facial injuries were younger, had a lower BMI, were cycling alone or with adults and rarely used a full-face helmet.

### **Helmet fit and position and risk of head injury**

Based on the crude estimates, poor helmet fit significantly increased the odds of head injury relative to the excellent fit category (OR = 3.26, 95% CI: 1.08–9.83) (Table 2). If the helmet tilted back (OR = 2.76, 95% CI: 1.47–5.18), shifted to the side (OR = 1.87, 95% CI: 1.03–3.42), or came off (OR = 6.77, 95% CI: 3.08–14.86), the odds of head injury increased significantly relative to the “stayed centred” group.

The adjusted ORs for good, fair and poor helmet fit were 0.96 (95% CI: 0.69–1.36), 1.93 (95% CI: 1.04–3.57), and 3.23 (95% CI: 0.78–13.41), respectively, compared with excellent helmet fit. Cyclists who reported a fair helmet fit had nearly twice the odds of incurring a head injury compared with those who reported an excellent helmet fit. After conducting the imputation, only those who reported poor helmet fit (OR = 3.38, 95% CI: 1.06–10.74) had significantly increased odds of head injury relative to those with excellent helmet fit.

After adjustment for co-variates, cyclists with a helmet that came off during the crash had a 7-fold increase in the odds of head injury compared with those whose helmet stayed centred (OR = 7.13, 95% CI: 2.94–17.29). Those with a helmet that tilted back had more than a three-fold increase in the odds of a head injury (OR = 3.54, 95% CI: 1.70–7.40). The adjusted estimates based on the imputed data were similar; the OR estimate for a helmet that tilted back was 2.90 (95% CI: 1.54–5.47) and the estimate for a helmet that came off was 6.72 (95% CI: 2.86–15.82). The result for a helmet that shifted to the side was also significant after imputation (OR = 1.91, 95% CI: 1.01–3.62).

### **Helmet fit and position and risk of facial injury**

Crude estimates showed increased odds of facial injury with a helmet that tilted back (OR = 4.19, 95% CI: 2.46–7.15), shifted to the side (OR = 1.98, 95% CI: 1.11–3.50) or came off (OR = 3.12, 95% CI: 1.19–8.22) (Table 3). However, when adjusted for BMI, cycling frequency and cycling speed, only those helmets that tilted back were associated with an increase in the odds of facial injury (OR = 4.49, 95% CI: 2.30–8.77). Poor fit was indicative of a harmful effect but was not statistically significant (OR = 3.10, 95% CI: 0.76–12.69).

Compared with the adjusted estimates from the original data, the imputed ORs for facial injury risk tended to be further from 1.00. The odds of facial injury increased significantly if the helmet tilted back (OR = 4.81, 95% CI: 2.74–8.46), shifted to the side (OR = 1.83, 95% CI: 1.04–3.19) or came off (OR = 3.31, 95% CI: 1.24–8.85).

### **Data quality and reliability**

For helmet fit, overall observed agreement was 87.5% and expected agreement was 81.0% (Table 4). Weighted kappa was calculated since the responses were ordered, and kappa was 0.34 (95% CI: 0.16–0.64), which represents fair agreement.<sup>14</sup> For head and face injury cases ( $n = 24$ ), observed agreement was 91.7% and expected agreement was 79.8%, resulting in a kappa of 0.59 (95% CI: 0.28–1.00), representing moderate agreement. For controls, kappa was 0.22 (95% CI: 0.00–0.44).

An un-weighted kappa score was calculated for helmet position. For head and face injury cases, observed agreement was 62.5%, expected agreement was 49.3% and kappa was 0.26 (95% CI: 0.00–0.54) or fair agreement. For controls, observed agreement was 90.6%, expected was 85.6%, and kappa was 0.35 (95% CI: 0.19–0.71), fair agreement.

## **Discussion**

This study provides updated evidence on the relationship between correct bicycle

**TABLE 1**  
**Cyclist and crash characteristics by case-control status for cyclists injured in Calgary and Edmonton, Alberta**

	Controls (n = 1694)		Head injury (n = 297)		Chi <sup>2</sup> ( $\chi^2$ ) p value	Facial injury (n = 289)		Chi <sup>2</sup> ( $\chi^2$ ) p value
	n	(%)	n	(%)		n	(%)	
<b>Sex</b>					.70			.88
Female	450	(26.6)	76	(25.6)		78	(27.0)	
Male	1244	(73.4)	221	(74.4)		211	(73.0)	
<b>Age, years</b>					.14			$\leq .001$
< 13	695	(41.0)	101	(34.0)		154	(53.3)	
13–17	394	(23.3)	77	(25.9)		41	(14.2)	
18–39	308	(18.2)	56	(18.9)		53	(8.0)	
$\geq 40$	297	(17.5)	63	(21.2)		41	(14.2)	
<b>BMI, kg/m<sup>2</sup></b>					.34			.03
< 18.50 (underweight)	407	(24.0)	69	(23.2)		89	(30.8)	
18.50–24.99 (normal)	783	(46.2)	154	(51.9)		125	(43.3)	
25.00–29.99 (overweight)	279	(16.5)	40	(13.5)		41	(14.2)	
> 30.00 (obese)	56	(3.3)	6	(2.0)		4	(1.4)	
Unknown <sup>a</sup>	169	(10.0)	28	(9.4)		30	(10.4)	
<b>Cyclist speed, km/h</b>					< .001			.20
< 25	1240	(73.2)	183	(61.6)		199	(68.9)	
$\geq 25$	181	(10.7)	42	(14.1)		33	(11.4)	
Unknown <sup>a</sup>	273	(16.1)	72	(24.2)		57	(19.7)	
<b>Cycling frequency</b>					.14			.89
At least once per week	1476	(87.1)	257	(86.5)		253	(87.5)	
At least once per month	102	(6.0)	13	(4.4)		12	(4.2)	
At least once per year	57	(3.4)	10	(3.4)		12	(4.2)	
Unknown <sup>a</sup>	59	(3.5)	17	(5.7)		12	(4.2)	
<b>Cycling with others</b>					< .001			.02
Cycling alone	545	(32.2)	127	(42.8)		103	(35.6)	
With adults	643	(38.0)	95	(32.0)		124	(42.9)	
With children only	493	(29.1)	74	(24.9)		59	(20.4)	
With someone else <sup>b</sup>	12	(0.7)	0	(0.0)		3	(1.0)	
Unknown <sup>a</sup>	1	(0.1)	1	(0.3)		0	(0.0)	
<b>Helmet type</b>					.23			$\leq .001$
Full-face helmet	258	(15.2)	34	(11.5)		17	(5.9)	
No face guard	1405	(82.9)	257	(86.5)		269	(93.1)	
Don't know about face guard <sup>c</sup>	26	(1.5)	4	(1.4)		2	(0.7)	
Unknown <sup>a</sup>	5	(0.3)	2	(0.7)		1	(0.4)	

**Abbreviation:** BMI, body mass index.

<sup>a</sup> The “unknown” category includes the responses “don’t know,” “refused to answer” and where the data were missing. This category was not included in the tests of significance.

<sup>b</sup> Includes responses that were not possible to categorize as “adult” or “child” companions (e.g. cycling with an instructor or a baby-sitter).

<sup>c</sup> The question about type of helmet was added in year two (2009) of data collection and so information on the use of a face guard was not available for participant interviews in year one (2008).

helmet fit and risk of head or facial injuries. While the overall protective effect of bicycle helmets has been well documented, specific information on helmet fit and position increases our understanding of their impact and provides evidence

that can be used by cyclists, helmet manufacturers and those promoting injury prevention.

Rivara et al.<sup>13</sup> reported an increase in head injury risk as a result of cyclists’ helmets

shifting back or coming off. Our results were approximately twice as high as those previously reported. We also found a relationship between head injury and a helmet that shifted to the side, an observation that had not been previously

**TABLE 2**  
**Odds ratio estimates for the relationship between helmet fit and head injury among cyclists injured in Calgary and Edmonton, Alberta**

	Controls (n = 1694)		Cases (n = 297)		Crude OR (95% CI)		Adjusted OR (95% CI)		Imputed adjusted OR <sup>a</sup> (95% CI)	
	n	(%)	n	(%)						
<b>Helmet fit<sup>b</sup></b>										
Excellent	1014	(59.9)	173	(58.1)	1.00	(reference)	1.00	(reference)	1.00	(reference)
Good	579	(34.2)	92	(30.9)	0.93	(0.71–1.22)	0.96	(0.69–1.36) <sup>c</sup>	0.97	(0.73–1.29)
Fair	81	(4.8)	22	(7.4)	1.59	(0.97–2.62)	1.93	(1.04–3.57) <sup>c</sup>	1.60	(0.96–2.66)
Poor	9	(0.5)	5	(1.7)	3.26	(1.08–9.83)	3.23	(0.78–13.41) <sup>c</sup>	3.38	(1.06–10.74)
<b>What happened to your helmet?<sup>d</sup></b>										
Stayed centred	1421	(83.9)	180	(60.4)	1.00	(reference)	1.00	(reference)	1.00	(reference)
Tilted back	40	(2.4)	14	(4.7)	2.76	(1.47–5.18)	3.54	(1.70–7.40) <sup>e</sup>	2.90	(1.54–5.47)
Shifted to side	59	(3.5)	14	(4.7)	1.87	(1.03–3.42)	1.84	(0.90–3.77) <sup>e</sup>	1.91	(1.01–3.63)
Came off	14	(0.8)	12	(4.0)	6.77	(3.08–14.86)	7.13	(2.94–17.29) <sup>e</sup>	6.72	(2.86–15.82)
Tilted forward	10	(0.6)	2	(0.7)	1.58	(0.34–7.26)	1.39	(0.17–11.61) <sup>e</sup>	1.52	(0.32–7.19)

**Abbreviations:** BMI, body mass index; CI, confidence interval; OR, odds ratio.

**Note:** Missing values in original data: age (n = 7), height (n = 159), weight (n = 82), helmet fit (n = 16), cyclist speed (n = 345), helmet position (n = 225), cycling frequency (n = 76) and cycling companion (n = 2).

<sup>a</sup> Estimates adjusted for cycling frequency, presence of cycling companion, speed, BMI, sex and age.

<sup>b</sup> Adjusted analysis includes 198 cases and 1244 controls before imputation.

<sup>c</sup> Estimates adjusted for cycling frequency, speed, BMI and age.

<sup>d</sup> Adjusted analysis includes 166 cases and 1178 controls before imputation.

<sup>e</sup> Estimates adjusted for speed, cycling companion and BMI.

**TABLE 3**  
**Odds ratio estimates for the relationship between helmet fit and facial injury among cyclists injured in Calgary and Edmonton, Alberta**

	Controls (n = 1694)		Cases (n = 289)		Crude OR (95% CI)		Adjusted OR <sup>a</sup> (95% CI)		Imputed adjusted OR <sup>b</sup> (95% CI)	
	n	(%)	n	(%)						
<b>Helmet fit<sup>c</sup></b>										
Excellent	1014	(59.9)	165	(57.1)	1.00	(reference)	1.00	(reference)	1.00	(reference)
Good	579	(34.2)	106	(36.7)	1.13	(0.86–1.47)	0.95	(0.69–1.32)	1.11	(0.85–1.46)
Fair	81	(4.8)	14	(4.8)	1.06	(0.59–1.92)	0.91	(0.42–1.98)	1.05	(0.58–1.93)
Poor	9	(0.5)	3	(1.0)	2.05	(0.55–7.65)	3.10	(0.76–12.69)	2.08	(0.54–8.02)
<b>What happened to your helmet?<sup>d</sup></b>										
Stayed centred	1421	(83.9)	195	(67.5)	1.00	(reference)	1.00	(reference)	1.00	(reference)
Tilted back	40	(2.4)	23	(8.0)	4.19	(2.46–7.15)	4.49	(2.30–8.77)	4.81	(2.74–8.46)
Shifted to side	59	(3.5)	16	(5.5)	1.98	(1.11–3.50)	1.51	(0.72–3.17)	1.83	(1.04–3.19)
Came off	14	(0.8)	6	(2.1)	3.12	(1.19–8.22)	3.08	(0.95–9.93)	3.31	(1.24–8.85)
Tilted forward	10	(0.6)	2	(0.7)	1.46	(0.32–6.70)	2.02	(0.41–9.99)	1.54	(0.35–6.85)

**Abbreviations:** BMI, body mass index; CI, confidence interval; OR, odds ratio.

**Note:** Missing values in original data: age (n = 6), height (n = 163), weight (n = 71), helmet fit (n = 12), cyclist speed (n = 330), helmet position (n = 194), cycling frequency (n = 71) and cycling companion (n = 1).

<sup>a</sup> Estimates adjusted for BMI, cycling frequency and cycling speed.

<sup>b</sup> Estimates adjusted for cycling frequency, cycling companion, speed, BMI, sex and age.

<sup>c</sup> Adjusted analysis includes 198 cases and 1244 controls before imputation.

<sup>d</sup> Adjusted analysis includes 170 cases and 1318 controls before imputation.

**TABLE 4**  
**Agreement and kappa for helmet fit and position by cases and controls for cyclists injured in Calgary and Edmonton, Alberta**

	Observed agreement, %	Expected agreement, %	$\kappa$	95% CI
<b>Cases (n = 24)</b>				
Helmet fit	91.7	79.8	0.59	(0.28–1.00)
Helmet position	62.5	49.3	0.26	(0.00–0.54)
<b>Controls (n = 53)</b>				
Helmet fit	85.5	81.6	0.22	(0.00–0.44)
Helmet position	90.6	85.6	0.35	(0.19–0.71)
<b>Overall (n = 77)</b>				
Helmet fit	87.5	81.0	0.34	(0.16–0.64)
Helmet position	81.8	72.0	0.35	(0.20–0.74)

**Abbreviations:** CI, confidence interval;  $\kappa$ , kappa.

reported. We did not find that self-reported helmet fit influenced the odds of a facial injury, but a helmet that came off during a crash increased the odds of facial injury 3-fold and a helmet that tilted back increased the odds of facial injury almost 5-fold.

Foss and Beirness<sup>21</sup> reported that incorrect helmet use is more prevalent in 1- to 5-year-olds and 6- to 15-year-olds compared with older cyclists and that those aged 6 to 15 years have a higher risk of head injury.<sup>21</sup> Their definition of incorrect helmet use included an unfastened chin strap or a helmet that was tipped back.<sup>21</sup> We also found that the youngest age group (< 13 years old) suffered a high proportion of head and facial injuries compared with older age groups, which may be related to having a helmet that tilted back in the crash.

Another Canadian study found that 4.3% of helmet users wore their helmet incorrectly, either tipped back, with the chin strap unfastened or with a baseball cap worn underneath.<sup>22</sup> A 2010 observational study in Alberta<sup>10</sup> showed that 16.6% of cyclists—and 21% of children aged under 13 years—used a helmet incorrectly. In our study, approximately 9% of those with head injuries and 6% of those with facial injuries reported fair or poor helmet fit compared with 5.3% of controls. These are likely underestimates, as Lee et al.<sup>9</sup> reported that the prevalence of correct helmet use varied from 46% to 100% among recent studies, noting inconsistencies in the definition of correct use.

Our findings on the importance of helmet fit provide a better understanding of the potential protective effect of bicycle helmets. Previous studies that documented that helmet use (vs. non-use) reduces the risk of a head or brain injury<sup>1</sup> may in fact underestimate the protective effect of helmets given that it is likely that a number of the participants in these studies were wearing a poorly fitting helmet or using the helmet incorrectly (e.g. strap not fastened). If so, this has implications for the promotion of helmet use, which should include a focus on how to wear helmets correctly in order to achieve the maximum protective benefit.

#### Limitations

If cyclists who did not participate differed in their helmet use compared with the study sample, there is potential for selection bias. Unfortunately, in addition to lack of information on helmet use for these patients, the nature of the data collection process made it impossible for us to determine whether or not those we could not reach or who refused to participate would have been cases or controls. If those who refused were more likely to wear their helmet incorrectly and this resulted in more severe injuries involving the head or face, then we would have underestimated the protective effect of a helmet that fit correctly or stayed centred. Helmet fit was self-reported, and therefore may be prone to misclassification if cyclists were more likely to indicate that the helmet fit better than it actually did. It may be that those without a head injury

would over-report excellent helmet fit and those with a head injury under-report excellent fit. If so, this would have resulted in an inflated estimate of the effect of poor helmet fit. Lee et al.<sup>9</sup> found that self-perceived helmet fit was often over-estimated compared with expert evaluation, meaning that the helmet fit risk estimates in our study could be biased. We had high observed agreement between the initial and follow-up reported helmet fit for cases (91.7%) and controls (85.5%); though kappa values were lower for controls and could potentially reflect misclassification bias of the odds ratios toward or away from the null. The poorer reliability estimates for helmet position were similar for cases and controls and may indicate misclassification that would push the odds ratios to the null.

We included several potential confounders that have been shown to relate to bicycling injury. These included cycling frequency, presence of a companion, speed, BMI, sex and age. In their study, Rivara et al.<sup>13</sup> presented unadjusted results after determining that crash severity did not influence the effect estimates for the relationship between head injury risk and helmet fit or position. Therefore, it is unlikely that other factors related to both bicycling head and facial injury and helmet fit could account for the effects we have identified.

#### Conclusion

Helmet fit and position during a crash can significantly affect the risk of head and

face injuries. Correct helmet use may be increased as a result of educational programs informing cyclists that wearing a helmet is not enough to provide full protection without considering proper fit. Manufacturers should continue to try to design easy-to-use helmets in many different shapes and sizes that stay in place to best protect the cyclist. Retail employees selling helmets must be trained in the principles of correct helmet use to convey this important information to consumers.

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# Canadian parents' attitudes and beliefs about bicycle helmet legislation in provinces with and without legislation

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## Abstract

**Introduction:** The objective of this study was to survey Canadian parents on their attitudes and beliefs about bicycle helmet legislation and to compare responses from parents living in provinces with and without legislation.

**Methods:** A national survey of 1002 parents of children aged under 18 years was conducted. Chi-square tests were used to compare responses from the surveyed parents in the different jurisdictions.

**Results:** Responses from parents living in provinces with legislation ( $n = 640$ ) and without legislation ( $n = 362$ ) were as follows: concern for injury (63% vs. 68%, nonsignificant [NS]); believe helmets are effective (98% vs. 98%, NS); child always wears a helmet (74% vs. 69%, NS); support legislation for children (95% vs. 83%,  $p < .001$ ); support legislation for all ages (85% vs. 75%,  $p < .001$ ); support police enforcement (83% vs. 76%,  $p = .003$ ); believe legislation decreases the amount of time their child bicycles (5% vs. 8%, NS).

**Conclusion:** Parents are highly supportive of bicycle helmet legislation in Canada. They believe that bicycle helmets are effective and that legislation does not decrease the amount of time a child spends bicycling. There was also a high level of support for legislation across all ages, and for police enforcement.

**Keywords:** helmets, legislation, surveys, child, attitude, public health, head protective devices, bicycle

## Introduction

Systematic reviews have shown that wearing bicycle helmets reduces the risk of head, brain and facial injuries and that helmet legislation increases helmet use and decreases head injury rates.<sup>1-3</sup> Many jurisdictions in Canada (6 out of 10 provinces) have legislated helmet use, and some municipalities have adopted more rigorous and universal legislation.<sup>4</sup>

Despite the supporting evidence, debate about the advantages of helmet use and helmet legislation continues.<sup>5,6</sup> This debate has not, however, included a societal perspective.

The objective of our study was to survey Canadian parents about their attitudes and beliefs towards bicycle helmet legislation and to compare responses from parents living in provinces with and without legislation.

## Methods

We designed our survey to examine several currently debated issues from the perspective of Canadian parents. The questions related to parents' perceptions of the effectiveness of bicycle helmets, their support for bicycle helmet legislation and enforcement and their perceptions of the effect of legislation on bicycle use. Additional demographic questions included age and sex of their child, age and education of the responding parent, family income and the province where the family lived. The survey was conducted from 1 February 2010 to 5 February 2010. The sampling frame was Canadian adults aged 18 years and over who were members of the LegerWeb online panel.\* This national online panel, which is used to conduct over 1000 surveys per year in Canada, consists of about 345 000 members, with between 10 000 and 20 000 new members added each month and a retention rate of 90%. Invitations to new panelists are made to ensure representativeness of the entire adult population in Canada by sex, age, income and region. To enhance participation, respondents are entered into monthly draws for prizes. For this study, panel members with children under the age of 18 years were randomly selected to receive an email invitation to the survey.

A sample size of 1000 was sufficient to determine the single proportion of all respondents supporting legislation with a

\* <http://www.legermarketing.com>

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margin of error of  $\pm 3\%$  with 95% confidence and to provide 90% power to detect a difference of 10% between respondents living in provinces with and without legislation. We used descriptive statistics to describe responses from the entire survey population and chi-square tests to compare responses from those living in provinces with and without legislation. We used Bonferroni correction to account for multiple comparisons (adjusted  $p < .004$  considered significant). We also conducted an exploratory analysis of the responses of those living in provinces with all-ages bicycle helmet legislation and those living in provinces with child-only legislation.

Ethics approval for the study was given by the Hospital for Sick Children Research Ethics Board.

## Results

Of 1128 parents invited to join the survey, 1002 responded (89% response rate), 640 from provinces with legislation (155 with all-ages legislation and 485 with child-only legislation) and 362 from provinces without. Only 3.6% of respondents indicated that their child or children had ever had a bicycle injury requiring medical attention. The characteristics of the parent respondents and their children are shown in Table 1. The proportion of respondents with a household income between \$50 000 and \$125 000 (53%, 95% confidence interval [CI]: 50%–56%) is similar to the national census for family income (51%).<sup>7</sup> The proportion of respondents who attained a university education (50%, 95% CI: 47%–53%) is higher than the national census for adults aged 25 to 64 years (23%).<sup>8</sup> The proportion of respondents by province was similar to population density by province according to national census data.<sup>9</sup>

Responses to various issues from parents living in provinces with and without legislation, respectively, were as follows: concern about injury (63% vs. 68%, non-significant [NS]); believe helmets are effective (98% vs. 98%, NS); child always wears a helmet (74% vs. 69%, NS); support child-only legislation (95% vs. 83%,  $p < .001$ ); support all-ages legislation (85% vs. 75%,

**TABLE 1**  
**Survey participant characteristics (N = 1002)**

Demographics	n	(%)
<b>Parent age, years</b>		
< 35	375	(37.4)
35–44	467	(46.6)
$\geq 45$	160	(16.0)
<b>Sex of surveyed parent</b>		
Male	465	(46.4)
<b>Parent education attained</b>		
High school / college	492	(49.1)
University	500	(49.9)
Prefer not to answer	10	(1.0)
<b>Household income, \$</b>		
< 50 000	178	(17.8)
50 000–124 999	528	(52.7)
$\geq 125 000$	160	(16.0)
Don't know / prefer not to answer	136	(13.6)
<b>Child age, years<sup>a</sup></b>		
< 1	138	(6.8)
1–4	829	(40.8)
5–9	777	(38.2)
10–14	217	(10.7)
15–17	72	(3.5)
<b>Sex of children</b>		
Male only	292	(29.1)
Female only	286	(28.5)
Both male and female	414	(41.3)
Prefer not to answer	10	(1.0)
<b>Province</b>		
British Columbia	100	(10.0)
Alberta	85	(8.5)
Saskatchewan	28	(2.8)
Manitoba	57	(5.7)
Ontario	400	(39.9)
Quebec	267	(26.7)
New Brunswick	31	(3.1)
Prince Edward Island	1	(0.1)
Nova Scotia	23	(2.3)
Newfoundland and Labrador	10	(1.0)
<b>Child has had bicycle injury requiring medical attention</b>		
Yes	36	(3.6)
No	957	(95.5)
Don't know / prefer not to answer	9	(0.9)

<sup>a</sup> The total number of children is greater than the number of participants because there are multiple children in families (n = 2033).

$p < .001$ ); support police enforcement (83% vs. 76%,  $p = .003$ ); believe legislation decreases the amount of time their child bicycles (5% vs. 8%, NS).

Responses from parents living in provinces with all-ages legislation and child-only legislation, respectively, were as follows: concern about injury (68% vs.

61%); believe helmets are effective (96% vs. 99%); child always wears a helmet (77% vs. 73%); support child-only legislation (97% vs. 94%); support all-ages legislation (91% vs. 84%); support police enforcement (89% vs. 82%); believe legislation decreases the amount of time their child bicycles (6% vs. 5%). None of these comparisons were statistically significant (at the  $p < .004$  level).

## Discussion

This national sample of Canadian parents living in provinces with and without bicycle helmet legislation has shown that many parents believe that bicycle helmets are effective and that legislation does not decrease the amount of time a child spends bicycling; there was also a high level of support for legislation across all ages and for police enforcement of this legislation.

An earlier survey, conducted in a Canadian city in 1991 prior to legislation, demonstrated 80% support for legislation.<sup>10</sup> This is similar to the rate of support that we found among parents living in provinces without legislation. The current 93% rate of support from parents living in provinces with legislation indicates a substantial increase over the past two decades.

Four of the 10 Canadian provinces (British Columbia, New Brunswick, Prince Edward Island and Nova Scotia) have all-ages helmet legislation; Alberta and Ontario have legislation for bicyclists aged less than 18 years; and the remaining provinces (Saskatchewan, Manitoba, Quebec, Newfoundland and Labrador) and the three territories (Yukon, Northwest Territories and Nunavut) have no legislation. This variety provides information for a natural experiment examining helmet use and beliefs. A recent analysis of data from the Canadian Community Health Survey found that self-reported bicycle helmet use in youth (12–18 years) increases as helmet legislation becomes more comprehensive: 33% in provinces with no legislation; 47% in provinces with child-only legislation; and 78% in provinces with all-ages legislation.<sup>11</sup> In our predominately pre-adolescent age group (86% were under the age of 10 years), comprehensiveness of the legisla-

tion was associated with parent-reported support of legislation (both child-only and all-ages) and police enforcement, but not with parent-reported child helmet use rates.

Ontario, one of the two provinces with child-only legislation, has debated whether to introduce all-ages legislation. In June 2012, the Office of the Chief Coroner<sup>12</sup> reported on their review of all 129 cycling deaths in Ontario between 2006 and 2010. Of these, 15% were aged 19 years or less and only 27% were wearing a helmet. The report recommended amending the Highway Traffic Act to make helmets mandatory for cyclists of all ages.<sup>12</sup> The results of our survey suggest that parents would strongly support this recommendation.

The ongoing debate about the potential benefit and harm of bicycle helmet legislation includes a concern that "...enforced laws discourage cycling, increasing the costs to society of obesity and lack of exercise and reducing overall safety of cycling..."<sup>13,p86</sup> However, direct observations of bicycling children in one Canadian city yearly between 1993 and 1999 found that the introduction of helmet legislation did not significantly affect the numbers of hours that children cycled.<sup>14</sup> In addition, our survey found that only 5% of parents who lived in a province with bicycle helmet legislation reported that this legislation decreased the amount of time their child cycled. Together, these studies of directly observed and parent-reported child behaviours suggest that legislation has promoted safety without reducing physical activity.

## Limitations

A limitation of this survey is the higher educational attainment of the parent respondents as compared with the national census. Nevertheless, that 70% of the parents surveyed reported that their child(ren) always wore a helmet is consistent with direct observational studies of bicyclists in Canadian provinces before and after the introduction of legislation.<sup>3,15,16</sup> For example, several years after the introduction of legislation in Alberta and Nova Scotia, 63% to 90% of children and adolescents were observed wearing a

helmet while cycling. Although these surveys, which used direct observation, are not able to assess the educational attainment of the parents, observation sites were selected randomly and the analysis controlled for neighborhood income quintile. In contrast, direct observations of children's helmet use six years after the introduction of legislation in Ontario found variation by the level of neighborhood income.<sup>17</sup> Therefore, it remains possible that parents' attitudes and beliefs about bicycle helmet legislation are influenced by their level of educational attainment and income.

There are several other potential limitations to this study. For example, data were collected in February, a month when few children cycle. Parental perception of children's helmet use, concern for injury and support for legislation may be higher during the seasons when children typically cycle. If true, then the estimates in this study would be considered conservative. In addition, although the response rate was high, there were no data available on non-responders for comparison. Finally, we acknowledge that only parents completed this survey. Other members of society should have an opportunity to participate in this debate, particularly when considering whether legislation should be restricted to children or encompass all ages.

## Conclusions

Parents of Canadian children are highly supportive of bicycle helmet legislation. This information provides a societal perspective, which may inform the current debate and may be useful for public health, knowledge translation professionals and policy makers in Canada and other countries.

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# Validation of a deprivation index for public health: a complex exercise illustrated by the Quebec index

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## Abstract

**Introduction:** Despite the widespread use of deprivation indices in public health, they are rarely explicitly or extensively validated, owing to the complex nature of the exercise.

**Methods:** Based on the proposals of British researchers, we sought to validate Quebec's material and social deprivation index using criteria of validity (content, criterion and construct validity), reliability and responsiveness, as well as other properties relevant to public health (comprehensibility, objectivity and practicality).

**Results:** We reviewed the international literature on deprivation indices, as well as publications and uses of the Quebec index, to which we added factual data.

**Conclusion:** Based on the review, it appears that the Quebec index responds favourably to the proposed validation criteria and properties. However, additional validations are required to better identify the contextual factors associated with the index.

**Keywords:** deprivation, social inequalities in health, index, validity, reliability, Quebec

## Introduction

Deprivation and other area-based socio-economic indices are used extensively in public health in a number of countries<sup>1-18</sup> including Canada.<sup>19-23</sup> Despite their widespread use, they have seldom been explicitly validated, except in a few mainly British studies.<sup>7,24-27</sup> Validating a deprivation index means verifying whether it adequately reflects the reality being measured. Validation is a complex exercise because the index must respond to a number of criteria and have certain properties that are useful in its field of application (in this case, public health).

The purpose of this study is to subject Quebec's material and social deprivation index<sup>23</sup> to these validation criteria and properties. The Quebec index was developed at the end of the 1990s and has since

been used in Quebec and Canada in various contexts. In this paper, we first describe the index and then present the validation criteria and properties, first with reference to the international literature, then to the Quebec index. Finally, we discuss the nature of the Quebec index and make proposals for additional validations.

## Quebec material and social deprivation index

The Quebec deprivation index was designed to illustrate social inequalities in health and in the use of health services. Its objectives are primarily exploratory and descriptive in nature. It applies to the entire Quebec population, by place of residence.

The design and creation of the index is based on Peter Townsend's ideas on

deprivation and the international literature on social determinants of health. The index has two dimensions, material deprivation and social deprivation. The index is also geographical: it is based on the smallest standardized Canadian census unit, composed of one or more blocks of neighbouring houses with a population of 400 to 700 persons. This unit is the enumeration area (EA) for the 1991 and 1996 censuses and the dissemination area (DA) for the 2001 and 2006 censuses.<sup>28</sup>

The Quebec deprivation index is made up of six socioeconomic indicators by EA or DA: the proportion of people 15 years and older with no high school diploma or certificate; the employment:population ratio of people aged 15 years and older; the average income of people aged 15 years and older; the proportion of people aged 15 years and older living alone; the proportion of people aged 15 years and older who are either separated, divorced or widowed; and the proportion of single-parent families. All but the last are adjusted according to the age and sex of the Quebec population.

We extracted two components from these indicators using principal component analysis (PCA): the material component, which is associated with employment, education and income, and the social component, which is associated with marital status, living alone and single-parent families. For each component, the PCA produces a factor score by EA or DA, indicating its relative level of deprivation. Depending on this score, Quebec EAs or DAs are grouped into quintiles (population groups of 20%) from the most privileged (quintile 1, Q1) to the least (quintile 5, Q5). Thus, it is possible to

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follow variations in deprivation for each dimension separately (Q1 to Q5) and for both dimensions simultaneously (Q1Q1 to Q5Q5).

## The validation of deprivation indices

Validation of deprivation indices, including the Quebec material and social deprivation index, is based on proposals in the literature<sup>7,24-27</sup> and, more specifically, on work focused on the surveillance and measurement of deprivation and social inequalities in health.<sup>24</sup> After reviewing the deprivation indices used in the United Kingdom, Carr-Hill and Chalmers-Dixon<sup>24</sup> suggested using three criteria to evaluate this type of index (validity, reliability and responsiveness) and also suggested considering other properties useful for health policies. While recognizing that the scientific community identify other criteria and properties,<sup>29</sup> we used the definition proposed by Carr-Hill and Chalmers-Dixon.<sup>24</sup>

We used three approaches to measure the validity of the deprivation indices. These three approaches are usually referred to as content validity, criterion validity and construct validity.

### Content validity

Content validity refers to the agreement between the general concept of deprivation, its main dimensions and the indicators selected to illustrate them:<sup>24</sup> Are the dimensions and indicators appropriate? Do they represent all the facets of deprivation that the index is attempting to reflect?

The conceptual foundations of the Quebec material and social deprivation index are mainly based on the proposals set forth by Peter Townsend,<sup>30</sup> for whom deprivation is a “state of observable and demonstrable disadvantage, relative to the local community or the wider society or nation to which an individual, family or group belongs.” The author distinguished between two forms of deprivation: material and social. The first, material deprivation, refers to the lack of the normal goods and amenities of modern living in various areas, such as food, housing, the environ-

ment and work. The second, social deprivation, which according to Townsend, is more difficult to define, refers to the fragility of social ties. This fragility may occur within the family unit or it may extend to close relationships, friends, confidants, neighbours and others who provide emotional and material support (social support). It can also reflect the difficulties associated with integration and participation in social relationships and other common activities within the local community, such as recreational or educational activities.

This brief definition of deprivation forms the basis for a number of deprivation indices.<sup>7,9,20,25,26,31-33</sup> The authors of these indices highlighted the relative character of deprivation, its subjective and objective aspects, and its material and social dimensions. The analysis of deprivation can, however, involve more than two dimensions or different fields<sup>13</sup> and overlap with other concepts, such as poverty, disadvantage, socio-economic status or position,<sup>1,6,10,15,16,26</sup> marginalization,<sup>22</sup> or social isolation or fragmentation.<sup>34,35</sup> In all cases, the concepts beneath these area-based deprivation indices and other socio-economic indicators remain underdeveloped.<sup>25-27</sup>

The area-based scale is, however, a fundamental element of deprivation indicators that distinguishes them from indicators related to individuals, even though they often serve as a substitute or proxy for each other and are sometimes compared.<sup>1,5,11,16,26,27</sup> An area-based indicator reflects a specific reality<sup>6,13,36</sup> that varies according to the scale considered.<sup>36,37</sup>

### Criterion validity

Criterion validity is used to verify whether the variations in a deprivation index correlate highly with those of an external measurement of deprivation.<sup>24</sup> Criterion validity is not used extensively because it is commonly accepted that there is no gold or reference standard for deprivation. Nevertheless, certain practices are similar. For example, some authors have compared the area-based variations of different deprivation indices with one another<sup>25,27,37</sup> or

with those of measurements involving individuals, even though they are different realities.<sup>1,16,26</sup> Moreover, certain authors have compared the area-based variations of a new index to indices already in use, such as Townsend's.<sup>6,7,15,16</sup>

Because there is no standard or reference measure for deprivation, we preferred to discuss the Quebec index in terms of convergence validity, as will be discussed later.

### Construct validity

Construct validity of a deprivation index in the health sector can take on a number of forms.<sup>24,29</sup> Above all, it aims to determine whether the construction is consistent with the concept of deprivation. Construct validity is also expressed through consistent relationships between the index and other measurements related to the concept of deprivation, on the one hand, and various health measures and the use of health services, on the other. These forms of validity will be more specifically addressed through *convergence validity* and *predictive validity*, respectively.

To operationalize his vision of deprivation, Townsend reviewed various indicators used in Great Britain, some from administrative bases and others from health surveys,<sup>30</sup> and proposed a material deprivation index combining four indicators.<sup>24</sup> Other authors added a social dimension by creating a separate social deprivation index,<sup>26</sup> or social isolation index,<sup>34</sup> combining a number of indicators, all from censuses.

To construct the Quebec index, we took into consideration these indicators and also conducted a literature review on the social environment and social inequalities in health.<sup>34,38-41</sup> We then selected our indicators on the basis of theoretical and practical criteria: affinity with one of the two forms of deprivation, known link with health, availability at a fine geographical scale in the census<sup>28</sup> and a limited number of indicators in the composition of the index (parsimony) to simplify comprehension. We selected six indicators through this process.

The integration of these indicators in the form of an index was not the subject of any explicit hypothesis. The intention was to let the “natural” area-based variations of the indicators express themselves without a priori grouping. For this, we used principal component analysis (PCA), an exploratory synthesis method widely used in the creation of geographically based indices,<sup>3,6,7,13,16,18,20,22,32,33</sup> while recognizing the relevance of using groups of experts<sup>8,19</sup> or equally weighted sums<sup>5,25,27</sup> for the integration of indicators related to certain indices.

The PCA revealed the presence of two components. In the 2006 census, the first component reflected the variations in education, employment and personal income<sup>42</sup> (see Table 1). The second component reflected the variations in the proportion of individuals who were living alone, separated, divorced, widowed or living in single-parent families. These results are similar to Townsend’s proposals concerning the two dimensions (material and social) of deprivation. However, they differ in terms of education, which according to Townsend, is associated with social deprivation. Moreover, these two components do not appear to be very explicit with respect to the forms of deprivation.

Work connecting the two dimensions of the Quebec index with other indicators

from censuses by EA or DA makes it possible to clarify these dimensions.<sup>43,44</sup> For example, social deprivation is closely associated with residential mobility (frequent moves) and the proportion of renters, two indicators used in the construction of social fragmentation and isolation indices.<sup>34,35</sup> The fact remains that the census is a limited source of data for reporting on the fragility of social networks.

### Convergence validity

It is therefore necessary to compare the index to external measures (not from censuses) that reflect deprivation and its various dimensions. We conducted three exercises of this kind.

We first compared the spatial variations in the deprivation index to those in the proportion of children living with families receiving last-resort financial assistance from the Government of Quebec (see Table 2). Such assistance is given to families whose liquid assets (cash, etc.) are less than a particular amount that corresponds to the size and needs of the family. It is the only source of income the family has to meet its basic needs (e.g. housing and food). Two-thirds of the families receiving this assistance are single-parent families.<sup>45</sup> Therefore, we expected material and social deprivation to increase with the proportion of children living with families receiving this assis-

tance, which is the case according to the statistics provided by Quebec’s Department of Employment and Social Solidarity.<sup>45</sup>

The other two exercises made it possible to better define the social dimension of the deprivation index.

One linked the variations in the Quebec index with those observed in an in-depth study of three areas in the Quebec City region.<sup>46-48</sup> Two of the areas had different health reports. The material deprivation index was similar in these areas, whereas the social deprivation index differed significantly. A telephone survey of 600 respondents in each area collected data on health and perceptions of the local environment. The use of a social cohesion index,<sup>49</sup> addressing the appeal of the local environment and sense of neighbourhood and community, produced coherent results with those obtained from the social deprivation indices. Where social deprivation was high, social cohesion was low, and vice versa. Qualitative interviews with residents revealed that being born in the area and having family members in the area were cohesive factors.

The last exercise was based on an analysis of a number of cycles of the Canadian Community Health Survey<sup>50</sup> and explored the links between certain social support measures at the individual level<sup>51</sup> and the social deprivation index in urban Quebec.<sup>52</sup> The exercise revealed that an increase in social deprivation went hand in hand with a decrease in three social support measures, that is, affection, positive social interactions, and emotional or informational support. These associations are independent from the age, gender, lifestyle, education and household income of the survey respondents.

In summary, not only do the indicators used in the construction of the social dimension of the index reflect family structure and marital status, the dimension also captures a broader reality. At the individual level, this reflects the fragility of social support for single-parent families and those who are living alone or who are separated, widowed or divorced. At the local scale, it reflects residential instability (very frequent moves<sup>34,35</sup>), which does

**TABLE 1**  
**Indicators and components of the index of material and social deprivation, Quebec, 2006**

Indicator	Component	
	Material	Social
No high school diploma or certificate <sup>a</sup>	-0.85	+0.04
Employment:population ratio <sup>a</sup>	+0.75	-0.18
Average personal income <sup>a</sup>	+0.83	-0.28
Living alone <sup>a</sup>	-0.12	+0.82
Separated, divorced or widowed <sup>a</sup>	-0.12	+0.85
Single-parent families	-0.21	+0.68
Explained variance, %	34	33
Cumulated variance, %	34	67

**Source:** Canadian Census, 2006.

**Note:** These values are factor loadings and can be interpreted as coefficients of correlation between indicators and components. The sign (+ or -) of the indicators on the material dimension should be reversed to be interpreted in terms of deprivation.

<sup>a</sup> Proportion of people among those aged 15 years and older, adjusted according to the age and sex of the Quebec population.

**TABLE 2**  
**Percentage of children living in families receiving last-resort financial assistance, by quintile<sup>a</sup> of material and social deprivation, Quebec, 2001**

		Social deprivation					Total material deprivation
		Q1	Q2	Q3	Q4	Q5	
Material deprivation	Q1	0.6	1.1	2.1	3.9	8.2	2.7
	Q2	1.6	2.9	4.2	7.6	13.5	5.2
	Q3	2.7	4.0	6.4	10.7	20.0	7.7
	Q4	4.3	5.6	9.2	15.5	26.0	11.3
	Q5	8.4	11.0	16.6	23.3	38.1	18.8
Total social deprivation		3.6	4.9	7.2	12.3	22.7	9.2

Source: Ministère de l'Emploi et de la Solidarité sociale.

<sup>a</sup> From Q1, the most privileged quintile, to Q5, the least privileged quintile.

not foster the establishment of roots, neighbourhood ties, or the development or knowledge of and access to local resources and assistance networks, which some associate with social cohesion and social capital.<sup>53</sup>

### Predictive validity

As we have seen, the primary objective of a deprivation index is to identify social inequalities in health and, therefore, the associations between deprivation and health.<sup>24</sup> These associations must be plausible, corroborate observations made in the literature, or be supported by credible explanations or hypotheses.

Predictive validity is by far the most widely used approach to demonstrate the quality of a deprivation index.<sup>24</sup> It is seen as “proof” of its performance. For example, links have been made with overall mortality,<sup>10,12,14,27</sup> premature mortality (0–64 years),<sup>4,18</sup> cause of death,<sup>3,18</sup> the incidence of cancer<sup>10</sup> (including lung cancer<sup>14</sup>), long-term disability,<sup>25–27</sup> perceived health,<sup>1,37</sup> smoking and nutrition,<sup>5</sup> low birth-weight, immunization status and lead poisoning among children,<sup>11,14</sup> sexually transmitted infections, tuberculosis and violence,<sup>54</sup> myocardial infarction,<sup>7</sup> hospitalization,<sup>14,27</sup> and use of medical<sup>8</sup> and psychiatric services.<sup>16</sup> Moreover, the strength of the relationship between deprivation and health varies according to the size of the basic spatial unit of the index. The smaller the spatial unit, the stronger the relationship.<sup>1,10,11,26,54</sup>

The Quebec deprivation index accounts for various health and social situations. It

is linked to global health indicators, namely, life expectancy and health expectancy at birth and different ages<sup>23,44,55,56</sup> and mortality, including overall mortality, mortality by medical cause (e.g. cancer, circulatory disease, trauma and stroke), mortality related to lifestyle (e.g. smoking), premature death (less than 75 years), death among young people (18 years or less) and survival.<sup>23,55–69</sup> For example, an increase in the rate of premature deaths was observed both in the early 1990s and the mid-2000s as a function of material and social deprivation (Figure 1). The same is true for other indicators, such as disability,<sup>56,64,70–72</sup> the incidence or prevalence of diabetes and high blood pressure,<sup>72–74</sup> self-reported health,<sup>70</sup> and protective and risk factors for health: flu vaccination, premature birth or low birth weight, smoking and exposure to second-hand smoke, obesity, food insecurity and physical inactivity.<sup>23,61,70,75–78</sup> Social issues, such as teenage pregnancy and cases of abuse, neglect and behavioural problems among young people, are also associated with deprivation.<sup>23,44,61</sup>

Such relationships were also observed in use of health services. An increase in visits to general practitioners was noted with increased deprivation, but an opposing trend was sometimes found for certain medical specialties.<sup>44,61</sup> This opposing trend was also true for certain free services available for young people aged under 18 years (eye exams) and under 10 years (dental appointments) (Figure 2). However, the use of local community service centres (CLSCs), as well as hospitalization, day surgery and stays in long-

term care facilities increased with material and social deprivation.<sup>44,61,70,79</sup> A recent example is the rate of hospitalization following influenza A(H1N1) infection (Figure 3).

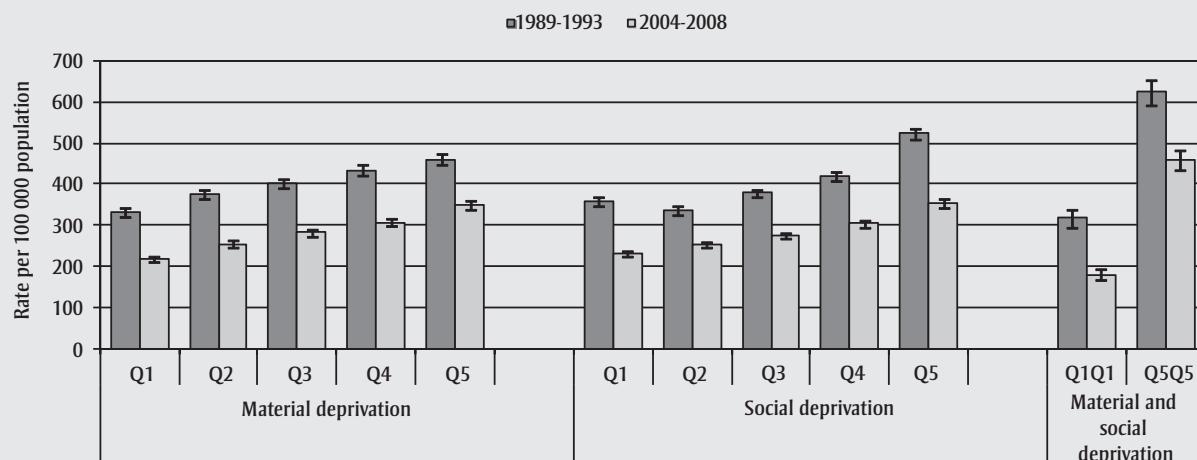
In summary, the Quebec deprivation index accounts for significant inequalities in health, even though their magnitude may vary depending on the theme under consideration. The two forms of deprivation (material and social) usually act independently.<sup>23,44,56–61,63–69,71–76,78,79</sup>

### Reliability

The reliability of a measurement tool is defined as its ability to produce the same result under the same circumstances.<sup>24</sup> For deprivation indices, this ability can be expressed through strong correlations between the indicators that form the index. These correlations are often tested using Cronbach's alpha. Some authors refer to an index's internal consistency.<sup>6,7,26</sup> This internal consistency, however, is not relevant when the index has more than one dimension.<sup>24</sup> The reliability of a deprivation index can also be expressed through correlation structure stability in time and space. The goal is to verify whether the correlation structure remains, regardless of the period and environment being considered.

The reliability of the Quebec deprivation index can be seen from the perspective of internal coherence for each dimension of deprivation. As seen in Table 1, close correlations exist between the indicators that make up each of the two dimensions

**FIGURE 1**  
Premature mortality rate by quintile<sup>a</sup> of material and social deprivation, Quebec, 1989–1993 and 2004–2008

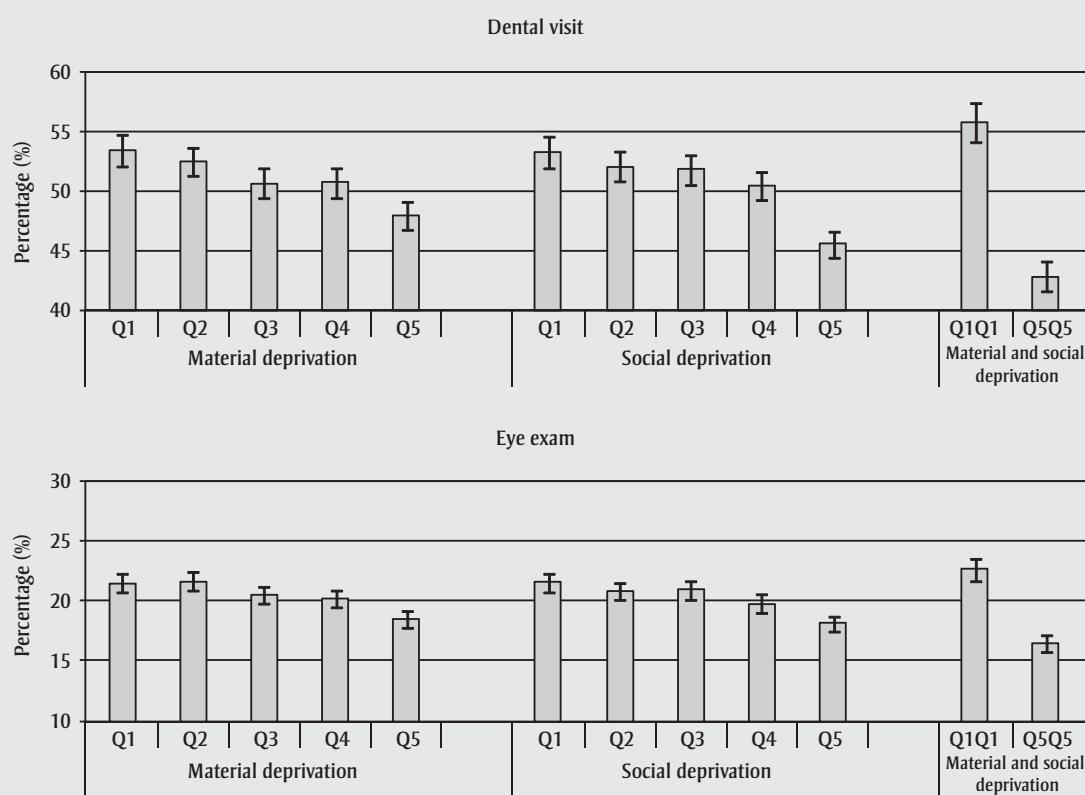


**Source:** 1991 and 2006 censuses; Quebec death records, 1989–1993 and 2004–2008.

**Note:** Death rates are adjusted by age, gender, geographical area and other form of deprivation.

<sup>a</sup>From Q1, the most privileged quintile, to Q5, the least privileged quintile.

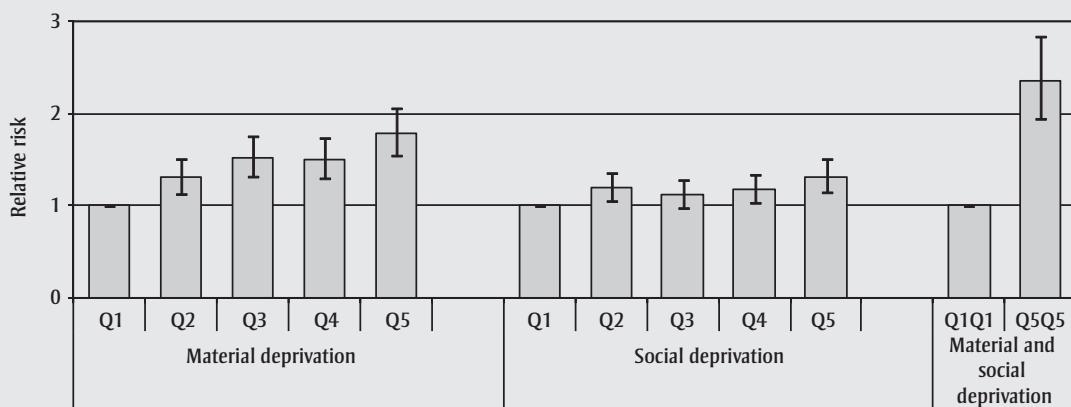
**FIGURE 2**  
Percentage of young people aged less than 10 years who have visited a dentist and of young people aged less than 18 years who have had an eye exam, by quintile<sup>a</sup> of material and social deprivation, Quebec, 2000–2002



**Source:** Calculations by the Institut national de santé publique du Québec based on data provided by the Régie de l'assurance maladie du Québec.

<sup>a</sup> From Q1, the most privileged quintile, to Q5, the least privileged quintile.

**FIGURE 3**  
**Relative risk of hospitalization following an A(H1N1) infection by quintile<sup>a</sup> of material and social deprivation, Quebec, April–December 2009**



**Source:** A(H1N1) surveillance record, MED-ÉCHO hospitalization records, Ministère de la santé et des services sociaux du Québec.

**Note:** The relative risk is adjusted by age, gender, geographical area and other form of deprivation.

<sup>a</sup> From Q1, the most privileged quintile, to Q5, the least privileged quintile.

(material and social) of the index. This fundamental structure of the index can be seen throughout Quebec and Canada<sup>42,68</sup> at various levels: regional, census metropolitan areas, cities of varying sizes and rural environments. It is also present for each census year between 1991 and 2006. Although the correlations between the indicators may vary slightly according to the location and period considered, the two-dimensional structure of the Quebec index is maintained.<sup>42</sup> This fundamental structure seems to be permanent, an essential quality for monitoring the social inequalities in health in time and space.

### Responsiveness

Responsiveness reflects the ability of a measurement tool to detect differences or changes according to the location, time and individual characteristics.<sup>24</sup> Variations in the deprivation index are observable at the national, regional and local levels, through the use of maps, for example.<sup>2,7,8,26,37</sup> They are also observable in relation to various health characteristics. The relationships vary according to the age and gender of the population,<sup>3,4,18,27</sup> with adults (aged 25–64 years) usually showing the highest inequalities in health. The inequalities change over the years (reducing or increasing) or with the area<sup>3,4,11,16</sup> and fluctuate according to the health issue under study (e.g. cause of death).<sup>10,16,27</sup>

The Quebec deprivation index was used to create an interactive atlas<sup>44,80</sup> that shows wide variations in deprivation at the provincial level and at a smaller level, in both urban and rural environments. These variations in the Quebec index are also associated with inequalities in health that relate to gender and age, with adults having the highest mortality ratios between groups at the extreme ends of material and social deprivation (Figure 4). Moreover, as is the case elsewhere,<sup>18,81–84</sup> the Quebec index has identified an increase in relative health differences in Quebec. According to the data presented (Figure 1), the premature mortality ratio between groups at the extreme ends of deprivation increased from 1.8 in 1989–1993 to 2.4 in 2004–2008. The Quebec index identified health inequalities of varying magnitude according to geographical area and fluctuating over time.<sup>62,64,66</sup> Thus, inequalities are growing throughout Quebec, except in the Montreal area, where they are actually bigger than in the rest of the province. Such health differences have also been demonstrated elsewhere in Canada.<sup>63,67,68</sup>

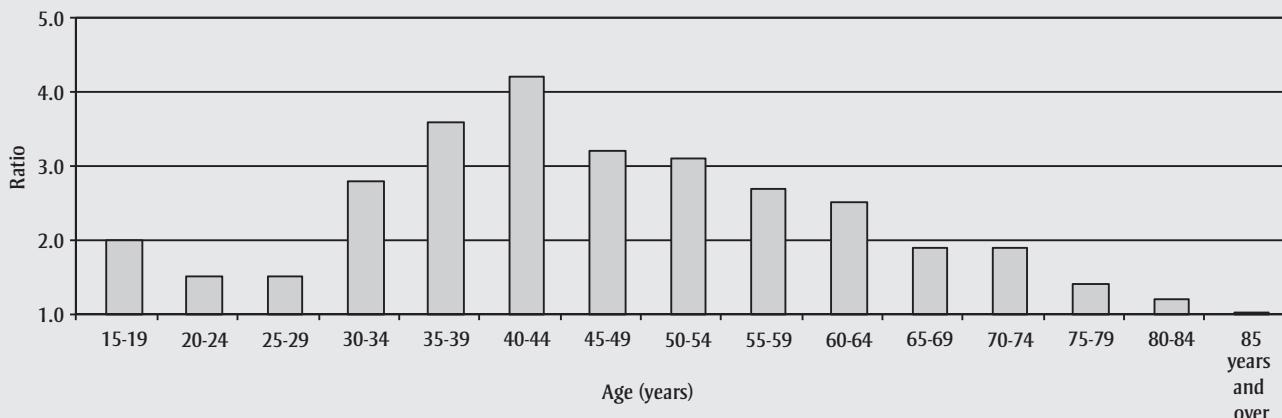
### Other properties

In the context of the development of public health policies or programs, deprivation indices must respond to requirements beyond those that are purely

technical or statistical.<sup>24</sup> This is the case for the comprehensibility of the index for an audience made up of decision makers and stakeholders in the field. The index must be easy to understand, appeal to common sense and be conducive to reasonable, unambiguous explanations. Thus, the contribution of the indicators to the index must be precise, clear and, if possible, quantified. The index must also be objective (cannot be manipulated) and be applicable to every part of the area being considered, at the national, regional and local levels. Finally, the index must respond to practical requirements. It must be possible to update it regularly, using the same method, and be manageable in terms of time and cost; it should also be possible to introduce it into health databases.

As we have seen, the Quebec deprivation index remains a simple measure, made up of two components and six indicators that are well known as being connected to health. Its structure is clear, and the weighting of the indicators in the index reflects their correlation with the components (Table 1). Its use demonstrates its comprehensibility for an audience made up of stakeholders and decision makers in the health and social service sectors in Quebec. Local variations in the index corroborated the perception of CLSC stakeholders,<sup>79,85</sup> and, at a provincial level,

**FIGURE 4**  
**Ratio of death rates between extreme quintiles of material and social deprivation (Q5Q5/Q1Q1) by age group, Quebec, 2000–2004**



**Source:** Institut national de santé publique du Québec, 2008; <http://www.inspq.qc.ca/Santescop/element.asp?NoEle=740>

these variations were used to develop departmental policies<sup>61</sup> and to allocate health resources among regions.<sup>86</sup> A recent compilation indicates that most of Quebec's regional health and social services agencies use the deprivation index to identify variations in their areas and the connections with various health and social issues.<sup>87</sup>

Although groups of experts were not involved in the design or initial construction of the deprivation index, many health experts (stakeholders and managers) at all geographical levels have since commented on, used and adapted the index to their needs and work contexts, contributing to its validation and evolution. For example, a local version of the index and an interpretation grid of the inequalities in the use of services were developed jointly with local CLSC stakeholders.<sup>79,85</sup> The grid compares the variations in the index and the knowledge of stakeholders regarding their organization directions and practices (e.g. target clientele, service access criteria), resources available locally (e.g. medical clinics, self-help groups and associations) and hard-to-reach populations (e.g. the homeless or individuals with mental health issues).

Finally, the relevance of the Quebec index depends on its availability over time and space. We have seen that the index exists

for 1991, 1996, 2001 and 2006, and that it covers all of Quebec (and Canada) in different versions: national, regional and local. There are supporting products (e.g. interactive maps, population tables, index assignment programs), which are all free and available online.<sup>80,88</sup> Tables and figures illustrating the health inequalities in Quebec using the deprivation index are regularly produced and posted online.<sup>89</sup>

## Conclusion

Despite the widespread use of deprivation indices, there have been few formal validation exercises. On the basis of the validation criteria proposed by Carr-Hill and Chalmers-Dixon,<sup>24</sup> it can be concluded that the Quebec material and social deprivation index responds favourably to various requirements for validity, reliability, responsiveness and use in public health.

However, there are limitations related to the geographical nature of the index. The index characterizes the socio-economic attributes of all residents of small areas. Although it is often used as a substitute for measurements related to individuals, the index is a measurement linked to an area. Studies, some of which are from Quebec and Canada,<sup>56,64,67,90</sup> show that the magnitude of health inequalities is underestimated through geographical measurement, espe-

cially in small cities and rural environments. They also reveal that health inequalities are associated with both types of measurements (those related to area and those related to individuals), independently, which signifies that they result from both geographical and individual realities.<sup>56,64,67,91-97</sup>

A better understanding of these geographical realities is therefore necessary to identify all the content and construct elements associated with a deprivation index. To achieve this, a research strategy at the local level combining theories, concepts, methods and indicators is necessary.<sup>98-101</sup> Reference frameworks on “contextual” factors associated with health must be used.<sup>53,98,102,103</sup> The social dimension of the index would particularly benefit from being associated with concepts and measurements of social cohesion and capital as well as their components (e.g. values, social support, informal social control and community participation). The material dimension would benefit from being associated with various fields, such as the physical environment (e.g. water and air), the built environment (e.g. housing and access to services), and public (e.g. schools, green space and public transportation) and private (e.g. food stores) infrastructure. This roadmap should be followed for future validation exercises of the Quebec index.

Finally, it should be noted that this index was designed to illustrate the existence of social health inequalities and that its purposes are exploratory and descriptive. The index is not an explanatory framework for these inequalities. For example, it does not consider dimensions related to health, such as immigration or Aboriginal status, even though these dimensions can be accounted for.<sup>63,66</sup> Rather, the Quebec index constitutes more of a marker of social and health inequalities and, as a result, is a relevant starting point toward more in-depth studies and increased understanding of these inequalities.

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# Coroners' records on suicide mortality in Montréal: limitations and implications in suicide prevention strategies

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## Abstract

**Introduction:** In Montréal, the characteristics of suicide cases may vary between different areas. The information collected by coroners during their investigations of suicides could be used to support local suicide-prevention planning actions.

**Methods:** This study analyzes all coroners' records on suicide in Montréal from 2007 to 2009 to (1) determine the usefulness of the data available; (2) develop a profile of cases; (3) examine local differences by comparing two areas, one with the highest suicide rate and the other with the lowest.

**Results:** The data collected revealed the lack of a systematic, standardized procedure for recording information about deaths by suicide. The rates of missing data varied, but were very high for antecedents of suicide attempts and recent events that could have precipitated the suicide. We observed differences in the characteristics of suicide cases according to area of residence.

**Conclusion:** By adopting a standardized procedure for collecting information on cases of suicide, coroners could provide local decision makers with a more accurate portrait of the people who die by suicide in their area. Local adjustments may improve suicide-prevention strategies.

**Keywords:** suicide, coroner, prevention, surveillance

## Introduction

Between 2000 and 2009, the suicide rate in Quebec fell significantly, from 16.8 per 100 000 to 12.5 per 100 000, while the Canadian rate remained relatively stable, decreasing from 11.4 to 10.7 per 100 000.<sup>1,2</sup> This decrease was not uniform in all population sub-groups.<sup>3</sup> For example, the decrease in the suicide rate in youth aged 15 to 19 years was notable (10% in males and 14% in females), but in those aged 50 years plus, the suicide rate has remained relatively stable for both sexes. This suggests that existing suicide-prevention strategies targeting older adults need to be improved. Even if universal suicide-prevention strategies

(e.g. means restriction) are effective,<sup>4</sup> experts generally agree that it is necessary to implement selective suicide-prevention strategies that target specific populations at risk and take into account factors such as age, socioeconomic status, cultural norms and the social environment.<sup>5-8</sup> Tailored interventions have proven effective at reducing suicide rates in older adults,<sup>5,9</sup> police officers<sup>10</sup> and the United States air force.<sup>11,12</sup>

Suicide rates in rural settings differ from those in urban settings.<sup>13</sup> The densely populated areas of Laval and Montréal have the lowest suicide rates in the province of Quebec. In 2009, the suicide rate in the Montréal metropolitan area was

10.1 per 100 000.<sup>2,14</sup> The Montréal metropolitan area is divided into 12 areas, each managed by a different health and social services centre (HSSC) with its own structure and set of services. With their community-based partners, for example, nongovernmental organizations and physicians, the HSSCs are responsible for implementing the most effective suicide-prevention strategies.<sup>15</sup>

Montréal's health and social services agency (Agence de la santé et des services sociaux de Montréal, ASSS) provides the HSSCs with general statistics on suicide rates in their areas and on the links between these rates and other indicators.<sup>16</sup> These statistics reveal considerable differences in the suicide rates in the different health service areas. For the period 2005 to 2009, the adjusted rate of death by suicide for an HSSC in the centre of Montréal was 17.4 per 100 000, while that of an HSSC at in the west of the city was 5.1 per 100 000.<sup>14</sup> Although these statistics are useful, they are insufficient to prepare even a summary profile of suicide cases in each area as they do not allow for the sociodemographic characteristics of the deceased or the circumstances surrounding the deaths to be known. Furthermore, such a profile would probably vary from one HSSC area to another, implying that the preventative actions taken need to be adjusted at the local level.

In Quebec, in accordance with *An Act Respecting the Determination of the Causes and Circumstances of Death*,<sup>17</sup> a coroner must identify the causes of all uncertain or violent deaths, including all cases of suicide. Each suicide is therefore subject

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to an investigation conducted by one of the province's 85 coroners. Coroners are physicians, lawyers or notaries who must have a minimum of four years of professional experience to be part-time coroners and eight to be full-time. Coroners are appointed by the Quebec government after an extensive interview process and on being recommended by the Ministry of Public Security. The Montréal metropolitan area has 13 coroners, mostly part-time physicians ( $n = 9$ ).

When investigating a death by suicide, coroners need to produce an investigation report but are not provided with a template or any guidelines. Police officers often help in the investigation, and friends and family are almost always consulted. Coroners rarely conclude the cause of death as undetermined (less than 2% of investigations in 2009). The rate of under-reported suicides is also believed to be so low that it does not affect the conclusions reached from analyzing coroners' reports.<sup>18</sup> As sources of information, coroners' records are therefore crucial for developing a profile of suicide cases, though the Coroner's Office has never provided anything beyond a minimal analysis based on sex, age and methods of suicide for the cases in each area.

The purpose of this study is to explore the information on deaths by suicide in Montréal-area coroners' records to: (1) determine whether these data can be used at the local level to monitor suicide trends and support the development of suicide-prevention strategies; (2) establish a comprehensive profile of suicide cases in 2007 through 2009; (3) examine local differences in the profile of suicide cases by comparing the two health service areas with the highest and lowest suicide rates.

The Chief Coroner's Office and Quebec's Ministry of Justice (*Ministère de la Justice*) reviewed and approved this research project before we began collecting our data.

## Methods

### Population

We included all residents of Montréal who, based on coroners' records, died in

2007, 2008 or 2009, and whose stated cause of death was death by suicide. Montréal is Quebec's economic hub, with close to 2 million inhabitants of diverse ethnicity and socioeconomic status. The HSSC area with the highest suicide rate (Area A) is in the downtown core and is one of the most populated neighbourhoods in Canada, with about 138 500 residents. Area A is also very socially diverse and includes marginal populations, such as homeless people, prostitutes and drug addicts, as well as young professionals and families.<sup>19</sup> The HSSC area with the lowest suicide rate (Area B) has about 217 000 residents and some of the best living conditions in Montréal (based on socioeconomic status). The population from this area consists mostly of English-speaking families with high annual incomes compared to the average in Montréal.<sup>20</sup>

- Mental disorders: Psychiatric pathology (depression, substance abuse, schizophrenia, bipolar disorder, etc.).
- Recent life events: Conjugal separation or loss of employment in the year before death.
- Suicidal behaviour: Any previous suicide attempts and the time between the previous attempt and the suicide death; suicidal verbalizations or behavioural changes suggesting a suicidal intent before the suicide death.
- Recent health services utilization: Professional assistance (physician, psychologist, HSSC, etc.) consulted in the year before death.
- Circumstances of death: Place (at home, in the workplace, etc.), the means used, whether a suicide note was found and signs of planning.

### Statistical analyses

We used the statistical software SPSS version X for Windows (IBM, Chicago, IL, US). Data not mentioned in the coroner's file for a case were identified as missing. The frequency of missing data was calculated for each variable. We then established a profile of the suicide cases through a descriptive analysis (frequency, percentage) of the available data, excluding the missing data. For example, we calculated the percentage of suicide cases who were employed at the time of their death by dividing the number of cases employed at time of death by the total number of cases whose files indicated an employment status. Differences in sex were examined using Student's t-test for age and chi-square tests for the other variables. Finally, we used chi-square tests to determine the differences between the two HSSC areas, Area A and Area B.

## Results

### Data available in the Coroner's records

The data collected from the coroner's records revealed that there was no standard investigative procedure used for deaths by suicide. The rate of missing data varied considerably from one variable to the next (Table 1). Besides basic information such as sex, age, place of

### Data sources

Data for our study came from the complete records prepared for each suicide case and kept in the office of Quebec's Chief Coroner. A single researcher examined the coroner's investigative report, the official report on the police investigation and, where applicable, the suicide note, results of toxicological tests, medical records and any other relevant information. These records, which must be consulted on site, were subsequently verified by another researcher.

### Data collection form and variables

Following an initial analysis of the coroners' investigative reports on deaths by suicide in 2009, we developed a data collection form. A researcher with many years' experience of collecting data from the Coroner's records subsequently revised this form. The final data collection form targeted the following information:

- Sociodemographic profile: Sex, age, marital status (single or cohabiting), parental status, employment status, household status (living alone or with others), the existence of financial problems or a criminal record, and postal code at the place of residence (HSSC area).

**TABLE 1**  
**Data on death by suicide missing from coroners' records, Montréal, Quebec, 2007–2009**

Variable	Missing data (N = 566)	n (%)
Sex		0 (0.0)
Age		0 (0.0)
Place of residence by postal code		4 (0.7)
Sociodemographic profile		
Not cohabiting		16 (2.8)
Unemployed		71 (12.5)
Childless		54 (9.5)
Living alone		0 (0.0)
Financial problems		250 (44.2)
Criminal record		1 (0.2)
Mental disorders		3 (0.5)
Physical illnesses		3 (0.5)
Recent life events ( $\leq 1$ year)		
Job loss		139 (24.6)
Conjugal separation		277 (48.9)
Suicidal behaviours		
Previous attempt(s)		243 (42.9)
Previous attempt(s) within past year		284 (50.2)
Suicidal verbalizations		84 (14.8)
Changes in behaviour		178 (31.4)
Recent health services utilization ( $\leq 1$ year)		0 (0.0)
Death circumstances		
Suicide note found		23 (4.1)
Signs of planning		429 (75.8)
Death at home		1 (0.2)
Method of suicide		0 (0.0)

suicide and means used—which were consistently noted in the records—other relevant information was not systematically recorded. For example, information on prior suicide attempts was missing from over 40% of the records.

#### **Profile of suicide cases in Montréal**

A total of 566 Montréal residents died by suicide in the years 2007, 2008 and 2009. The results show that 74.4% of the suicide deaths were among men and that over half (52.3%) were aged 40 to 64 years (Table 2). Signs of social isolation—not cohabiting, unemployment, no children or living alone—were common. These signs tended to be cumulative: 55.0% of our subjects had three signs of social isolation while only 4.1% had none (data not

shown). Many had at least one mental disorder (63.1%), in particular depression (32.3%) and substance abuse (30.0%). Conjugal separation was the most commonly reported recent life event in the coroners' records (13.6%). Three out of five cases (59.9%) had consulted at least one source of professional assistance in the year before death, with family physicians (35.7%) and psychiatrists (27.7%) consulted most often.

Financial problems and criminal records were reported more often among men than among women. Women were more likely to have consulted professional assistance in the year before their deaths. Women were also more likely to die by suicide at home. The means of suicide also varied by sex: hanging was more common

among men, while poisoning was more common among women (see Table 2).

#### **Comparison of HSSC areas with the lowest and highest suicide rates**

Compared with Area A, suicide cases in Area B experienced less social isolation: they were less likely to be living alone and more likely to be married or cohabiting and to have children (see Table 3). They were also less likely to have had a criminal record or recent financial problems or to have previously attempted suicide. The means used also differed: cases in Area A tended to use poisoning while cases in Area B tended to use strangulation.

#### **Discussion**

In this study we analyzed all the coroner's records of death by suicide in Montréal from 2007 to 2009. Using a data extraction form, we combed through 566 files for information on suicide. In addition to establishing a profile of all the people who died by suicide, this process revealed the absence of a systematic, standardized procedure that coroners can use to collect information on death by suicide. The goal of our study was to examine the potential of coroners' files as a source of valid and useful information for local surveillance of suicide and planning of suicide-prevention actions. Given such a high rate of missing data and the lack of standardization in the coroners' practices, we cannot recommend that they be used for this purpose.

Many other studies—in Quebec,<sup>21</sup> Canada<sup>22</sup> and the United States<sup>23</sup>—have described the incomplete nature of the information collected by coroners. Many factors may explain the extent of the missing data. First, there is no standard method for drafting reports and collecting data for the official record. As a result, some coroners focus on looking for the causes of suicide, while others stop the investigation as soon as they have determined whether the cause of death was intentional, accidental or due to homicide. Finally, the absence of electronic health records in Quebec makes access to important medical data—such as a diagnosis of mental disorders or hospitalizations for

**TABLE 2**  
**Profile of suicide cases, Montréal, Quebec, 2007–2009**

Characteristic	Total	Female (n = 145)	Male (n = 421)	p value
	n (%)	n (%)	n (%)	
Age, years				
15–19	18 (3.2)	5 (3.4)	13 (3.1)	.831
20–29	79 (13.9)	19 (13.1)	60 (14.3)	.731
30–39	95 (16.8)	22 (15.3)	73 (17.3)	.547
40–49	142 (25.1)	35 (24.1)	107 (25.4)	.760
50–64	154 (27.2)	42 (28.9)	112 (26.6)	.581
≥ 65	78 (13.8)	22 (15.2)	56 (13.3)	.573
Sociodemographic profile				
Not cohabiting	398 (70.3)	102 (70.3)	296 (70.3)	.994
Unemployed	334 (59.0)	91 (62.8)	243 (57.7)	.900
Childless	296 (52.3)	63 (43.4)	233 (55.3)	.001
Living alone	279 (49.3)	71 (48.9)	208 (49.4)	.927
Financial problems	202 (35.7)	37 (25.5)	165 (39.2)	.001
Criminal record	112 (19.8)	14 (9.7)	98 (23.3)	.000
Mental disorders				
At least one disorder	357 (63.1)	101 (69.7)	256 (60.1)	.038
Depression	183 (32.3)	56 (38.6)	127 (30.2)	.058
Substance abuse	170 (30.0)	40 (27.6)	130 (30.9)	.464
Bipolar disorder	51 (9.0)	22 (15.2)	29 (6.9)	.003
Schizophrenia	48 (8.5)	13 (9.0)	35 (8.3)	.803
Recent life events ( $\leq 1$ year)				
Conjugal separation	77 (13.6)	16 (11.0)	61 (14.5)	.147
Job loss	51 (9.0)	8 (5.5)	43 (10.2)	.082
Suicidal behaviours				
Previous suicide attempt	208 (36.7)	72 (49.7)	136 (32.3)	.081
Previous suicide attempt within past year	91 (16.1)	31 (21.4)	60 (14.3)	.583
Suicidal verbalizations	304 (53.7)	85 (58.6)	219 (52.0)	.185
Behavioural changes	271 (47.8)	67 (46.2)	204 (48.5)	.081
Recent health services utilization ( $\leq 1$ year)				
At least 1 service	339 (59.9)	105 (72.4)	234 (55.6)	.000
Family physician	202 (35.7)	63 (43.4)	139 (33.0)	.024
Psychiatrist	157 (27.7)	59 (40.7)	98 (23.3)	.000
Psychologist	23 (4.1)	10 (6.9)	13 (3.1)	.045
Death circumstances				
Suicide note	246 (43.5)	72 (49.7)	174 (41.3)	.110
Signs of planning	117 (20.7)	39 (26.9)	78 (18.5)	.461
Death at home	381 (67.3)	110 (75.9)	271 (64.4)	.012
Means of death				
Strangulation	259 (45.7)	41 (28.3)	218 (51.8)	.000
Poisoning	130 (22.9)	61 (42.1)	69 (16.4)	.000
Fall	44 (7.8)	13 (9.0)	31 (7.4)	.534
Firearm	26 (4.6)	6 (4.1)	20 (4.8)	.761
Drowning	20 (3.6)	6 (4.1)	14 (3.3)	.648
Subway	19 (3.4)	4 (2.8)	15 (3.6)	.643
Other	68 (12.0)	14 (9.6)	54 (12.7)	.311

attempted suicide—difficult for coroners to obtain.

The data collected by coroners in their investigations could prove highly useful in suicide prevention. Coroners have direct and privileged access to the family of the deceased and to additional sources of information, such as the police report, the toxicology report and the medical record. All these sources of information could help us better understand the circumstances surrounding deaths by suicide and develop a profile of suicide cases that could inform decision making around suicide prevention. Unfortunately, coroners' records are often incomplete sources of information. In almost half of the files, there is no information on prior suicide attempts or on recent events that may have precipitated the suicide, such as a conjugal separation or job loss. In contrast, diagnoses of mental disorders and a history of health services utilization are always available in coroner's files. One explanation may be that coroners adhere to a biomedical model in which suicide is seen as a medical complication of a mental illness.<sup>24</sup> As previously mentioned, Montréal's coroners are mostly physicians. However, even if the coroners always investigate mental disorders, they seem to underestimate their prevalence. Almost two-thirds (63.1%) of the files mentioned at least one disorder while this proportion ranged from 80% to 96% in psychological autopsies.<sup>25,26</sup> The same can be said of health service use in the year before the suicide: according to the coroners' records, 36% of the cases consulted a general practitioner in the year preceding their death, whereas this figure is between 76% and 86% in rigorous studies of the issue.<sup>27,28</sup> A standardized data collection form that covers all the parameters relevant to preventing suicide would help to reduce the amount of missing data in coroners' records.

In the United States, the Centers for Disease Control and Prevention (CDC) have sponsored the development of a National Violent Death Reporting System (NVDRS).<sup>29,30</sup> This active, state-based surveillance system collects risk factor data on all violent deaths, including homicides, suicides and unintentional fire-

**TABLE 3**  
**Profiles of suicide cases in HSSC Area A and Area B, Montréal, Quebec, 2007–2009**

Characteristic	Area A (n = 85)	Area B (n = 32)	p value
	n (%)	n (%)	
Sex (male)	64 (75)	23 (72)	.706
Age, years			
15–64	74 (87)	24 (75)	.115
≥ 65	11 (13)	8 (25)	.113
Sociodemographic profile			
Not cohabiting	70 (82)	15 (47)	.000
Unemployed	48 (57)	18 (56)	.956
Childless	61 (72)	13 (41)	.001
Living alone	53 (62)	9 (28)	.001
Financial problems	35 (41)	4 (13)	.005
Criminal record	20 (24)	2 (6)	.033
Mental disorders			
At least 1 disorder	55 (65)	16 (50)	.145
Depression	27 (32)	12 (38)	.557
Substance abuse	31 (37)	2 (6)	.001
Bipolar disorder	5 (6)	1 (3)	.547
Schizophrenia	12 (14)	1 (3)	.092
Suicidal manifestations			
Previous suicide attempt	44 (52)	8 (25)	.001
Previous suicide attempt within past year	20 (24)	2 (6)	.085
Suicidal verbalizations	49 (58)	21 (66)	.667
Behavioural changes	35 (41)	16 (19)	.874
Recent health services utilization (within past year)			
At least 1 service	53 (62)	17 (53)	.364
Family physician	30 (35)	11 (34)	.926
Psychiatrist	22 (26)	8 (25)	.922
Psychologist	6 (7)	3 (9)	.675
Death circumstances			
Suicide note	40 (47)	11 (34)	.181
Signs of planning	12 (14)	9 (28)	.754
Death at home	63 (74)	21 (66)	.363
Suicide method			
Strangulation	32 (38)	15 (47)	.364
Poisoning	32 (38)	4 (13)	.009
Fall	12 (14)	0 (0)	.025
Firearm	2 (2)	3 (9)	.094
Drowning	0 (0)	2 (6)	.020

**Abbreviation:** HSSC, Health and social services centre.

arms deaths. The detailed information stored in the system is used to help develop, implement and evaluate strategies designed to reduce and prevent violence-related deaths. Precipitating circumstances are particularly carefully

investigated (e.g. mental health diagnoses and treatment, substance abuse problems, interpersonal problems involving intimate partners, recent deaths in the family or among friends, financial problems, interpersonal violence, etc.).<sup>31</sup> This tool could

also prove highly useful in developing more comprehensive and structured investigation forms for use by coroners in Quebec.

Improving the quality of the data collected by coroners and making it more complete will not, however, guarantee its use by local decision makers, who do not currently have access to this information. To alleviate this problem, work has begun on a regional observatory of attempted and completed suicide in Montréal. Suicide Action Montréal and the Centre for Research and Intervention on Suicide and Euthanasia (CRISE) of the Université du Québec à Montréal will be jointly responsible for the observatory. The observatory will access all available data on people who died by suicide (including data from the Coroner's Office and administrative data about physician claims and hospitalization). This data will be anonymized and securely stored to protect personal information. A team of researchers will have a mandate to regularly produce useful local profiles for the program's decision makers and planners. With infrastructure in place dedicated to making use of the data collected by coroners, we can expect this information to lead to improvements in targeted suicide-prevention strategies.

The large variance in suicide rates in the 12 HSSC areas in Montréal is undoubtedly due in part to the great social diversity of this city. This study is unique in that we were able to develop different profiles of the suicide cases in two HSSC areas: in Area A, with the highest suicide rate, suicide cases are often socially isolated and have a substance abuse problem, while in Area B, with the lowest suicide rate, a higher number of suicide cases appear to be socially well integrated and their rate of substance abuse is low. However, these data should be interpreted with caution because of the low number of cases (n = 117), particularly in the area with the lowest suicide rate (n = 32). The findings nonetheless suggest that distinct preventive actions could be taken with these two subpopulations to improve the effectiveness of suicide-prevention strategies. If HSSC mental health teams had better knowledge of the characteristics of

suicide cases in their area, they could adjust their interventions accordingly, for example, by monitoring people more closely when they present a specific risk profile.

### **Strengths and limitations**

By analyzing coroners' records, we have expanded our knowledge of suicide cases in Montreal from 2007 to 2009. However, the originality of the study lies not only in the fact that we have revealed shortcomings in the process used to investigate deaths by suicide, but also in that we have shown the potential positive implications of being able to have detailed and valid local data.

However, several factors limit the conclusions that can be drawn from this study. First, by using coroners' files as our only source of data, the results are limited by the uneven quality of the compiled information and the absence of some important information. In order to obtain a fuller and more accurate profile, it would have been necessary to perform psychological autopsies. This research procedure consists of conducting structured interviews with the family and friends of suicide cases to accurately establish the person's physical and mental state at time of death and investigate the circumstances leading up to their death. Had we used the administrative databases of Quebec's health insurance authority (the Régie de l'Assurance maladie du Québec), we could have also described with certainty the person's use of medical resources in the year leading up to their death. We could have also confirmed or added certain diagnoses of mental health problems. For reasons of feasibility and due to the exploratory nature of this study, we limited our analysis to a three-year period. Great care should be exercised when interpreting the results from areas that had few suicides during this period.

### **Conclusion**

Almost all decisions to do with implementing suicide-prevention actions are made at the local level. HSSCs play a key role by developing services for their client base and ensuring that their actions are

co-ordinated with those of all their community-based partners. In order to be effective in this role, HSSCs need detailed data on suicide cases in their areas. With its 12 HSSCs, Montreal has a very heterogeneous population. Our study has shown that this diversity can also be seen in geographic variations in local profiles of suicide cases. General profiles of the entire population of Montreal are of limited use to decision makers. We need to go beyond general findings and provide them with more detailed information.

The scale of suicide and its tragic consequences for thousands of Canadians each year requires the strongest possible actions, and coroners have an important role to play in reducing suicide rates by helping us better understand the causes of suicide. They can help greatly advance knowledge in this area by applying a systematic, standardized data collection procedure to suicide cases. Such knowledge may lead to better targeted and more effective actions in at-risk individuals.

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# Prevalence of self-reported hysterectomy among Canadian women, 2000/2001–2008

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## Abstract

**Background:** Hysterectomy is one of the most frequently performed surgical procedures among Canadian women. The consequence is a population that no longer requires cervical cancer screening. The objective of our analysis was to provide more accurate estimates of eligible participation in cervical screening by estimating the age-specific prevalence of hysterectomy among Canadian women aged 20 to 69 by province and territory between 2000/2001 and 2008.

**Methods:** Self-reported hysterectomy prevalence was obtained from the 2000/2001, 2003 and 2008 Canadian Community Health Survey. Age-specific prevalence and 95% confidence intervals (CIs) were estimated for Canada and provinces and territories for the three time periods.

**Results:** Interprovincial variations in hysterectomy prevalence were observed among women in each age group and time period. Among women aged 50 to 59, prevalence was as high as 35.1% (95% CI: 25.8–44.3) ( $p < .01$ ) in 2008 and appeared to decrease in all provinces from 2000/2001 to 2008.

**Conclusion:** Interprovincial and time period variation suggest that using hysterectomy prevalence to adjust the population eligible for cervical cancer screening may be helpful to inform more comparable screening participation rates. In addition, both cervical cancer incidence and mortality rates can be adjusted by hysterectomy to ensure estimates across time and provinces and territories are also comparable.

**Keywords:** *hysterectomy prevalence, cervical cancer screening participation rates, hysterectomy epidemiology*

## Introduction

With nearly 47 000 procedures performed in 2008 to 2009 in Canada,<sup>1</sup> hysterectomy is second only to Caesarean section as the most frequently performed surgical procedure in Canadian women. Complete hysterectomy involves the removal of the uterus and cervix; partial supra-cervical hysterectomy, which is less frequently performed, involves the removal of the uterine fundus. Hysterectomy can be elective, for benign gynecologic conditions, or emergent, for uncontrollable hemorrhage,

to treat various malignant conditions, and to prevent cancer in pre-cancerous cervical conditions and in carriers of the hereditary non-polyposis colorectal cancer genes who are predisposed to endometrial and ovarian cancers. The indications for hysterectomy are becoming more rigorous with respect to its necessity and frequency, resulting in changes in the annual incidence of hysterectomy and therefore the number of women living without a cervix.<sup>2–4</sup>

Pap smear screening is recommended for all women who have ever been sexually

active, but is generally not required among women who no longer have a cervix. The exception to this is among women with a history of treatment for carcinoma in situ (severe cervical dysplasia). As a result, women who have had a hysterectomy and have never been treated for cervical dysplasia should neither be targeted for population-based cervical cancer screening nor included in summary participation screening statistics. When estimates of screening participation have been corrected for history of hysterectomy, the result has been a stabilization of participation across age groups. However, this approach has not been used across all provinces.<sup>5</sup> This is increasingly important in Canada, where participation in cervical cancer screening is used as a benchmark for assessing the performance of national and provincial cancer control and health care delivery systems.<sup>6</sup> An accurate assessment of the target population and screening participation can only be made if women living without a cervix are removed from the denominator. Recognizing the need to correct for history of hysterectomy is in alignment with the Canadian Task Force Guidelines that state that the guidelines do not apply to women who do not have a cervix as a result of hysterectomy.<sup>7</sup>

Canadian health care professionals do not agree on the standard for the use of hysterectomy in treating benign uterine conditions.<sup>8</sup> The incidence of hysterectomy varies over time and across regions,<sup>9–12</sup> suggesting that the prevalence of women living without a cervix also varies. This variance is a result of regional differences in incidence of uterine pathology and physician and patient fac-

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tors.<sup>9,13,14</sup> Physician-related factors include disagreement on indications for hysterectomy, differences in training and variation in regional practices;<sup>2,9,10,13,14</sup> patient factors relate to personal preference and beliefs or attitudes towards hysterectomy.<sup>10,13</sup>

The objective of our analysis was to estimate the prevalence of hysterectomy among Canadian women aged 20 to 69 years, by province and territory and over time.

## Methods

### Data sources

We used data from the Canadian Community Health Survey (CCHS) cycles 1.1 (2000/2001) and 2.1 (2003) and the CCHS Annual Component (2008) to estimate prevalence of hysterectomy. In all three time periods, CCHS data were collected over a 12-month period. Data were unavailable for CCHS cycle 3.1 (2005), the 2007 Annual Component or CCHS 2007–2008.<sup>15–17</sup>

The CCHS is a cross-sectional population health survey targeting Canadians aged 12 years and older living in private dwellings in all provinces and territories. Excluded are full-time members of the Canadian Forces and residents of institutions, certain remote areas and Indian Reserves and Crown Lands.<sup>15–17</sup> Until (and including) 2005, CCHS data were collected every two years; since 2007, data have been collected annually.<sup>17</sup>

Respondents 18 years or older were asked, “Have you had a hysterectomy (in other words, has your uterus been removed)?” to which they could answer yes or no.<sup>18–20</sup> This question can be found in the mammography modules of the CCHS cycles 1.1 (2000/2001) and 2.1 (2003) and in the Annual component, 2008.<sup>18–20</sup>

### Data analysis

Frequency estimates were produced to estimate hysterectomy prevalence. We analyzed hysterectomy prevalence for women aged 20 to 69 years by 10-year age groups, nationally and by each pro-

vince and territory, and differences between provincial hysterectomy estimates in a given time period using Ontario as the reference.<sup>21</sup> Weight adjustments, coefficients of variation, standard errors and 95% confidence intervals (CIs) were analyzed using the bootstrap method.<sup>16</sup> Prevalence estimates with fewer than 30 sampled respondents and/or coefficients of variation (CV) higher than 33.3% were suppressed, and prevalence estimates with CV between 16.6% and 33.3% were identified as needing to be interpreted with caution.<sup>15–17</sup> CV is commonly used by Statistics Canada to determine the quality of an estimate obtained from survey samples when applying the bootstrap method.<sup>15–17</sup> Statistical significance ( $p < .05$  and  $p < .01$ ) was determined using variance estimates for difference between ratios analysis ( $t$  test) available through the bootstrap method.<sup>21</sup>

## Results

We observed interprovincial variations in hysterectomy prevalence among women in each age group and time period. Hysterectomy prevalence among 20- to 29-year olds and 30- to 39-year olds in the majority of regions was suppressed due to small sample sizes and/or higher CV ( $> 33.3\%$ ). For the same reasons, hysterectomy prevalence was suppressed for Yukon, Northwest Territories and Nunavut in all age groups in all three time periods.

In 2008, the prevalence of hysterectomy ranged from 9.6% to 21.2% in women aged 40 to 49 years. The differences were statistically significant only between Nova Scotia (21.2%, 95% CI: 13.1–29.3) and New Brunswick (19.5%, 95% CI: 12.6–26.5) when compared to Ontario (9.6%, 95% CI: 7.1–12.1) ( $p < .05$ ) (Figure 1). Between 2000/2001 and 2008, the prevalence appeared to increase in three provinces, decrease in three and remain stable in one; however, all estimates were characterized by wide and overlapping confidence intervals (Table 1). In women aged 50 to 59 years, prevalence was as high as 35.1% (95% CI: 25.8–44.3) ( $p < .01$ ) in 2008 (in Newfoundland and Labrador) and appeared to decrease in all provinces from 2000/2001 to 2008

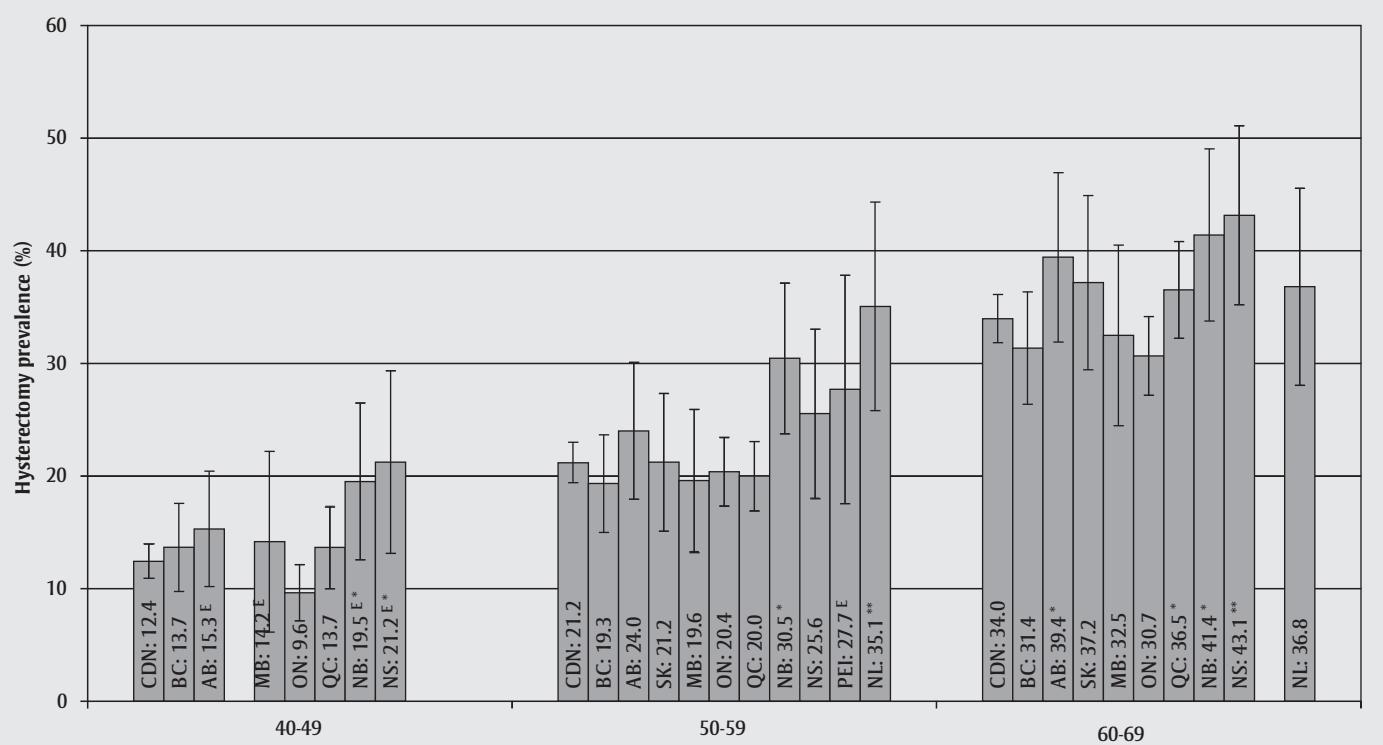
(Figure 1; Table 1), although estimates were characterized by wide and overlapping CIs in all provinces apart from Nova Scotia, Quebec and Ontario. In women aged 60 to 69 years, the prevalence of hysterectomy ranged from 30.7% to 43.1% in 2008. When compared to Ontario (30.7%, 95% CI: 27.2–34.2), the differences were statistically significant for Nova Scotia (43.1%, 95% CI: 35.2–51.1), New Brunswick (41.4%, 95% CI: 33.8–49.0), Quebec (36.5%, 95% CI: 32.2–40.8) and Alberta (39.4%, 95% CI: 31.9–47.0) (Figure 1). In this age group, prevalence appeared to decrease between 2000/2001 and 2008 in all provinces but one, where it remained stable (Table 1).

## Discussion

The prevalence of hysterectomy in Canada declined from 2000/2001 to 2008 and varied by province, with over half showing gradual decline over time in the 50- to 59- and 60- to 69-year age groups. We did not report patterns for the youngest age groups (20- to 29- and 30- to 39-year) due to the relative rarity of the procedure. Provincial variation in the incidence of hysterectomy in this time period has been previously demonstrated and shows similar trends to that of the prevalence data.<sup>11</sup> The variations observed across the provinces demonstrate how important it is to accurately report provincial prevalence since these will affect participation in cervical cancer screening rates and adjustment for cervical cancer incidence and mortality rates.<sup>22</sup>

Direct comparison of our analysis of hysterectomy prevalence to international estimates is difficult, primarily because of the different analysis periods and age ranges used.<sup>13,23–25</sup> However, most developed countries appear to have experienced a decline in new cases of women undergoing hysterectomy.<sup>26,27</sup> Within Canada, the lower prevalence seen in certain provinces may reflect a variation in the practice of limiting hysterectomy and a shift to conservative treatments for discretionary conditions. Among women aged 60 to 69 years, the smaller reductions in prevalence over time are likely because this cohort underwent hysterectomy before more conservative treatments

**FIGURE 1**  
**Self-reported hysterectomy prevalence rates in Canada among women aged 40 to 49, 50 to 59 and 60 to 69 in 2008**



**Abbreviations:** AB, Alberta; BC, British Columbia; CDN, Canada; CV, coefficients of variation; MB, Manitoba; NB, New Brunswick; NL, Newfoundland and Labrador; NS, Nova Scotia; ON, Ontario; PEI, Prince Edward Island; QC, Quebec; SK, Saskatchewan.

**Note:** Data for 40-49 year olds in NL, PEI, SK and 60-69 year olds in PEI is too unreliable to be published.

<sup>E</sup> Use with caution (CV: 16.6-33.3%).

\*  $p < .05$

\*\*  $p < .01$

became more common. Treatments such as the progesterone intrauterine device and endometrial ablation did not become widely available until the last decade.<sup>28</sup> Reduced prevalence of Canadian women living with a history of hysterectomy will probably continue to be observed until a minimum level is reached when its use will be limited to non-elective treatment for hemorrhagic emergencies and malignancies.<sup>29</sup>

The consequence of including in the denominator women who have had hysterectomies results in overestimating the target population and underestimating cervical cancer screening participation. A significant proportion of invasive cervical cancer cases in Canada, 40% to 50%, occur in the under-screened and never-screened population; while some provinces achieve almost 80% screening coverage for the

population at risk once in three years, half the women presenting with invasive cervical cancer had not been screened.<sup>5</sup> In addition, failure to remove women without a cervix from the denominator calculations results in less accurate comparisons of target populations and screening participation across programs and age groups: a recent Canadian report estimated overall participation at 70.2% (uncorrected for hysterectomy) and 74.1% (corrected).<sup>5</sup> More importantly, these results demonstrated the stabilizing effect of correction resulting in more uniform participation across age groups.<sup>5</sup>

#### Limitations

Our estimates of prevalence are limited by the nature of self-reported responses to CCHS questions including those about hysterectomy. There is also no indication of hysterectomy type, resulting in an

overestimate of total hysterectomy. However, partial supra-cervical hysterectomy is uncommon (less than 10%) in Canada, and thus it is not likely to contribute significantly to the numbers.<sup>30</sup> Removal of the cervix only, trachelectomy, is also a very uncommon procedure used to treat early stage cervical cancer. It, too, will not significantly affect the numbers.<sup>31,32</sup> Other limitations include data unavailability in certain years.

#### Conclusion

Our analysis contributes to the current knowledge of hysterectomy epidemiology in Canada. Given provincial and age variations, up-to-date knowledge of hysterectomy prevalence will contribute to more accurate population denominators for post-hoc calculation of cervical cancer screening participation rates.

**TABLE 1**  
**Prevalence of hysterectomy rates in 2000/2001, 2003 and 2008, Canada and provinces, by age group**

Age group, years	Province	Year						Difference between 2000/2001 and 2008	
		2000/2001		2003		2008			
		%	(95% CI)	%	(95% CI)	%	(95% CI)		
40–49	NL	18.9	(15.0–22.9)	15.1 <sup>e</sup>	(9.7–20.5)	— <sup>f</sup>	— <sup>f</sup>	—	
	PEI	18.6	(13.1–24.0)	25.6 <sup>e</sup>	(16.0–35.1)	— <sup>f</sup>	— <sup>f</sup>	—	
	NS	18.2	(14.4–22.1)	25.6	(18.2–33.1)	21.2 <sup>e</sup>	(13.1–29.3)	3.0	
	NB	21.2	(17.1–25.3)	20.9	(15.6–26.2)	19.5 <sup>e</sup>	(12.6–26.5)	-1.7	
	QC	14.7	(12.6–16.7)	13.4	(11.3–15.6)	13.7	(10.0–17.3)	-1.0	
	ON	12.4	(11.0–13.8)	10.6	(9.3–11.9)	9.6	(7.1–12.1)	-2.7	
	MB	9.2 <sup>e</sup>	(6.1–12.3)	11.6	(8.0–15.1)	14.2 <sup>e</sup>	(6.2–22.2)	5.0	
	SK	16.2	(12.5–19.8)	16.7 <sup>e</sup>	(11.1–22.3)	— <sup>f</sup>	— <sup>f</sup>	—	
	AB	14.3	(11.6–17.1)	13.7	(10.7–16.7)	15.3 <sup>e</sup>	(10.2–20.4)	1.0	
	BC	13.6	(11.5–15.6)	13.8	(11.3–16.4)	13.7	(9.8–17.6)	0.1	
50–59	Canada	13.9	(13.0–14.8)	13.0	(12.1–13.9)	12.4	(10.9–13.9)	-1.5	
	NL	35.4	(29.4–41.3)	34.8	(28.7–40.9)	35.1	(25.8–44.3)	-0.3	
	PEI	29.7	(22.8–36.7)	34.2	(24.3–44.2)	27.7 <sup>e</sup>	(17.6–37.8)	-2.0	
	NS	39.8	(34.5–45.1)	36.8	(30.9–42.6)	25.6	(18.1–33.0)	-14.2	
	NB	38.6	(33.0–44.3)	36.9	(31.3–42.4)	30.5	(23.8–37.2)	-8.2	
	QC	31.3	(28.2–34.4)	31.0	(28.0–34.1)	20.0	(16.9–23.1)	-11.3	
	ON	26.9	(24.5–29.3)	24.8	(22.8–26.7)	20.4	(17.4–23.4)	-6.5	
	MB	24.4	(19.4–29.5)	17.3	(13.1–21.6)	19.6	(13.3–25.9)	-4.8	
	SK	30.3	(25.0–35.6)	24.5	(20.0–29.1)	21.2	(15.1–27.4)	-9.0	
	AB	33.4	(29.0–37.8)	24.5	(20.6–28.4)	24.0	(18.0–30.1)	-9.4	
60–69	BC	25.8	(22.8–28.9)	25.8	(22.5–29.0)	19.3	(15.0–23.7)	-6.5	
	Canada	29.4	(28.0–30.8)	27.2	(25.9–28.4)	21.2	(19.4–23.0)	-8.2	
	NL	37.7	(30.0–45.4)	38.1	(31.2–45.0)	36.8	(28.1–45.6)	-0.9	
	PEI	43.6	(36.6–50.6)	36.6	(26.2–46.9)	— <sup>f</sup>	— <sup>f</sup>	—	
	NS	42.4	(35.2–49.5)	49.7	(42.4–57.0)	43.1	(35.2–51.1)	0.8	
	NB	42.8	(36.2–49.4)	47.0	(39.9–54.1)	41.4	(33.8–49.0)	-1.4	
	QC	42.8	(38.8–46.9)	37.7	(34.6–40.8)	36.5	(32.2–40.8)	-6.3	
	ON	34.2	(31.3–37.1)	32.7	(30.3–35.1)	30.7	(27.2–34.2)	-3.5	
	MB	40.8	(34.1–47.6)	38.5	(31.6–45.3)	32.5	(24.5–40.5)	-8.3	
	SK	41.1	(35.3–46.8)	34.4	(28.5–40.3)	37.2	(29.4–44.9)	-3.9	
70+ years	AB	40.3	(35.2–45.4)	40.5	(35.6–45.3)	39.4	(31.9–47.0)	-0.8	
	BC	35.3	(31.5–39.1)	36.2	(32.3–40.2)	31.4	(26.4–36.3)	-3.9	
	Canada	38.1	(36.4–39.8)	36.4	(35.0–37.9)	34.0	(31.8–36.1)	-4.1	

**Abbreviations:** AB, Alberta; BC, British Columbia; CV, coefficients of variation; MB, Manitoba; NB, New Brunswick; NL, Newfoundland and Labrador; NS, Nova Scotia; ON, Ontario; PEI, Prince Edward Island; QC, Quebec; SK, Saskatchewan.

<sup>e</sup> Use with caution (CV = 16.6%–33.3%).

<sup>f</sup> Too unreliable to be published (n < 30 and/or CV > 33.3%).

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# Metabolic syndrome and chronic disease

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## Abstract

**Introduction:** Metabolic syndrome (MetS) is a combination of risk markers that appear to promote the development of chronic disease. We examined the burden of MetS in Canada through its current and projected association with chronic disease.

**Methods:** We used measures from the Canadian Health Measures Survey 2007–2009 to identify the prevalence of MetS in Canadian adults and examine associations between sociodemographic factors and major chronic diseases. We estimated the projected cumulative incidence of diabetes and percent risk of a fatal cardiovascular event using the Diabetes Population Risk Tool (DPoRT) and Framingham algorithms.

**Results:** After adjusting for age, we found that 14.9% of Canadian adults had MetS. Rates were similar in both sexes, but higher in those who are non-Caucasian or overweight or obese ( $p < .001$  for all three). The importance of MetS for public health was demonstrated by its significant association with chronic disease relative to the general population, particularly for diagnosed (11.2% vs. 3.4%) and undiagnosed (6.0% vs. 1.1%) type 2 diabetes. The ten-year incidence estimate for diabetes and mean percent risk of a fatal cardiovascular disease (CVD) event were higher in those with MetS compared to those without (18.0% vs. 7.1% for diabetes, and 4.1% vs. 0.8% for CVD).

**Conclusion:** MetS is prevalent in Canadian adults and a high proportion of individuals with MetS have diagnosed or undiagnosed chronic conditions. Projection estimates for the incidence of chronic disease associated with MetS demonstrate higher rates in individuals with this condition. Thus, MetS may be a relevant risk factor in the development of chronic disease.

## Introduction

The vast majority of patients in the Canadian healthcare system are living with one or more chronic diseases.<sup>1</sup> Cardiovascular disease, chronic obstructive pulmonary disease, cancer and diabetes are the most common causes of hospitalization and premature death in Canada, accounting for almost three-quarters of all deaths.<sup>2</sup> Together, these chronic diseases account for 80% of primary care visits and more than two-thirds of medical costs.<sup>1,3</sup> Knowing more about the risk factors and indicators for chronic disease may, therefore, help

public health efforts aimed at addressing this growing concern.

Metabolic syndrome (MetS) is a condition that describes the clustering of risk markers that increase an individual's likelihood of developing chronic disease.<sup>4</sup> A number of leading chronic conditions have been shown to be associated with MetS. These include cardiovascular disease (CVD)<sup>5</sup>, type 2 diabetes,<sup>6</sup> cancers,<sup>7</sup> and chronic kidney disease (CKD)<sup>8</sup>.

The growing prevalence of obesity and sedentary lifestyles contributes to the prevalence of MetS.<sup>9–11</sup> While the patho-

genesis of MetS may be attributed to obesity and metabolic susceptibility,<sup>12</sup> a variety of socioeconomic factors have also been shown to influence the prevalence of MetS. For example, Canadian adults with a postgraduate degree had half the odds of acquiring MetS compared with those who have completed high school (odds ratio [OR] = 0.45, 95% confidence interval [CI]: 0.25–0.81).<sup>13</sup> Ethnicity also affects observed prevalence rates (OR = 0.54, 95% CI: 0.4–0.73 in non-Hispanic Blacks relative to non-Hispanic Whites).<sup>14</sup> Considering differences based on ethnicity has resulted in a variety of official MetS definitions being sanctioned by international health authorities.<sup>4,15,16</sup> MetS has also been described as a progressive disorder; the several components of MetS tend to worsen over time and collectively contribute to an increased risk for chronic disease.<sup>17</sup>

Hivert et al.<sup>18</sup> demonstrated the utility of MetS as a relevant public health tool. Using electronic health records to identify and track patients with MetS for future development of CVD and diabetes, they showed that patients with MetS had a higher incidence of these chronic conditions and incurred higher healthcare costs than did those patients without MetS.<sup>18</sup> This signifies an important role for MetS as a chronic disease indicator that could benefit individual health as well as healthcare costs and resources.<sup>18</sup> The limited availability of prevalence estimates derived from Canadian data to date has meant that international estimates are often used instead. It is therefore important to develop Canadian findings on MetS and its association with chronic conditions.

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In this study, our aim was to (1) estimate the prevalence of MetS in the Canadian adult population; (2) examine the relationship between MetS, risk factors and chronic disease; and (3) characterize the future risk of chronic diseases associated with MetS through measures of undiagnosed disease, as well as through 10-year projections for diabetes and CVD, using established prediction tools.

## Methods

### Data source

We used data from the 2007–2009 Canadian Health Measures Survey (CHMS).<sup>19</sup> This cross-sectional survey, conducted by Statistics Canada, recruited a representative sample of 5600 Canadians aged 6 to 79 years, which covers about 96.3% of the Canadian population. The survey used a mobile examination clinic to measure, for example, participants' blood pressure (BP) and serum factors. Information about current health status, socioeconomic variables, etc., was gathered through a general household interview.<sup>19</sup> Statistics Canada provides weights for each participant that capture the number of people represented by that participant in the population and account for non-response and the demographic distribution of the population. Additional information on sampling and estimations is described elsewhere.<sup>20,21</sup>

### Study population

Some of the CHMS study participants ( $n = 2634$ ) were asked to fast before the tests at the mobile examination clinic; we used data from this subsample in this study. The response rate for this subsample was 85.2%, which when combined with the overall response rate for the CHMS, makes the overall fasting subsample response rate 46.3%.<sup>19,20,22</sup> Pregnant women ( $n = 8$ ) and individuals aged under 20 years ( $n = 933$ ) were excluded from the analysis, leaving a study population of 1693 participants. For analyses using this subsample, Statistics Canada provided separate weights, based on the 2006 Census, for fasting participants, to ensure that analyses in this restricted subpopulation would remain representa-

tive of the entire Canadian population. These weighting factors account for non-response and for the demographic distribution of the country. Missing values were removed prior to analyses.

To test for potential selection bias as a result of various exclusion criteria, we performed a sensitivity analysis to compare the baseline demographic status of our study population with national-level estimates. Comparing our study popula-

tion with recent Canadian estimates, we found that our study population (Table 1) showed similar estimates for age,<sup>23</sup> education,<sup>24</sup> gender,<sup>25</sup> ethnicity<sup>26</sup> and income,<sup>27</sup> indicating that it is representative of the general Canadian population.

### Key definitions

#### Metabolic syndrome

We used the revised National Cholesterol Education Program (NCEP) Adult

**TABLE 1**  
Characteristics of the study population (N = 1693)

Characteristics	N	%	95% CI
<b>Sex</b>			
Women	886	50.4	49.8–50.9
Men	807	49.6	49.1–50.2
<b>Age, years</b>			
20–39	536	37.8	37.1–38.4
40–59	603	41.3	40.8–41.8
60–80	554	20.9	20.6–21.2
Mean age (SE), years	45.3 (0.2)		
<b>Cultural / ethnic background</b>			
Caucasian	1441	84.3	74.2–94.4
Non-Caucasian	205	15.7 <sup>E</sup>	5.6–25.8
<b>Total household income, \$</b>			
≤ 29 999	290	14.6	11.6–17.7
30 000–49 999	324	18.4	16.3–20.5
50 000–79 999	400	26.4	22.5–30.3
≥ 80 000	583	40.6	33.6–42.9
<b>Highest level of education</b>			
Less than secondary	206	11.4	7.6–15.2
Secondary graduate	289	18.8	13.1–24.5
Some post-secondary / post-secondary graduate	1178	69.8	61.5–78.2
<b>Smoking status</b>			
Never smoked	810	45.7	41.8–49.5
Former smoker	553	31.2	27.9–34.5
Current smoker – daily or occasional	325	23.1	20.6–25.6
<b>Leisure time physical activity</b>			
Active / moderately active	800	44.3	37.2–51.5
Inactive	893	55.7	48.5–62.8
<b>BMI, kg/m<sup>2</sup></b>			
< 25	676	43.5	37.8–49.2
25–29	638	37.8	33.8–41.8
≥ 30	351	18.7	15.6–21.2

**Source:** Canadian Health Measures Survey, 2007–2009, clinic dataset.

**Abbreviations:** BMI, body mass index; CI, confidence interval; SE, standard error.

**Notes:** Missing data (not applicable, not stated, don't know) not included in calculation of proportions.

Percentages have been weighted using CHMS survey weights.

<sup>E</sup> Interpret with caution (coefficient of variation: 16.6%–33.3%).

Treatment Panel III definition for MetS, which uses revised waist circumference criteria.<sup>4</sup> We also examined prevalence rates of MetS using the International Diabetes Federation (IDF) and Harmonized definitions.<sup>15,16</sup>

### Undiagnosed and diagnosed chronic conditions

In the absence of any longitudinal data to determine whether individuals with MetS may develop chronic diseases with time, we determined whether participants may have had an undiagnosed condition. This is treated as a proxy measure for future chronic disease risk. Participants were deemed to have a particular condition undiagnosed if they said that they did not have the condition but had measurable physical attributes of the condition.

Diagnosed hypertension was based on a positive response to the question “Do you have high blood pressure?” or from self-reported use of specific medications (list available from the authors on request). Average systolic BP and diastolic BP were derived from an average of six blood pressure measurements.<sup>22,28,29</sup> We determined that individuals had undiagnosed hypertension if they reported no diagnosed hypertension but had BP readings above 140/90 mmHg (for either reading).

Diagnosed diabetes (type 2) was based on positive responses to the questions, “Do you have diabetes?” and “Were you diagnosed with non-insulin dependent diabetes (type 2)?” or from self-reported use of specific medications (list available from the authors on request).<sup>22</sup> As with BP, we determined that individuals had undiagnosed diabetes if they gave a negative response to questions about having physician-diagnosed diabetes but their fasting plasma glucose levels measured at 7.0 mmol/L or more. Individuals with type 1 diabetes were not included in the analysis.

Diagnosed CKD was based on a positive response to the question “Do you suffer from kidney dysfunction or disease?”<sup>22</sup> Undiagnosed CKD was based on a negative response to this question plus either a low measured glomerular filtration rate ( $\leq 60$  mL/min using the Modification of

Diet and Renal Disease Study equation<sup>30</sup>) or a high measured microalbumin to creatinine ratio ( $> 2.65$  mg/mmol).

Diagnosed dyslipidemia was based on a positive response to the question “Have you ever been told by a health professional that your blood cholesterol was high?”<sup>22</sup> Undiagnosed dyslipidemia was based on a negative response to this question plus the participant either meeting both the total cholesterol to high density lipoprotein (HDL) ratio ( $\geq 5.5$  in men,  $\geq 4.5$  in women) and low density lipoprotein (LDL) criteria ( $\geq 3.5$  mmol/L) or using appropriate medications (list available from the authors on request).

### Descriptive variables

Analyses are described by sex, age (at clinic visit), education, ethnicity (self-reported cultural or racial group, not including Aboriginal populations) and total household income. Lifestyle factors include measured body mass index (BMI) and self-reported leisure time physical activity and smoking status.<sup>19</sup>

### Analysis

We undertook multivariate analyses using statistical software SAS Enterprise Guide 4.1 (Cary, NC, US).<sup>31</sup> National estimates were calculated with the CHMS weights for the subsample of the population who had fasted and were age-adjusted using Canadian Census data. We calculated variance estimates using Statistics Canada Bootvar software (Statistics Canada, Ottawa, ON) and followed their reporting guidelines. Horvitz-Thompson estimation was used to analyze statistical significance following a *t* distribution with 11 degrees of freedom.

We examined prevalence estimates using the frequency procedure on SAS Enterprise Guide 4.1, and adjusted for these as described for individual reported estimates in the Results section. OR estimates were calculated from logistic regression models and adjusted for age and sex, where mentioned. Ten-year cumulative incidence projections for type 2 diabetes were estimated using the Diabetes Population Risk Tool (DPoRT).<sup>32</sup>

Originally developed using the National Population Health Survey, this prediction tool uses commonly collected survey data, such as self-reported estimates for health behaviours and sociodemographic factors, to predict the risk of developing incident physician-diagnosed diabetes. Sex-specific Weibull survival models were used to create DPoRT for individuals without diabetes mellitus, who are not pregnant and who are aged over 20 years. Predictive variables used in the model include age, sex, self-reported ethnicity, self-reported BMI, immigrant status (for women), education, smoking status and history of hypertension and heart disease, all of which were available for our analysis.<sup>32</sup>

We used the lipid-based Framingham 10-year risk calculator to estimate the risk of a fatal general CVD event, defined as either coronary death, myocardial infarction, coronary insufficiency, angina, ischemic stroke, hemorrhagic stroke, transient ischemic attack, peripheral artery disease or heart failure. This risk prediction tool was originally created using data from the Framingham Heart Study and Framingham Offspring Study. Sex-specific Cox proportional hazards regressions were used to relate various risk factors to the incidence of fatal general CVD events. Mathematical CVD risk functions derived from this were then used in the development of the Framingham Risk Tool. Results are presented as high risk ( $\geq 20\%$ ) or intermediate and high risk ( $\geq 10\%$ ). The population subset for CVD projections was restricted to individuals aged 30 to 74 years who had no previous history of a CVD event.<sup>33</sup>

### Ethics approval

Approval to conduct our study was obtained from the Ottawa Hospital Research Ethics Board (Protocol # 20120767-01H) prior to commencement.

### Results

The majority of the survey participants were Caucasian, physically inactive and former or current smokers. Most had at least some post-secondary education and an annual household income of more than \$50 000. The mean age of the study

population was 45 years, and the population was equally represented by each sex (Table 1).

Participants were deemed to have MetS when they met three or more rNCEP MetS criteria, resulting in a crude prevalence of 15.5% and an age-adjusted prevalence of 14.9%. In the overall population, 34.9% had no MetS risk markers, whereas 29.5% had one and 20.2% had two. The most prevalent MetS risk markers among those identified as having MetS were waist circumference (89.2%), hypertriglyceridemia (82.3%), low HDL cholesterol (75.4%), high fasting plasma glucose (53.3%) and high systolic or diastolic BP (40.3%) (Figure 1).

The rNCEP estimates were compared to prevalence estimates based on the IDF and Harmonized definitions, both of which resulted in significantly larger prevalence estimates (crude prevalence: IDF = 23.1%, Harmonized = 19.6%; age-adjusted prevalence estimates: IDF = 22.3%, Harmonized = 19.1%) (Table 2).

The prevalence of MetS varied by age group, but the difference by sex for each age group was not statistically significant (Figure 2). Variation occurred according to

smoking status as well, although these patterns varied by sex (Table 2). On the other hand, ethnic background significantly influenced prevalence rates, with people of non-Caucasian origin having a higher prevalence than those of Caucasian origin. For both sexes, a high BMI and being physically inactive were significantly associated with a higher prevalence of MetS.

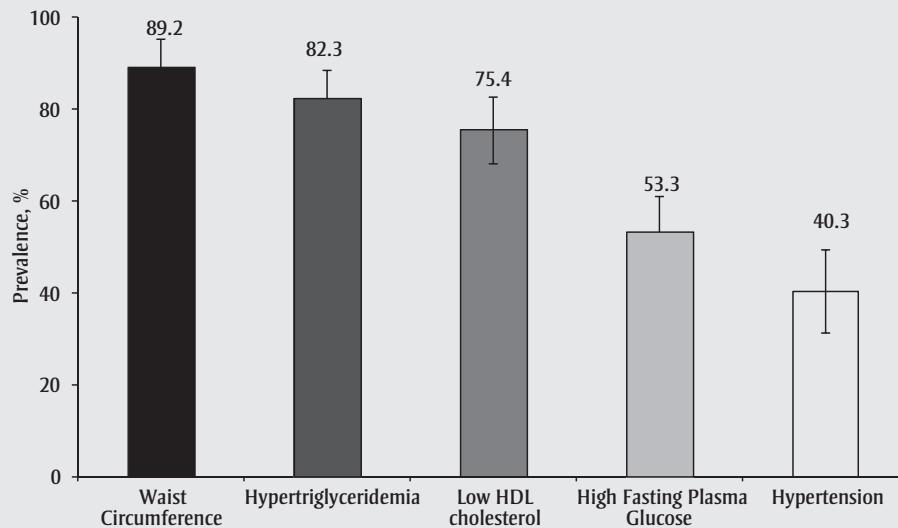
The odds of MetS varied according to participant characteristics, and was significantly associated with being non-Caucasian and older (Table 2). Other characteristics were also significant, although this varied based on sex. For example, the odds of MetS was significantly associated with being a current smoker in women but not in men.

We examined the prevalence of chronic conditions across three population groups: the overall population, individuals with obesity ( $BMI \geq 30 \text{ kg/m}^2$ ) and individuals with MetS. Undiagnosed disease was more prevalent in those with MetS compared with those with obesity or the overall study population for all conditions examined, and was most prominent for dyslipidemia (28.3% vs. 18.5% and 10.0%, respectively) (Table 3). Note that the rate of undiagnosed diabetes was more than

five times higher in those with MetS than in the overall population (6.0% vs. 1.1%,  $p = .009$ ; interpret with caution).

We estimated the future burden of type 2 diabetes and CVD that can be attributed to MetS using existing algorithms. The mean 10-year predicted risk of diabetes in individuals with MetS, as opposed to those without, is 18.0% (95% CI: 15.3–20.7) versus 7.1% (95% CI: 6.2–8.1). The proportion of Canadian adults anticipated to develop diabetes between 2007 and 2017 is thus 8.7% (95% CI: 7.5–9.9) (Figure 3). Similarly, the mean predicted risks for fatal CVD are 4.1% (95% CI: 2.3–6.0; interpret with caution) vs. 0.8% (95% CI: 0.6–1.0). The risk of CVD can be further analyzed as being high, that is, a 20% or higher risk of a CVD event in 10 years, or as intermediate to high, a 10% to 20% CVD risk in 10 years. The proportion of Canadian adults with MetS with a high risk of a CVD event is 6.81% (95% CI: 3.2–10.4,  $p = .004$  relative to those without MetS; interpret with caution). Furthermore, the proportion of Canadian adults at intermediate to high risk of a CVD event is 8.9% (95% CI: 4.3–13.6; interpret with caution) in those with MetS, compared with 2.0% (95% CI: 1.3–2.7,  $p = .008$ ) in those without MetS.

**FIGURE 1**  
**Prevalence of different metabolic syndrome risk markers in individuals with metabolic syndrome, CHMS 2007–2009**



**Abbreviation:** HDL, high density lipoprotein.

**TABLE 2**  
**Metabolic syndrome prevalence and odds ratios according to population characteristics,  
CHMS 2007–2009**

Definitions	Prevalence			Odds Ratios	
	%	95% CI	p value	OR	95% CI
rNCEP ATP III					
Crude	15.5	12.0–19.0	—		
Adjusted	14.9	13.3–16.6			
IDF					
Crude	23.1	20.4–25.8	< .001		
Adjusted	22.3	20.4–24.3			
Harmonized					
Crude	19.6	15.9–23.2	< .001		
Adjusted	19.1	17.3–20.9			
<b>Characteristics</b>					
<b>Overall population</b>					
Sex <sup>a,b</sup>					
Men (ref)	14.5	10.4–18.6	—	1	—
Women	16.5	12.6–20.3	.25	1.12	0.87–1.42
Ethnicity <sup>a,b,c</sup>					
Caucasian (ref)	15.5	12.1–18.8	—	1	—
Non-Caucasian	16.6 <sup>f</sup>	5.4–27.7	< .001	2.66	1.29–5.45
<b>Men</b>					
Age <sup>b</sup>					
20–39 (ref)	8.0 <sup>f</sup>	4.4–11.5	—	1	—
40–59	14.5 <sup>f</sup>	6.7–22.4	.05	1.48	0.67–3.26
60–80	26.9	21.3–32.5	.012	3.33	2.07–5.34
Smoking status <sup>a,b</sup>					
Current	6.6 <sup>f</sup>	2.0–11.1	.01	0.65	0.23–1.86
Former	24.1	15.5–32.7	.12	1.54	0.66–3.61
Never (ref)	11.4 <sup>f</sup>	5.6–17.3	—	1	—
LTPA <sup>a,b</sup>					
Active (ref)	12.0	8.5–15.6	—	1	—
Inactive	16.9 <sup>f</sup>	10.0–23.9	.001	1.39	0.69–2.78
BMI, kg/m <sup>2</sup> <sup>a</sup>					
< 25 (ref)	— <sup>f</sup>	—	—	1	—
25–29	15.8	10.4–21.2	< .001	— <sup>f</sup>	—
≥ 30	38.6	25.5–51.8	< .001	— <sup>f</sup>	—
<b>Women</b>					
Age <sup>b</sup>					
20–39 (ref)	— <sup>f</sup>	—	—	1	—
40–59	18.7 <sup>f</sup>	11.7–25.7	.003	3.67	1.20–11.17
60–80	31.5	24.3–38.6	< .001	7.43	2.62–21.05
Smoking status <sup>a,b</sup>					
Current	21.1	13.6–28.5	.71	3.15	1.63–6.07
Former	21.3 <sup>f</sup>	10.8–31.8	.38	2.06	0.93–4.59
Never (ref)	11.0	8.7–13.3	—	1	—

Continued on the following page

## Discussion

### Prevalence of metabolic syndrome

Comparing prevalence for MetS using the same rNCEP definition, the age-adjusted rate in Canada is less than half that reported in the United States (14.9% vs. 34.4%),<sup>14</sup> but similar to previously published findings for the Canadian population.<sup>34</sup> Using newly suggested IDF definitions, which take into account variations in waist circumference for different ethnic groups, or the Harmonized definition, the age-adjusted prevalence of MetS in Canada is higher than with the rNCEP (22.3% and 19.1%, respectively), showing that the choice of definition for MetS does appear to matter.

We chose to use the rNCEP definition for MetS in our study to facilitate comparisons with previously published epidemiological data.<sup>14</sup> The rNCEP definition was reasonably accurate in representing the ethnic composition of our study population (84% Caucasian; Table 1). While sample size limitations did not allow us to explore variations in MetS prevalence based on self-reported ethnic origin, when this information was used to apply the IDF definition of MetS, it appears as though more people are being included as having MetS.<sup>15</sup>

### Risk factors and metabolic syndrome

Our findings indicate that the prevalence of MetS in Canada is associated with age, ethnicity, BMI and leisure time physical activity. Older age was significantly associated with MetS, but the patterns of prevalence varied by age and sex. Prevalence was higher in men than in women in the 30- to 39-year age group. Thereafter, the prevalence of MetS increases steadily in women, exceeding the prevalence of MetS in men, from age 40 through 60 to 74 years, after which time it levels off. In men, the steady increase in prevalence seems to occur after the age of 40. Tjepkema<sup>35</sup> suggested that this transition reflects the marked increase in rates of obesity in men after age 45 years. In the same study, Tjepkema<sup>35</sup> also showed that obesity rates increase steadily in women until age 65

**TABLE 2 (continued)**  
**Metabolic syndrome prevalence and odds ratios according to population characteristics, CHMS 2007–2009**

Characteristics	Prevalence			Odds Ratios	
	%	95% CI	p value	OR	95% CI
<b>LTPA<sup>a,b</sup></b>					
Active (ref)	10.5 <sup>E</sup>	6.6–14.5	—	1	—
Inactive	20.2	15.4–25.0	< .001	1.76	1.13–2.73
<b>BMI, kg/m<sup>2</sup> <sup>a</sup></b>					
< 25 (ref)	— <sup>F</sup>	—	—	1	—
25–29	22.9	16.1–30.0	< .001	— <sup>F</sup>	—
≥ 30	43.2	34.2–52.2	< .001	— <sup>F</sup>	—

**Source:** Canadian Health Measures Survey, 2007–2009, clinic dataset.

**Abbreviations:** BMI, Body Mass Index; CHMS, Canadian Health Measures Survey; CI, confidence interval; IDF, International Diabetes Federation; LTPA, leisure time physical activity; ref, reference; rNCEP ATP, revised National Cholesterol Education Program Adult Treatment Panel III.

**Note:** The adjusted prevalence estimate is age-adjusted to the Canadian Census information.

<sup>a</sup> Odds ratio adjusted for age.

<sup>b</sup> Odds ratio adjusted for BMI.

<sup>c</sup> Odds ratio adjusted for sex.

<sup>E</sup> Interpret with caution (coefficient of variation: 16.6%–33.3%).

<sup>F</sup> Cannot be reported (coefficient of variation: > 33.3%).

years. The changes in prevalence that we observed align with reported increased rates of MetS in peri- and post-menopausal women.<sup>36</sup>

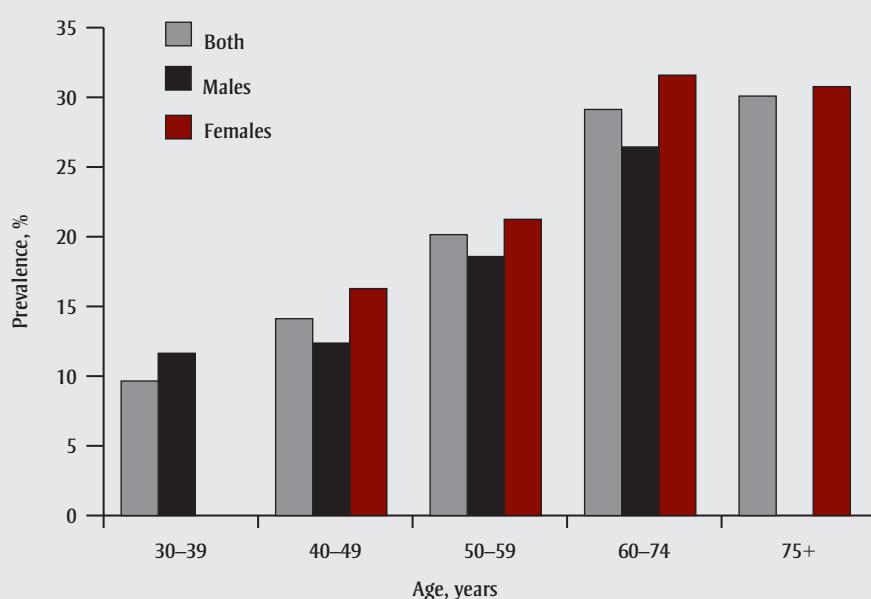
The odds of MetS were significantly higher in non-Caucasian individuals, and we found greater risk of MetS in non-Caucasian Canadians than was found

in Mexican American and non-Hispanic white individuals in the United States.<sup>14</sup> In addition to Hispanic and African Canadians, we included Filipino, Chinese, South Asian, Arab and other populations in our study. It is possible that the inclusion of these additional groups may account for the difference in the odds of MetS by ethnicity between the two studies. Previous findings using the rNCEP definition also showed higher prevalence rates in some of the ethnic groups included in our study relative to our overall population.<sup>37,38</sup>

Our results indicate that being physically active lowers the odds of MetS compared with being inactive, although this lower risk is only statistically significant in women. Our analysis clearly shows that rates of overweight and obesity are high in adults, with a prevalence of almost 57%. This is of concern given the close association of obesity with MetS, as well as with pre-diabetes.<sup>39</sup>

MetS is commonly associated with pre-diabetes, wherein individuals have elevated plasma glucose levels as well as

**FIGURE 2**  
**Prevalence of metabolic syndrome by gender and by age group, CHMS 2007–2009**



**Source:** Canadian Health Measures Survey, 2007–2009, clinic dataset.

**Abbreviation:** CHMS, Canadian Health Measures Survey.

**Note:** For all reported age groups, except for ages 60–74 years, estimates should be interpreted with caution (coefficient of variation: 16.6%–33.3%). Estimates that could not be reported (coefficient of variation: > 33.3%) were not included in the figure.

**TABLE 3**  
**Prevalence of diagnosed and undiagnosed chronic conditions in the overall population and in individuals with obesity and with metabolic syndrome, CHMS 2007–2009**

	Overall		Obesity		Metabolic Syndrome		<i>p</i> value <sup>b</sup>		
	%	95% CI	%	95% CI	<i>p</i> value <sup>a</sup>	%	95% CI	<i>p</i> value <sup>a</sup>	
<b>Hypertension</b>									
Diagnosed	17.2	14.2–20.1	33.6	25.2–41.9	.001	36.1	29.0–43.1	< .001	.61
Undiagnosed	0.7 <sup>E</sup>	0.2–1.1	— <sup>F</sup>	—	—	— <sup>F</sup>	—	—	—
<b>Diabetes</b>									
Diagnosed	3.4	2.4–4.5	8.0	5.2–10.8	.003	11.2 <sup>E</sup>	6.7–15.6	.003	.07
Undiagnosed	1.1 <sup>E</sup>	0.6–1.7	4.4 <sup>E</sup>	1.5–7.2	.02	6.0 <sup>E</sup>	2.2–9.8	.009	.27
<b>Chronic Kidney Disease</b>									
Diagnosed	1.9	1.4–2.4	— <sup>F</sup>	—	—	4.0 <sup>E</sup>	1.2–6.8	.13	—
Undiagnosed	10.0	8.1–11.9	15.2 <sup>E</sup>	9.0–21.5	.11	22.2	14.9–29.5	.002	.10
<b>Dyslipidemia</b>									
Diagnosed	29.4	26.5–32.3	37.0	31.3–42.6	.02	50.8	46.6–55.1	< .001	< .001
Undiagnosed	10.0	6.9–13.1	18.5	12.3–24.7	.006	28.3	22.5–34.1	< .001	.006

**Source:** Canadian Health Measures Survey, 2007–2009, clinic dataset.

**Abbreviations:** CHMS, Canadian Health Measures Survey; CI, confidence interval.

<sup>a</sup> These *p* values represent the significance of the difference between population subgroups and the overall population.

<sup>b</sup> This *p* value represents the significance of the difference between population subgroups.

<sup>E</sup> Interpret with caution (coefficient of variation: 16.6%–33.3%).

<sup>F</sup> Cannot be reported (coefficient of variation: > 33.3%).

systemic inflammation. It is also associated with characteristics such as pro-thrombotic state and dyslipidemia, which may account for its link to cardiovascular risk.<sup>40</sup> The increased risk of type 2 diabetes and of a fatal CVD event in individuals with MetS is thus not surprising, given the research demonstrating these associations.<sup>5,41</sup> The proportion of individuals identified as being at risk of developing diabetes in the next 10 years, relative to those without MetS, indicates the role of MetS as a potential chronic disease indicator. These findings are corroborated by a 2010 study that estimated risk of diabetes for Canadians at 8.9%.<sup>42</sup> When considering the projections for CVD, which estimate the risk of a fatal event, the concern is clear.

We need to be aware of a possible overlap in definitions for chronic disease risk factors and for MetS. In the case of dyslipidemia, this overlap may contribute to the high rates of abnormal lipid levels in those with MetS. The risk marker of low HDL cholesterol was prevalent in 75% of the population with MetS, but it is worth noting that the definition of dyslipidemia was based on a high total cholesterol to

HDL cholesterol ratio combined with elevated LDL levels. Similarly, MetS is defined based on waist circumference, not BMI, which makes both populations distinct but potentially related.

#### *Public health impact of metabolic syndrome*

Independent of race/ethnicity, age, sex and health status, evidence shows an increased risk of developing certain chronic diseases with each additional MetS risk marker.<sup>41</sup> Reaven<sup>43</sup> suggests that even though an individual may not meet the number of risk markers (3 or more) necessary to be diagnosed with MetS, they may still be at risk of future disease and should therefore not be overlooked. We found that 50% the study population had one or two MetS risk markers, by no means a small proportion.

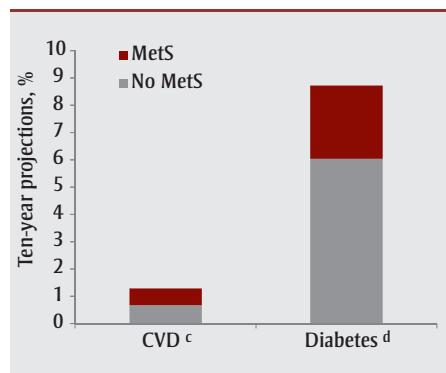
We compared MetS with a well-studied chronic disease risk factor, obesity. Our findings demonstrated a higher prevalence of chronic disease in individuals with MetS compared with those with obesity (shown in Table 3), although the differences were not statistically significant. A

previous study has described MetS as more predictive of future disease than obesity alone.<sup>44</sup> The greater association between chronic disease and MetS in our study may, therefore, further signify a public health utility for MetS as a key indicator of disease risk.

#### *Limitations*

Working with the CHMS data, sample size proved to be a limiting factor in providing reportable estimates for key covariates, such as for sociodemographic characteristics, and limited the scope of the study to a national viewpoint, since it is not built to produce regional estimates. Further, the use of self-reported information for activities such as smoking or leisure time physical activity may have proven to be a limitation. Due to the lack of pertinent variables to measure undiagnosed diabetes, our definition is limited in scope and interpretations should be made with caution. To limit the effects of confounders, BMI, age and sex were all controlled for in multivariate analyses. The removal of missing values may have contributed to a downward bias in our diabetes risk projections since the proportion of missing

**FIGURE 3**  
Ten-year projections for the cumulative incidence of diabetes<sup>a</sup> and mean percent risk of a fatal CVD<sup>b</sup> event in individuals with or without MetS,<sup>c</sup> CHMS 2007–2009



**Source:** Canadian Health Measures Survey, 2007–2009, clinic dataset.

**Abbreviations:** CVD, cardiovascular disease; CHMS, Canadian Health Measures Survey; CI, confidence interval; MetS, metabolic syndrome.

**Note:** Given the identified population prevalence of MetS among Canadian adults (85.1% without MetS, 14.9% with MetS), this suggests a projected 10-year risk of a fatal CVD event as 1.29%, and a projected 10-year cumulative incidence of diabetes as 8.7% (95% CI: 7.5–9.9).

<sup>a</sup> Estimated using the Diabetes Population Risk Tool (DPoRT).<sup>32</sup>

<sup>b</sup> Calculated using the lipid-based Framingham 10-year risk calculator.<sup>33</sup> The population subset for CVD projections was restricted to adults aged 30–74 years who have no previous history of a CVD event.

<sup>c</sup> Projections: With MetS = 4.1% (95% CI: 2.3–6.0),  $p < .01$ ; without MetS = 0.8% (95% CI: 0.6–1.0),  $p < .01$ .

<sup>d</sup> Projections: With MetS = 18.0% (95% CI: 15.3–20.7),  $p < .01$ ; without MetS = 7.1% (95% CI: 6.2–8.1),  $p < .01$ .

values for BMI tends to be higher among females. However, since missing values for women only represent a small proportion of all responses for BMI among females, their removal should not skew our results.

## Conclusion

MetS represents a condition that is strongly associated with factors such as obesity, ethnicity and leisure time physical activity. Our study demonstrates the differential pattern by which MetS affects specific subpopulations and indicates an association between MetS and major chronic conditions.<sup>45</sup> Since Canadians with MetS have significantly higher rates of undiagnosed chronic diseases than the overall population and higher predicted rates of

future chronic disease, it may be of value for clinicians to include MetS, in addition to obesity, as an indicator for chronic disease and useful for public health policy-makers to consider MetS when directing preventive population health efforts.

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# Impact of individual and ecological characteristics on small for gestational age births: an observational study in Quebec

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## Abstract

**Introduction:** We evaluated associations between ecological variables and the risk of very small for gestational age (VSGA) birth in Quebec in 2000–2008.

**Methods:** Ecological variables came from the Canadian Community Health Survey, the Canadian census and Quebec's birth registry; individual variables also came from Quebec's birth registry. Odds ratios (ORs) adjusted for mother's age, academic qualification, parity, marital status and country of birth were estimated using multilevel logistic regression (generalized estimating equations method).

**Results:** Births in neighbourhoods with a high proportion of people leading a sedentary lifestyle (OR: 1.07, 95% confidence interval [CI]: 1.01–1.11) and those with a high/middle proportion of residents with food insecurity (OR: 1.09, 95% CI: 1.05–1.15; OR: 1.05, 95% CI: 1.01–1.11) had higher odds of VSGA birth. Those with middle proportion of married residents had lower odds of VSGA birth (OR: 0.94, 95% CI: 0.90–0.98).

**Keywords:** birth weight, fetal health, reproductive health, social epidemiology, health behaviour, sedentary lifestyle, food insecurity

## Introduction

Individuals with sub-optimal fetal development that results in small for gestational age (SGA) or very small for gestational age (VSGA) birth are at an increased risk of neonatal illness and are more likely to develop type 2 diabetes, hypertension, metabolic syndrome and coronary diseases in adulthood.<sup>1</sup>

Risk factors for sub-optimal fetal development include characteristics of maternal age, race, parity, partnership status, education and smoking.<sup>1–3</sup> Neighbourhood deprivation is also associated with health<sup>4</sup> and with a number of modifiable individual risk factors such as smoking and alcohol consumption during pregnancy.<sup>5</sup>

Unfortunately, past ecological analyses were often mostly based on available data rather than on plausible social pathways.<sup>4,6</sup> In Canada and in the United States, this yielded a set of widely explored neighbourhood census-derived features, including economic deprivation,<sup>7–22</sup> race,<sup>10,11,15,17,19</sup> crime,<sup>15,23</sup> and single-headed households.<sup>19</sup>

A few studies used data from large specific surveys on features of the built and social environment.<sup>8,11,16,24,25</sup> The researchers observed that social support<sup>24</sup> and availability or use of neighbourhood services<sup>11,16</sup> were associated with the risk of adverse birth outcomes, while built environment<sup>16</sup> and availability of restaurants and supermarkets<sup>8</sup> were not. Residents' sedentary lifestyles were previously asso-

ciated with a higher risk of SGA in a model that was built only from ecological variables for public health purposes.<sup>25</sup> To our knowledge, residents' food consumption was not included in previous ecological analyses of SGA or VSGA.

We had access to information on singleton births through Quebec's birth registration forms. We collected information about Quebec's local community services centres (CLSC) from three sources: Quebec's birth registration forms, a survey on Canadian residents and the Canadian census. While hypothesizing the model shown in Figure 1 to identify program levers for intervention, we evaluated associations between individual variables and the outcome of VSGA. We also evaluated associations between single and aggregated CLSC territory variables and VSGA.

## Methods

### Study population and setting

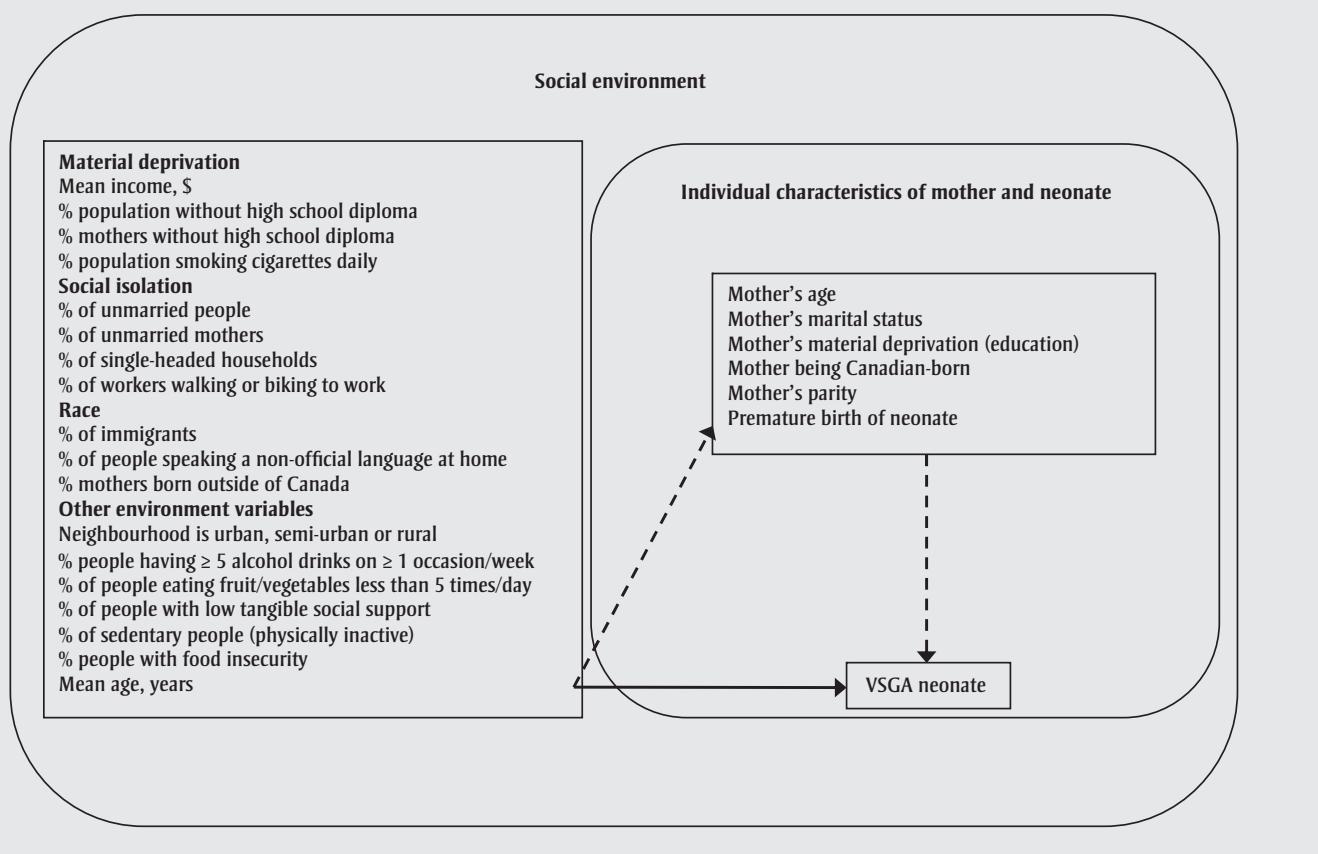
The population of this observational study consisted of singleton live births that took place between 2000 and 2008 and their mothers, in Quebec, Canada. Because the survey data from the northern regions of Nord-du-Québec, Terres-Cries-de-la-Baie-James and Nunavik were not methodologically comparable to other provincial regions, we did not include them. Neonates with missing weight or gestational age, those born at less than 22 weeks or more than 43 weeks gestation

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**FIGURE 1**  
**Mother and neonate's individual explanatory variables from the birth registry, Quebec, Canada, 2000–2008**



**Abbreviation:** VSGA, very small for gestational age.

**Note:** Accounting for associations of contextual variables through individual variables (dashed arrows) enabled the study of contextual associations above and beyond association through individual variables (full arrow).

and those with implausible weight for gestational age were also excluded.<sup>26</sup>

### Territory definition

Territories were the 143 CLSCs, the first level of organization of the Quebec health care system. CLSCs had an average of 46 727 residents and 4666 singleton live births from 2000 to 2008.

### Variables

#### Outcome

Neonates with a weight for gestational age below the 5<sup>th</sup> percentile on the Canadian sex-specific standardized scale were identified as VSGA.<sup>27</sup>

#### Individual variables

We categorized individual characteristics gathered from birth registration forms.

These included maternal age at delivery (< 20, 20–24, 25–29, 30–34, ≥ 35 years); marital status (married in a civil or religious ceremony vs. unmarried); highest academic qualification (less than high school, high school diploma, college, university and higher); mother's place of birth (Canada vs. not Canada) and parity (primiparous vs. multiparous).

#### Aggregated ecological variables

Aggregated ecological variables for births and the whole population of the CLSC (men, other women, youth and the elderly) summarize the average level of a characteristic within the CLSC territory population (Table 1). We calculated birth-oriented variables over CLSC territories by pooling individual data. Population-oriented variables were obtained both by producing proportion-like values from the responses of individuals surveyed in the Canadian

Community Health Survey (CCHS)<sup>25,28</sup> and by pooling census profiles of sub-territories. The proportions were coded into first, second and third tertiles (for the lowest, middle and upper-most parts of the distribution). The first tertile was the reference for all variables except for mean income, where the third tertile was the reference.

We imputed missing values using the SAS multiple imputation (MI) procedure, with the MCMC method for categorical individual variables and the EM algorithm with the logit transform for proportions.<sup>29</sup>

#### Data sources

Birth registration forms from 2000 to 2008 are part of Quebec's registry of demographic events.<sup>30</sup> The forms include information on all live births (weight at birth, maternal age at delivery, marital status,

**TABLE 1**  
**Explanatory ecological variables at the local community services centre (CLSC) level, Quebec, Canada, 2000–2008**

Target population and data source	Ecological variable
Birth registry information (2000–2008)	
Births	Mothers without high school diploma, %
Births	Mothers born outside of Canada, %
Births	Unmarried mothers, %
Canadian Community Health Survey (2000–2001; 2003; 2005; 2007–2008)	
Population of $\geq 12$ years <sup>a</sup>	People smoking cigarettes daily, % <sup>b</sup>
Population of $\geq 12$ years <sup>a</sup>	People drinking $\geq$ five alcohol drinks at each occasion $\geq 1$ per week, % <sup>b</sup>
Population of $\geq 12$ years <sup>a</sup>	People eating fruit and vegetables $<$ 5 times per day, % <sup>b</sup>
Population of $\geq 12$ years <sup>a</sup>	People with low tangible social support, % <sup>b,c</sup>
Population of $\geq 12$ years <sup>a</sup>	Sedentary (physically inactive) people in the past 3 months, % <sup>b</sup>
Population of $\geq 12$ years <sup>a</sup>	People with food insecurity in the past 12 months, % <sup>b</sup>
Census profiles (2000 and 2006)	
Total population	Urban/rural continuum (local community services centre combines only urban sub-territories, rural and urban sub-territories or only rural sub-territories)
Population 25–64 years (2006) and $\geq 20$ years (2001)	People without high school diploma, %
Total population	Mean age, years
Total population	Immigrants, %
Total population	People speaking a non-official language at home, %
Population $\geq 15$ years old with income	Mean income, \$
Population $\geq 15$ years old	Unmarried people, %
Households (private)	Single-headed households, %
Workers $\geq 15$ years old	Workers walking or biking to work, %

<sup>a</sup> Includes only individuals living at home.

<sup>b</sup> Proportion-like value that excludes year-cycle and data collection method effects of the survey.

<sup>c</sup>  $< 15$  out of 95 on the Social Support Survey subscale of the Medical Outcome Study.

mother's highest academic qualification, mother's place of birth, parity) and the postal code of the mothers' residence at time of giving birth.

The CCHS is a cross-sectional survey that has, to date, been conducted in four year-long cycles (2000–2001, 2003, 2005 and 2007–2008).<sup>28</sup> To increase statistical power, we pooled the four survey year-cycles.<sup>31</sup>

The 2001 and 2006 census profiles are available at two sub-territory levels: census tracts and census subdivisions.<sup>32</sup> Tracts were used in metropolitan areas and subdivisions elsewhere. Hence, sub-territories had similar population sizes. Sub-territory profiles were aggregated by CLSC regardless of the year of data collection.

### Statistical analysis

CLSC values were linked to individual births based on the mothers' postal code

of residence. Odds ratios (OR) were used to estimate relative risks.

### Regression

We estimated adjusted ORs for individual variables ( $OR_{Adjusted}^I$ ) using a multilevel logistic regression fitted through generalized estimating equations (GEE). We chose the mother as the first level and the CLSC as the second.<sup>33</sup> The GEE method provides consistent OR estimates for the population even though the correlation between mothers from the same CLSC is unknown. We assumed this correlation to be small; hence the “independence working correlation” structure was provided as a starting point for the computations. We obtained empirical standard error estimates and thus avoided problems with correlation misspecification.<sup>34</sup>

A deviance test determined whether CLSCs explained a significant part of the

unexplained variation resulting from the individual model with interaction terms.

We obtained crude ORs ( $OR_{Crude}^E$ ) and ORs adjusted for individual variables and interaction terms ( $OR_{Adjusted\ I}^E$ ) using the GEE method for each ecological variable. Interactions between individual variables were selected using the stepwise method with the option “hierarchy = multiple” of the logistic procedure (entry/stay  $p$  values  $< .001$ ). A final model was built using variables with significant  $OR_{Adjusted\ I}^E$  values as candidates in a stepwise method and by forcing inclusion of individual variables as well as interaction terms (entry/stay  $p$  values of .25/.05). GEE parameter estimates adjusted for individual variables and for other ecological variables ( $OR_{Adjusted\ IE}^E$ ) were produced for every ecological variable.

Ecological results were restricted to showing those variables with differences in

crude ORs. We presented a maximum of one material deprivation, racial and social isolation variable (Figure 1) by dataset (all data available from the authors on request).

The adjusted OR values ( $OR^{I}_{Adjusted}$ ,  $OR^{E}_{Adjusted\ I}$  and  $OR^{E}_{Adjusted\ IE}$ ) were validated by two sensitivity analyses, first, with non-imputed data, and second, by incorporating variables at the smallest possible territory level, that is, census and birth data at the sub-territory level (there are 2368 sub-territories) plus CCHS data at the CLSC level.

The Commission d'accès à l'information du Québec and the Ethics Committee of the Université Laval approved this

research project. Analysis was carried out using SAS version 9.2 (MI, LOGISTIC and GENMOD procedures).<sup>29</sup> Regression results were considered statistically significant if  $p$  values were less than .05.

## Results

### Descriptive analysis

Of the 676 165 singleton births recorded in all of Quebec's regions between 2000 and 2008, 7379 were to mothers from northern regions, 850 could not be linked to CLSCs, 67 had no SGA status (missing weight or gestational age), 452 had less than 22 weeks or more than 43 weeks gestation and 163 had implausible weights for gestational age. Thus, our population

consisted of a total of 667 254 births in 143 CLSCs.

### Regression

Every individual variable was significantly associated with VSGA (Table 2). Mothers without and with a high school diploma and with a college diploma were at a higher risk ( $OR^{I}_{Adjusted} = 2.08$ , 1.53 and 1.14, respectfully) of VSGA compared with mothers with a university degree; first-time mothers were also at a higher risk ( $OR^{I}_{Adjusted} = 1.96$ ) than other women, all other individual variables being equal.

CLSCs represented a significant part of the unexplained variation that resulted from the individual model with interactions

**TABLE 2**  
**Adjusted odds ratios for VSGA singleton live births according to maternal individual explanatory variables, Quebec, Canada, 2000–2008**

Variable	% imputed <sup>a</sup>	N	%	$OR^{I}_{Adjusted}$ <sup>b</sup> Estimate	95% CI <sup>c</sup>
Age, years	0.0		100.0		< .001 <sup>d</sup>
< 20		21 566	3.2	0.90	0.83–0.98
20–24		114 780	17.2	1.00	0.96–1.04
25–29 <sup>e</sup>		235 120	35.2	1.00	—
30–34		198 985	29.8	1.08	1.03–1.12
≥ 35		96 803	14.5	1.39	1.31–1.47
Marital status	0.0		100.0		< .001 <sup>d</sup>
Married <sup>e</sup>		268 130	40.2	1.00	—
Unmarried		399 124	59.8	1.18	1.13–1.23
Highest academic qualification	8.7		10.1		< .001 <sup>d</sup>
University degree <sup>e</sup>		229 122	34.3	1.00	—
College degree		173 265	26.0	1.14	1.10–1.19
High school diploma		197 485	29.6	1.53	1.47–1.60
< High school		67 382	10.1	2.08	1.96–2.21
Mother's country of birth	1.2		100.0		< .001 <sup>d</sup>
Canada <sup>e</sup>		540 272	81.0	1.00	—
Other		126 982	19.0	1.28	1.20–1.36
Parity	0.0		47.3		< .001 <sup>d</sup>
Multiparous <sup>d</sup>		351 539	52.7	1.00	—
Primiparous		315 715	47.3	1.96	1.90–2.03

**Abbreviations:** CI, confidence interval; OR, odds ratio; VSGA, very small for gestational age.

<sup>a</sup> Percentage of births with imputed values.

<sup>b</sup> Odds ratio adjusted for individual variables (mother's age, mother's marital status, mother's academic degree, mother's country of birth and mother's parity).

<sup>c</sup> Confidence intervals built using robust variance estimates resulting from a multilevel model fitted using generalized estimating equations (GEE).

<sup>d</sup>  $p$  value of test of global difference.

<sup>e</sup> Reference category.

(chi-square statistic = 497.3  $p < .001$ ;  $df = 142$ ). For this reason, it was appropriate to include aggregated CLSC variables in the model.

There were significant crude associations between VSGA and every ecological variable presented except for “people eating fruit and vegetables less than five times a day” and “urban/rural continuum” (Table 3; additional data are available from the authors on request). Adjusted ORs ( $OR_{Adjusted}^E$ ) were slightly lower than crude values ( $OR_{Crude}^E$ ), though confidence intervals did not indicate significant differences. When accounting for individual variables, births in CLSCs with lowest mean income ( $OR_{Adjusted}^E = 1.12$ ) and variables ranking in the third tertile of the following categories had higher risks of VSGA: mothers without high school diploma ( $OR_{Adjusted}^E = 1.12$ ); immigrants ( $OR_{Adjusted}^E = 1.06$ ); mothers born outside of Canada ( $OR_{Adjusted}^E = 1.08$ ); people speaking a non-official language at home ( $OR_{Adjusted}^E = 1.08$ ) and single-headed households ( $OR_{Adjusted}^E = 1.11$ ) (Table 3). Births in CLSCs ranking in second or third tertiles of food insecurity ( $OR_{Adjusted}^E = 1.08; 1.14$ ) and sedentariness ( $OR_{Adjusted}^E = 1.06; 1.11$ ) also had higher risks of VSGA, while those in CLSCs ranking in the second tertile with respect to unmarried residents ( $OR_{Adjusted}^E = 0.93$ ) had lower risks.

The final model incorporated ecological variables of food insecurity, sedentariness and partnership status. Births in CLSCs ranking in the second or third tertile of people with food insecurity had higher risks of VSGA ( $OR_{Adjusted IE}^E = 1.05; 1.09$ ) when adjusted for all individual variables, unmarried residents and sedentariness. Births in CLSCs ranking in the third tertile of sedentariness also had higher risks of VSGA ( $OR_{Adjusted IE}^E = 1.07$ ) when adjusting for these same variables. In a similar manner, births in CLSCs with middle proportion of unmarried residents had lower risks of VSGA ( $OR_{Adjusted IE}^E = 0.94$ ) (Table 3).

Adjusted ORs ( $OR_{Adjusted}^I$ ,  $OR_{Adjusted}^E$  and  $OR_{Adjusted IE}^E$ ) would have been similar had we used non-imputed data. Some  $OR_{Adjusted}^I$  values (for mothers  $\geq 35$  years, for mothers with high school diploma, for those with less than high

school, as well as for primiparous mothers) would have been smaller and  $OR_{Adjusted}^E$  and  $OR_{Adjusted IE}^E$  would have been similar had we studied 5<sup>th</sup> to 10<sup>th</sup> percentile of neonatal weights. Likewise,  $OR_{Adjusted}^E$  and  $OR_{Adjusted IE}^E$  would have been similar had they been assessed with a logistic model incorporating variables at the smallest possible territory level. Exceptions apply to third tertile mothers without a high school diploma and second tertile single-headed households that had higher  $OR_{Adjusted}^E$  values in the latter analysis.

## Discussion

We adopted a comprehensive approach to understanding the determinants of fetal health in Quebec, Canada, by using ecological information from a separate survey, birth data and the census in a context in which individual data were available. We found associations between VSGA and ecological variables from each source of data independent of individual variables. Neither census data, survey data nor Quebec's birth data contained such a wide spectrum of relevant area variables. The ecological variables of food insecurity and sedentariness were pertinent for inclusion in a model with several ecological variables. Both were significantly associated with VSGA. Those ecological variables are not necessarily proxies for individual food insecurity and sedentariness. For example, in previous analyses an income below the low-income cut-off in the CLSC reflected both social isolation and race, whereas mean income reflected material deprivation.<sup>25</sup>

Some of the ecological variables we investigated in this research have also been examined in Canadian and American studies.<sup>7,9,13,14,19</sup> When individual variables and a few ecological variables were available and accounted for, significant associations were found between SGA and the low-income cut-off both among the births in Quebec from 1991 to 2000<sup>14</sup> and among births in Montréal from 1997 to 2001.<sup>9</sup> There was also a significant association between SGA and material deprivation measured by area income in Ontario from 2004 to 2006.<sup>13</sup>

When individual variables and several ecological variables were accounted for, social isolation and race (measured by single-headed households, low income and ethnicity) were no longer significantly associated with low birth weight among South Carolina births from 2000 to 2003.<sup>19</sup> These variables were not included in our final model with several ecological variables.

## Limitations

There are a few limitations worth highlighting. First, we were interested in sub-optimal fetal development as measured by the VSGA indicator. Some constitutionally small births may not have been a result of sub-optimal fetal development but, being classified as VSGA, contributed to a non-differential misclassification bias of the outcome. Such misclassification was minimized using the VSGA instead of the SGA indicator.

CLSC exposure was potentially misclassified. By pooling data, we implicitly postulated that CLSC tertiles remained the same throughout the years. Moreover, information about relocated mothers was unavailable. According to 2006 census data,<sup>35</sup> about 3.5% of women were incorrectly assigned to the CLSC tertile we had attributed to them. These misclassifications contributed to a small bias toward the null value.

Our results might have been subject to confounding of unmeasured individual factors such as maternal characteristics of social isolation, lifestyle (smoking, caffeine, high alcohol consumption, abuse or sedentariness) and health status (daily caloric intake, maternal body mass index [BMI], maternal hypertension or diabetes in pregnancy).

Our pooled data did not allow us to distinguish the effect of ecological exposure during pregnancy from prior exposure and to note whether the association of deprivation with VSGA has changed over time.

Finally, we were limited by the relatively little knowledge available on the spatial scale that is likely to be relevant to this

**TABLE 3**  
**Crude and adjusted odds ratios for VSGA singleton live births according to ecological variables, Quebec, Canada, 2000–2008**

Variable <sup>a</sup>	Percent imputed <sup>b</sup> %	Population		OR <sup>c</sup> Crude		OR <sup>d</sup> Adjusted		OR <sup>e</sup> AdjustedIE	
		N	(%)	Estimate	95% CI	Estimate	95% CI	Estimate	95% CI
Mean income, \$	0.0				.001 <sup>f</sup>			.012 <sup>f</sup>	
Highest tertile (28 798–56 036) (reference)		331 133	(49.6)	1.00	—	1.00	—	—	—
Middle tertile (25 269–28 797)		223 233	(33.5)	1.07	1.00–1.15	1.03	0.98–1.09	—	—
Lowest tertile (16 144–25 268)		112 888	(16.9)	1.22	1.13–1.33	1.12	1.02–1.15	—	—
Mother without high school diploma, %	0.0				< .001 <sup>f</sup>			.01 <sup>f</sup>	
Lowest tertile (1.9–9.3) (reference)		309 090	(41.3)	1.00	—	1.00	—	—	—
Middle tertile (9.3–13.1)		229 173	(34.3)	1.13	1.06–1.21	1.05	1.00–1.11	—	—
Highest tertile (13.1–41.6)		128 991	(19.3)	1.25	1.15–1.37	1.12	1.04–1.20	—	—
Smoking cigarettes daily, %	1.4				.04 <sup>f</sup>			NS <sup>f</sup>	
Lowest tertile (0.5–20.4) (reference)		275 503	(41.3)	1.00	—	1.00	—	—	—
Middle tertile (20.5–25.8)		218 642	(32.8)	1.05	0.97–1.14	1.02	0.97–1.08	—	—
Highest tertile (25.9–47.1)		173 109	(25.9)	1.13	1.03–1.23	1.06	0.99–1.13	—	—
Immigrants, %	0.1				.01 <sup>f</sup>			.01 <sup>f</sup>	
Lowest tertile (0.2–1.3) (reference)		106 403	(15.9)	1.00	—	1.00	—	—	—
Middle tertile (1.3–4.8)		234 675	(35.2)	0.96	0.89–1.04	0.98	0.92–1.05	—	—
Highest tertile (4.9–61.8)		326 176	(48.9)	1.09	1.01–1.17	1.06	1.00–1.13	—	—
Mother born in another country, %	0.0				.02 <sup>f</sup>			.03 <sup>f</sup>	
Lowest tertile (0.0–1.9) (reference)		111 383	(16.7)	1.00	—	1.00	—	—	—
Middle tertile (2.0–8.1)		216 916	(32.5)	1.00	0.92–1.09	1.01	0.94–1.09	—	—
Highest tertile (8.2–88.1)		338 955	(50.8)	1.11	1.01–1.21	1.08	1.00–1.16	—	—
Unmarried mothers, %	0.0				.01 <sup>f</sup>			NS <sup>f</sup>	
Lowest tertile (14.9–64.9) (reference)		315 619	(47.3)	1.00	—	1.00	—	—	—
Middle tertile (65.0–75.8)		230 812	(34.6)	0.90	0.84–0.97	0.94	0.90–0.99	—	—
Highest tertile (75.8–90.4)		120 823	(18.1)	1.01	0.94–1.09	0.99	0.94–1.05	—	—
Unmarried residents, %	0.0				.005 <sup>f</sup>			.03 <sup>f</sup>	.04 <sup>f</sup>
Lowest tertile (43.9–58.2) (reference)		203 717	(30.5)	1.00	—	1.00	—	1.00	—
Middle tertile (58.3–61.6)		219 668	(32.9)	0.93	0.85–1.02	0.93	0.87–0.99	0.94	0.90–0.98
Highest tertile (61.7–86.0)		243 869	(36.5)	1.05	0.96–1.15	0.98	0.93–1.05	0.95	0.91–1.00 <sup>g</sup>
Walking or biking to work, %	0.0				.008 <sup>f</sup>			NS <sup>f</sup>	
Lowest tertile (2.4–6.8) (reference)		323 121	(48.4)	1.00	—	1.00	—	—	—
Middle tertile (6.8–10.2)		202 876	(30.4)	1.08	1.01–1.15	1.02	0.97–1.07	—	—
Highest tertile (10.3–64.0)		141 257	(21.2)	1.17	1.07–1.27	1.08	1.01–1.16	—	—
People with food insecurity, %	5.6				< .001 <sup>f</sup>			< .001 <sup>f</sup>	.001 <sup>f</sup>
Lowest tertile (2.5–10.5) (reference)		222 636	(33.4)	1.00	—	1.00	—	1.00	—
Middle tertile (10.6–15.1)		238 685	(35.8)	1.13	1.05–1.22	1.08	1.01–1.15	1.05	1.01–1.11
Highest tertile (15.2–36.4)		205 933	(30.9)	1.25	1.16–1.34	1.14	1.07–1.21	1.09	1.05–1.15
Sedentariness, %	1.4				.001 <sup>f</sup>			.005 <sup>f</sup>	.05 <sup>f</sup>
Lowest tertile (1.7–9.9) (reference)		215 997	(32.4)	1.00	—	1.00	—	1.00	—
Middle tertile (9.9–14.4)		209 287	(31.4)	1.10	1.03–1.18	1.06	1.01–1.12	1.03	0.98–1.07
Highest tertile (14.4–75.3)		241 970	(36.3)	1.20	1.11–1.29	1.11	1.05–1.18	1.07	1.01–1.11
≥ 5 alcohol drinks ≥ once per week, %	2.1				.01 <sup>f</sup>			NS <sup>f</sup>	
Lowest tertile (0.0–6.9) (reference)		256 571	(38.5)	1.00	—	1.00	—	—	—
Middle tertile (6.9–9.7)		260 022	(39.0)	0.91	0.85–0.98	0.94	0.90–0.99	—	—
Highest tertile (9.7–20.9)		150 661	(22.6)	1.04	0.95–1.13	1.00	0.94–1.07	—	—

Continued on the following page

**TABLE 3 (continued)**  
**Crude and adjusted odds ratios for VSGA singleton live births according to ecological variables, Quebec, Canada, 2000–2008**

Variable <sup>a</sup>	Percent imputed <sup>b</sup> %	Population		OR <sup>E</sup> Crude <sup>c</sup>		OR <sup>E</sup> Adjusted <sup>d</sup>		OR <sup>E</sup> AdjustedIE <sup>e</sup>	
		N	(%)	Estimate	95% CI	Estimate	95% CI	Estimate	95% CI
Mean age, years	0.0			.003 <sup>f</sup>		.04 <sup>f</sup>			
Lowest tertile (25.9–38.3) (reference)	264 998	(39.7)	1.00	—	1.00	—	—	—	—
Middle tertile (38.3–40.5)	246 054	(36.9)	0.99	0.91–1.07	0.98	0.93–1.04	—	—	—
Highest tertile (40.5–51.8)	156 202	(23.4)	1.10	1.02–1.20	1.05	0.98–1.12	—	—	—

**Abbreviations:** CI, confidence interval; NS, non significant; OR, odds ratio; VSGA, very small for gestational age.

**Note:** Confidence interval built using robust variance estimates resulting from a multilevel model fitted through generalized estimating equations.

<sup>a</sup> The interpretation of an ecological portrait as a proxy of the corresponding individual variable could be inappropriate.

<sup>b</sup> Percentage of local community services centres with imputed value.

<sup>c</sup> Crude odds ratio.

<sup>d</sup> Odds ratio adjusted for individual variables including interaction terms (mother's age, mother's marital status, mother's academic degree, mother's country of birth, mother's parity, academic degree × marital status, country of birth × age, country of birth × marital status, academic degree × country of birth, age × parity and academic degree × parity).

<sup>e</sup> Odds ratio adjusted for contextual variables (people with food insecurity and inactive people) and for individual variables including interaction terms.

<sup>f</sup> p value for test for global difference.

<sup>g</sup> Value < 1.0.

specific health outcome.<sup>36</sup> For this reason, sensitivity analyses were done on data pooled by sub-territories.

Mechanisms through which CLSC food insecurity could be associated with lower birth weight for gestational age include interpersonal factors, which have been shown to be consistently related to dietary behaviours in young people.<sup>37</sup> Higher pre-pregnancy weight in mothers, an unmeasured factor, could also lead to gestational diabetes.<sup>38</sup>

Residents from CLSCs with less sedentariness or inactivity are certainly globally healthier and have a lower incidence of chronic diseases and disabilities.<sup>39</sup> Mothers from these CLSCs have a better chance of being physically active themselves. Inactivity of residents might be as a result of the built environment encouraging (or otherwise) activity,<sup>37,39,40</sup> rather than the social environment doing so.<sup>37</sup> In addition, activity also reflects the global understanding of public health messages (people eating well, exercising, not smoking, etc.).<sup>37</sup> Results appear relevant for other countries with similar social welfare systems.

In this effort to enlarge the set of ecological determinants of fetal health, we incorporated data aggregated from a

sophisticated Canadian survey with census and birth data to build diversified community-defined portraits. The use of portraits derived from a broad range of variables allowed for the identification of ecological associations between VSGA and marital status, food insecurity and sedentariness of residents. These ecological associations were not identified as “contextual associations” as mothers’ food insecurity and sedentariness were not adjusted for in the analyses even though many other individual characteristics were.

Results of this study add to the growing body of evidence suggesting that ecological social processes affect fetal health. Future Canadian studies could benefit from the inclusion of information gathered by large surveys such as the CCHS to the narrow set of census data to depict and use details of neighbourhood contexts in a comprehensive approach.

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# An environmental scan of policies in support of chronic disease self-management in Canada

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## Abstract

**Introduction:** The evidence supporting chronic disease self-management warrants further attention. Our aim was to identify existing policies, strategies and frameworks that support self-management initiatives.

**Methods:** This descriptive study was conducted as an environmental scan, consisting of an Internet search of government and other publicly available websites, and interviews with jurisdictional representatives identified through the Health Council of Canada and academic networking.

**Results:** We interviewed 16 representatives from all provinces and territories in Canada and found 30 publicly available and relevant provincial and national documents. Most provinces and territories have policies that incorporate aspects of chronic disease self-management. Alberta and British Columbia have the most detailed policies. Both feature primary care prominently and are not disease specific. Both also have provincial level implementation of chronic disease self-management programming. Canada's northern territories all lacked specific policies supporting chronic disease self-management despite a significant burden of disease.

**Conclusion:** Engaging patients in self-management of their chronic diseases is important and effective. Although most provinces and territories have policies that incorporate aspects of chronic disease self-management, they were often embedded within other initiatives and/or policy documents framed around specific diseases or populations. This approach could limit the potential reach and effect of self-management.

**Keywords:** *chronic disease self-management, self-management support, health policy, primary care, environmental scan*

## Introduction

Chronic disease is Canada's most prominent health care problem, costing more than \$80 billion each year<sup>1,2</sup> and causing increased use of emergency departments, extended hospital stays, reduced quality of life and increased mortality rates.<sup>3-10</sup> Improving the quality of care for people with chronic diseases is complex,<sup>11</sup> requiring timely diagnosis and treatment, access to primary and specialist care and a focus on self-management tasks and decisions.<sup>12,13</sup>

Supporting people in self-management has been shown to be effective at improving outcomes and has been promoted across the widest array of conditions and populations.<sup>14-20</sup> Self-management support (SMS) focuses on the individuals and their families by using collaborative goal setting and a variety of self-efficacy strategies.<sup>16</sup> These strategies enable patients, together with their health care providers, to medically manage their illnesses more effectively, carry out normal roles and activities and manage the emotional impact of their

illnesses.<sup>15</sup> Adams et al.<sup>21</sup> further this definition by highlighting what health care providers can do through "the systematic provision of education and supportive interventions by health care staff"<sup>21,p57</sup> to increase patients' skills and confidence in managing their health problems, including regular assessment of progress and problems, goal setting and support in problem-solving.

There is much interest in implementing SMS programs in Canada. However, many programs are being implemented in isolation, often by disease-specific organizations or local public health or community-based organizations.<sup>22</sup> But while the patients and their communities, health providers and the health care delivery system are certainly linchpins in the success of chronic disease support and care, federal, provincial and territorial governments have major roles to play because they set and implement public policy for health and health care across Canada.

While there is some mention of the importance of self-care and self-management in national strategies, such as healthy aging<sup>23</sup> and the Canadian Diabetes strategy,<sup>24</sup> little is known about provincial and territorial government policy directions associated with SMS, despite that these governments are responsible for health and health care within their jurisdictions.

As part of a broader project on chronic disease care and self-management conducted with the Health Council of Canada (HCC),<sup>25</sup> we performed an environmental scan to identify provincial and territorial

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government strategic policy documents that support patient self-management.<sup>26</sup> The HCC is an independent, not-for-profit organization established by the country's first ministers in 2003 to monitor the health care system within the context of the Health Accords. The HCC has focused some of its attention on the prevention and management of chronic conditions to encourage discussion of the changes to public policy, health care management and health services delivery required to improve health outcomes for all Canadians.<sup>27</sup>

The intent of this report is to increase awareness of provincial activities and policy directions to allow jurisdictions to build on emerging trends across the country.

## Methods

We conducted the environmental scan of SMS and chronic disease care in three phases: (1) an online scan using the Google search engine to identify publicly available policies that support or influence SMS initiatives; (2) interviews with jurisdictional representatives of the HCC to gain an inside perspective on existing policies and strategies and future plans related to SMS; (3) a second online scan based on interview findings.

The aim of the first online scan was to identify publicly available policy documents at the provincial and territorial level. We defined policy as any course of action or broad direction endorsed by a body of authority in government and included frameworks, strategies, action plans and official priority documents.<sup>28</sup>

Three people from our research team scanned online literature and websites from each of the provinces and territories in September 2011 to identify policies, legislation, strategies and frameworks that discussed or focused on SMS and programs or their implementation. Keywords used in the search were "self-management," "self-care," "self-management support," "chronic conditions," "policy," "action plan," "framework," "strategy" and "initiative." Relevant findings were organized in a database using Microsoft

Excel version 12 (2007; Redmond, WA, US), tracking the year and details of each initiative.

Next, for a more in-depth and accurate view of existing policies, we interviewed individuals involved in policy in the ministries of health. Jurisdictional representatives from all provinces and territories, with the exception of Quebec, were identified and invited by email to participate in a 30-minute telephone interview through the network of the HCC. At the time, Quebec was not in a formal partnership with the HCC so we identified our Quebec participant through academic networking. All the jurisdictional representatives invited agreed to participate and granted informed consent. The interview process was approved by the Ottawa Hospital Research Ethics Board.

The interview guide used for these semi-structured interviews is available from the authors on request. The principal investigator (CL) or the research assistant (KM) conducted the interviews between September and October 2011, with the Quebec interview conducted in May 2012. Interviews were recorded and transcribed by the research assistant. Copies of the interview transcripts were sent to each interviewee for approval to increase the trustworthiness of the results.

The third step of the study, which took place in July 2012, consisted of a focused online scan to identify newly released or updated policy documents that had been identified by the interviewees as forthcoming. The iterative analysis used examples of other policy scans for guidance.<sup>29-31</sup> Based on the work by Dixon-Woods et al.<sup>32</sup> we used a descriptive narrative approach with thematic analysis. This approach has been identified as appropriate for reviews that focus on policy.<sup>32</sup> Two members of the research team reviewed the policy documents and the interview transcripts to identify themes. Several team meetings were held during the analysis phase to discuss findings and come to an agreement upon key themes.<sup>32</sup>

## Results

Through our Internet scan and interviews with 16 representatives from all provinces and territories in Canada, we learned that most provinces and territories have a policy, framework or strategy that incorporates aspects of chronic disease management. However, they vary significantly in terms of number of available policy documents that explicitly acknowledge the role of self-management (see Table 1). Our online scan to identify policies that support or influence SMS initiatives found 30 publicly available and relevant provincial and national documents.

Most provinces have implemented SMS programs, the most common one being the Stanford Chronic Disease Self-Management Program (see Table 2), although these are often run through small-scale community organizations or the local health regions. Of all the provinces, Alberta and British Columbia have the most detailed policies supporting patient self-management. They offer their widely available self-management programs mainly through provincial health organizations (as opposed to disease-specific and or grassroots community groups). These programs focus on patient-centred care and include primary health care and primary care.

For example, Alberta has an overarching vision for the future of health care, called Vision 2020,<sup>33</sup> that focuses on the needs of the patient. In addition, the development of its model of chronic disease management care and the launch of integrated community-based programming across the province promotes a well-rounded approach to supporting patients with chronic conditions. SMS is one of the main pillars of the model and programming. The Stanford Chronic Disease Self-Management Program is now offered across the province through Alberta Health Services as the Better Choices, Better Health program. The program is a component of integrated community-based programming, and patients can be referred to it by their physicians or staff from one of the other integrated programs. Other programs offered under the umbrella of integrated community-based

**TABLE 1**  
**Examples of policy documents relevant to self-management of chronic diseases**

Jurisdiction	Document title	Document type	Link
Alberta	Alberta's model for chronic disease management care (2008) Vision 2020 (2008)	Framework Strategy	<a href="http://www.albertahealthservices.ca/4058.asp">http://www.albertahealthservices.ca/4058.asp</a> <a href="http://www.health.alberta.ca/initiatives/vision-2020.html">http://www.health.alberta.ca/initiatives/vision-2020.html</a>
British Columbia	Becoming the Best: Alberta's 5-Year Health Action Plan, 2010-2015 (2007) Expanded Chronic Care Model (2003) Primary Health Care Charter: A Collaborative Approach (2007)	Action Plan Framework Strategy	Not available online <a href="http://www.primaryhealthcarebc.ca/resource_eccm.html">http://www.primaryhealthcarebc.ca/resource_eccm.html</a> <a href="http://www.primaryhealthcarebc.ca/">http://www.primaryhealthcarebc.ca/</a>
Patients as Partners (2007)		Initiative	<a href="http://www.impactbc.ca/patients-as-partners">http://www.impactbc.ca/patients-as-partners</a>
Manitoba	Self-Management in Primary Care in Manitoba: The Way Forward (2011)	Discussion Paper	<a href="http://www.gov.mb.ca/health/primarycare/self_management.html">http://www.gov.mb.ca/health/primarycare/self_management.html</a>
New Brunswick	A Chronic Disease Prevention and Management Framework for New Brunswick (2010)	Framework	<a href="http://www.gnb.ca/0051/pub/pdf/2010/6960e-final.pdf">http://www.gnb.ca/0051/pub/pdf/2010/6960e-final.pdf</a>
Newfoundland and Labrador	Comprehensive Diabetes Strategy for New Brunswickers (2011) Improving Health Together: A Policy Framework for Chronic Disease Prevention and Management in Newfoundland and Labrador (2011)	Strategy Framework	<a href="http://www.gnb.ca/0053/phc/pdf/2011/8023e.pdf">http://www.gnb.ca/0053/phc/pdf/2011/8023e.pdf</a> <a href="http://www.health.gov.nl.ca/health/chronicdisease/Improving_Health_Together.pdf">http://www.health.gov.nl.ca/health/chronicdisease/Improving_Health_Together.pdf</a>
Northwest Territories	Chronic Disease Policy Framework (under development) Chronic Disease Management Strategy (under development, in partnership with the Canadian Health Services Research Foundation)	Framework Strategy	Not available online Not available online. For more information, see: Leith E, Kirwan C, Verma JY, Lewis K, Robertson S. Re-imaging healthcare: the Northwest Territories transitions to an integrated chronic disease management strategy. <i>Health Quarterly</i> . 2012;15(1):19-21.
Nova Scotia	Chronic Disease Prevention and Management Strategy, based on the Expanded Chronic Care Model (under development) Nova Scotia Chronic Disease Prevention Strategy (2003) Strategy for Positive Aging in Nova Scotia (2005) Chronic Disease Management Action Plan (2011)	Strategy Strategy Action Plan Action Plan	<a href="http://www.gov.ns.ca/hpp/publications/CDP_Strategy_Report_Final_October30.pdf">http://www.gov.ns.ca/hpp/publications/CDP_Strategy_Report_Final_October30.pdf</a> <a href="http://www.gov.ns.ca/seniors/pub/2005_StrategyPositiveAging.pdf">http://www.gov.ns.ca/seniors/pub/2005_StrategyPositiveAging.pdf</a> Not available online <a href="http://www.gov.ns.ca/health/reports/pubs/Action_Plan_Chronic_Pain.pdf">http://www.gov.ns.ca/health/reports/pubs/Action_Plan_Chronic_Pain.pdf</a>
Nunavut	Action Plan for the Organization and Delivery of Chronic Pain Services in Nova Scotia (2006) Chronic Disease Prevention Strategy Public Health Strategy (2008)	Strategy Strategy	Not available online <a href="http://www.hss.gov.nu.ca/en/Public%20Health%20Strategy.aspx">http://www.hss.gov.nu.ca/en/Public%20Health%20Strategy.aspx</a>
Ontario	Preventing and Managing Chronic Disease: Ontario's Framework (2007) Ontario Diabetes Strategy (2008)	Framework Strategy	<a href="http://www.health.gov.on.ca/english/providers/program/cdpm/index.html">http://www.health.gov.on.ca/english/providers/program/cdpm/index.html</a> <a href="http://www.health.gov.on.ca/en/ms/diabetes/en/about_diabetes_strategy.html">http://www.health.gov.on.ca/en/ms/diabetes/en/about_diabetes_strategy.html</a>
Prince Edward Island	Prince Edward Island Strategy for Healthy Living (2008)	Strategy	<a href="http://www.gov.pe.ca/health/index.php?37;number=102088&amp;lang=E">http://www.gov.pe.ca/health/index.php?37;number=102088&amp;lang=E</a>
Quebec	Cadre de référence pour la prévention et la gestion des maladies chroniques physiques en première ligne [French Only] (2012) Stratégie de prévention et de gestion des maladies chroniques et Plan d'action 2008-2013 (2008)	Framework	<a href="http://msss.gouv.qc.ca/fr/document/publication.nsf/4b1768b3f849519c852568fd0061480d/c9fcbe57cd7ce85257a8500766b62;OpenDocument">http://msss.gouv.qc.ca/fr/document/publication.nsf/4b1768b3f849519c852568fd0061480d/c9fcbe57cd7ce85257a8500766b62;OpenDocument</a>
Saskatchewan	The Diabetes Provincial Plan (2004) Self-Management Support Action Plan (2006) Tobacco cessation legislation	Action Plan Action Plan Legislation	<a href="http://www.frsq.gouv.qc.ca/fr/financement/pdf_2010_2011/Strategie_maladies_chroniques.pdf">http://www.frsq.gouv.qc.ca/fr/financement/pdf_2010_2011/Strategie_maladies_chroniques.pdf</a> <a href="http://www.health.gov.sk.ca/provincial-diabetes.plan">http://www.health.gov.sk.ca/provincial-diabetes.plan</a> <a href="http://www.health.gov.sk.ca/quitting-smoking">http://www.health.gov.sk.ca/quitting-smoking</a>
Yukon	Aging Well Strategy (under development) Chronic Disease Prevention and Management Strategy (under development)	Strategy Strategy	Not available online. For more information, see <a href="http://www.hss.gov.yk.ca/news/10-025.php">www.hss.gov.yk.ca/news/10-025.php</a> Not available online
Federal	Canadian Diabetes Strategy (2005)	Strategy	<a href="http://www.hsc.gc.ca/ahc-asc/activit/strateg/diabete-eng.php">http://www.hsc.gc.ca/ahc-asc/activit/strateg/diabete-eng.php</a>

**TABLE 2**  
**Examples of Chronic Disease Self-Management Programs across Canada**

Province/territory	Program	Link/source	Additional information
Alberta	Stanford Chronic Disease Self-Management Program (CDSMP) “Better Choices, Better Health”  CDSMP “Get Better Together: Building Capacity for Chronic Disease Self-Management”	<a href="http://www.albertahealthservices.ca/services.asp?pid=service&amp;rid=1054851">http://www.albertahealthservices.ca/services.asp?pid=service&amp;rid=1054851</a>  <a href="http://www.gov.mb.ca/health/chronicdisease/cden/docs/2007/thursday/keyzer.pdf">http://www.gov.mb.ca/health/chronicdisease/cden/docs/2007/thursday/keyzer.pdf</a>	This Stanford program runs province-wide and is a component of the integrated community-based programming. Patients can be referred to it by their physicians or staff from one of the other integrated programs  A modified Stanford model that is co-ordinated provincially by the Wellness Institute within the Winnipeg Regional Health Authority. It offers self-management programs across the province and is open to all patients with chronic diseases. These programs are led by both professional and peer leaders
New Brunswick	CDSMP “My Choices – My Health”	<a href="http://www.gnb.ca/0053/phc/workshop-e.asp">http://www.gnb.ca/0053/phc/workshop-e.asp</a>	This permanent program is based on the Stanford CDSMP and is offered in both official languages
Newfoundland and Labrador	Stanford CDSMP	<a href="http://patienteducation.stanford.edu/programs/cdsmp.html">http://patienteducation.stanford.edu/programs/cdsmp.html</a>	This Stanford program is not offered province-wide yet. Only three out of four regional health authorities have run sessions, but all health authorities have master trainers available to lead the program
Nova Scotia	CDSMP ‘Your Way to Wellness’  CPSMP “The Chronic Pain Self Management Program”, “You’re in Charge”, “You’re in Charge”	<a href="https://yourway2wellness.gov.ns.ca/">https://yourway2wellness.gov.ns.ca/</a>  <a href="http://www.southshorehealth.ca/education-programs/bone-health.html">http://www.southshorehealth.ca/education-programs/bone-health.html</a>  <a href="http://www.cat.ca/otnow/sept%2011/youre.pdf">http://www.cat.ca/otnow/sept%2011/youre.pdf</a> <a href="http://www.iwk.nshealth.ca/index.cfm?objectid=924CF1E6-AF34-AF7E-2E6D746123614962">http://www.iwk.nshealth.ca/index.cfm?objectid=924CF1E6-AF34-AF7E-2E6D746123614962</a>	A self-management program for people living with or supporting someone with a chronic health condition  A program offered in Nova Scotia’s chronic pain clinics that follows the Stanford CPSMP model  A weekend-long self-management workshop specifically designed for youth with chronic conditions, sometimes including family members
Ontario	Many different titles, e.g. Stanford CDSMP “Living a Healthy Life with Chronic Conditions”	<a href="https://www.healthyifeworkshop.ca/">https://www.healthyifeworkshop.ca/</a> <a href="http://www.livinghealthychamplain.ca">http://www.livinghealthychamplain.ca</a>	Many different programs, which are often in collaboration with academic health centres, offer self-management programs to patients with different chronic diseases. These programs are mainly based on the Stanford model with many specifically targeting people with diabetes.
Prince Edward Island	Stanford CDSMP	<a href="http://patienteducation.stanford.edu/programs/cdsmp.html">http://patienteducation.stanford.edu/programs/cdsmp.html</a>	Prince Edward Island offers the standard Stanford CDSMP course throughout the province
Saskatchewan	CDSMP “LiveWell Chronic Disease Management”	<a href="http://www.saskatoonhealthregion.ca/your_health/ps_cdm_about_livewell.htm">http://www.saskatoonhealthregion.ca/your_health/ps_cdm_about_livewell.htm</a>	Saskatchewan has a central hub for several programs and services across the province called the LiveWell Chronic Disease Management Programs and Services. These programs and services target both patients with chronic conditions and their caregivers
Quebec	Living a Healthy Life with Chronic Conditions (CDSMP/CPSMP): “My tool Box”/“L’atelier”	<a href="http://mytoolbox.mcgill.ca/en/">http://mytoolbox.mcgill.ca/en/</a>	A CDSMP and a CPSMP are offered in both French and English. Both follow the Stanford CDSMP course
Yukon	“Chronic Conditions Support Program”	<a href="http://www.hss.gov.yk.ca/csp.php">http://www.hss.gov.yk.ca/csp.php</a>	The Yukon Department of Health and Social Services no longer offers a Stanford CDSMP, in large part due to the difficulties in finding a sufficient number of interested participants. The currently available Chronic Conditions Support Program is offered to both patients with chronic conditions and health professionals engaged in their care. The program is not primarily a self-management program, but does contain a few components that are related to self-management. It is offered in both French and English

Abbreviations: CDSMP, chronic disease self-management program; CPSMP, chronic pain self-management program.

programming include supervised exercise programs and nutrition information through either a dietician or a group workshop. Primary Care Networks in Alberta also strongly encourages self-management. The networks play a large role in the integrated community-based programming because of their ability to enhance care co-ordination and collaboration through shared care among the appropriate providers.

Similarly, self-management is identified in the mission, vision and goals of the British Columbia Ministry of Health. The ministry initiative, Patients as Partners, part of the 2007 Primary Health Charter,<sup>34</sup> specifically addresses self-management implementation and evaluation in asking primary health care providers and organizations to develop additional ways to support the central role of patients as partners in their own care. The province offers many SMS programs, including Chronic Disease Self-Management; Online Chronic Disease Self-Management; Arthritis/Fibromyalgia Self-Management; Chronic Pain Self-Management; Diabetes Self-Management; Active Choices; A Matter of Balance: Managing Concerns about Falls; Bounce Back: Reclaim Your Health; InterCultural Online Health Network; Patient Voices Network's Peer Coaching; Dietician Services at HealthLink BC; and QuitNow Services.

Manitoba has also recently released a discussion paper specifically targeting self-management in primary care.

### **Frameworks**

Many of the other provinces have chronic disease management and prevention frameworks that include self-management as a core component. For example, Ontario, New Brunswick and Quebec have aligned their Chronic Disease Management and Prevention (CDMP) Frameworks, based on the Expanded Chronic Care Model,<sup>34,35</sup> to build future strategies and policies for the prevention and management of chronic diseases. The Expanded Chronic Care Model itself builds on the well-known Chronic Care Model (CCM),<sup>36</sup> which has been shown to enhance the delivery and quality of care and control

health care costs.<sup>14,19,37</sup> The Expanded Chronic Care Model is more suited to the Canadian health care environment because it more effectively integrates health promotion and prevention in both the health system and communities.

Newfoundland and Labrador has also adopted a Chronic Disease Policy Framework that includes six policy statements, one which focuses on self-management.<sup>38</sup> It has eight priority areas: arthritis, cancer, chronic pain, diabetes, heart disease, lung disease, kidney disease and stroke. It covers all four regional health authorities in the province.

### **Strategies**

The Unit for Population Health and Chronic Disease Prevention at Dalhousie University, in collaboration with the Nova Scotia Department of Health, developed the Nova Scotia Chronic Disease Prevention Strategy in 2003; however, it does not explicitly emphasize self-management. The Strategy for Positive Aging in Nova Scotia, published in 2005, does speak of the importance of self-management for seniors.

### **Disease-specific policies with a focus on self-management**

Many of the provinces have policies that focus on disease-specific conditions, such as diabetes, arthritis, stroke and chronic obstructive pulmonary disease. For example, The Ontario Diabetes Strategy, launched in 2008, emphasizes patients' self-management as an important component. Under this strategy, funding was allocated to cover a four-year plan to execute a multidimensional approach to diabetes care that addresses the growing needs of the Ontario population. The Ontario Diabetes Strategy appears to be the leading strategy in Ontario in terms of incorporating self-management. However, the interviewed experts in the field expressed the belief that there is a need to go beyond a disease-specific strategy toward a general policy that addresses self-management of chronic diseases as a whole, especially in patients with multimorbidities.

Saskatchewan's Provincial Diabetes Plan, released in February 2004, emphasizes the role of self-management. The Saskatchewan Ministry of Health and local health authorities have also set in place guidelines that mandate the delivery of SMS.

In Prince Edward Island, self-management of specific chronic diseases is also addressed in some programs, such as those for diabetes and arthritis. The province has also been piloting programs for chronic obstructive pulmonary disease, hypertension and weight management that include self-management components. Prince Edward Island does not have a specific policy document to support self-management of chronic diseases in general. Instead, it offers education and training for health care providers that incorporates self-management principles.

### **Lack of policies, frameworks, strategies in the North**

#### **Nunavut**

Our policy scan, further supported by our interview with a local expert in Nunavut, revealed that the territory does not have policy documents or strategies that specifically address the issue of self-management for patients with chronic diseases. In addition, there are currently no active self-management programs to support either patients or health professionals in Nunavut.

#### **Northwest Territories**

There are no policies in place in the Northwest Territories that specifically support the design and implementation of self-management programs for patients with chronic diseases, although a chronic disease management strategy is being developed by the Department of Health and Social Services, and a first draft of the document had been developed and was under review. SMS is recognized as an important component of the chronic disease management strategy and was included in the draft. The number of programs that fully integrate self-management is limited in the region; some diabetes education programs and a small number of other disease-specific pro-

grams, such as mental health programs, have incorporated elements of self-management. A chronic disease management strategy will provide opportunities to enhance the role of self-management in these programs and design new programs that better address the need for SMS in the Northwest Territories.

### **Yukon**

The Department of Health and Social Services has applied for funding to begin developing a chronic disease prevention and management strategy. According to the experts we interviewed, the aim is to include self-management in this strategy. The Stanford Chronic Disease Self-Management Program is no longer being offered by the Department of Health and Social Services, largely due to difficulties in finding a sufficient number of interested patients. The Chronic Conditions Support Program is offered to both patients with chronic conditions and health professionals engaged in their care. The program is not primarily a self-management program, but does contain a few related components.

## **Discussion**

Through our scan of environmental policies, we found that although most provinces and territories have policies that incorporate aspects of chronic disease self-management, these policies were often embedded within other initiatives and/or policy documents framed around specific populations or diseases. The lack of specific self-management policies in all of Canada's North was surprising given that these regions have the highest burden of chronic diseases in the country.<sup>39,40</sup> Residents also have many challenges in accessing care. Other competing health priorities, combined with the geographical spread of the population, may be reasons for self-management being under-developed here.

Great potential for improving health does exist in the North given that the most common and effective chronic disease self-management programs<sup>15,41</sup> are based on the peer support model that does not rely on access to trained health care professionals. In addition, many of the programs have already been adapted and success-

fully implemented for many cultures and into different languages.<sup>42-44</sup>

Canada has many disease-focused strategies that incorporate self-management as a theme. For example, SMS programs in Ontario are mainly funded as part of the Ontario Diabetes Strategy. This diminishes the ability to integrate care on a programmatic level as performance measures are then often linked to specific diseases and not to the population. Although diabetes care is often framed as a first step or template in tackling chronic diseases, the self-management approaches in diabetes remain tethered to disease-specific medical management, such as content knowledge on diabetes and learning medical tasks (i.e. managing insulin). In addition, the population that is targeted by these SMS programs are people with diabetes, which tends to exclude groups of people with other chronic diseases.

It is critical to maintain focus on a more generic approach (dealing with fatigue, action planning for a healthy lifestyle, etc.) that addresses all three dimensions of self-management: patients medically managing their illness; carrying out normal roles and activities; and managing the emotional impact.<sup>15</sup> Focusing on common risk factors across all chronic diseases is a basic principle of the Chronic Care Model approach.<sup>36</sup> The World Health Organization recommends that "sound and explicit government policy is the key to effective prevention and control of chronic diseases."<sup>45,p2</sup> A generic strategy that takes a life course perspective and is co-ordinated among decision makers across sectors is recommended.<sup>45</sup>

Alberta and British Columbia, the provinces that seem to have the most comprehensive self-management approaches, are also the ones with the most detailed policies/strategies that are not disease specific. Both feature primary health care and primary care prominently. The role of the primary care provider can be seen as foundational in supporting patient self-management. The nature of primary care and its position within the health care system makes it a perfect target for such interventions. Primary care not only has access to most patients with chronic con-

ditions but can also address different medical conditions beyond one specific disease. Primary care providers are in an ideal position to play a central role in preventing and managing chronic conditions, as 95% of Canadians with a chronic disease report having a regular family physician.<sup>46</sup> Primary care visits provide a unique opportunity to monitor patients' health and to encourage self-management,<sup>47-49</sup> as the majority of Canadians perceive their family physician to be a credible resource of health information and value their advice.<sup>50,51</sup> As these provinces move forward with strategies grounded more in the primary health care community rather than disease areas, it will be important to evaluate the impact the different provincial policies have on program reach and overall effectiveness. To date, there is still very little published evidence that describes the overall reach of SMS programs in all provinces.<sup>52</sup>

Future research examining the association of policy and program reach and effect in self-management of chronic diseases is needed.

### **Limitations**

The findings of this study are limited by several factors including participation bias and issues related to timing. We relied mainly on the initial contact list of jurisdictional representatives provided by the HCC. Although we did speak to representatives from all the provinces and territories and we did follow up for verification and/or clarification as needed, individual depth of knowledge varied, probably as a result of how much time they had spent in that position and their overall knowledge of the governmental system. These aspects were not specifically assessed.

In addition, a common limitation of policy scans relates to much of the material being time sensitive and linked to political agendas and public statements; thus, material was not necessarily publicly available when we were conducting our research. We attempted to minimize this limitation through interviewing the experts in the field as well as by conduct-

ing an updated online scan after the interviews, in July 2012.

## Conclusion

Evidence suggests that engaging patients in self-management of their chronic diseases is important and effective. Although most provinces and territories have policies that incorporate aspects of chronic disease self-management, these policies are often embedded within other initiatives and/or policy documents framed around specific diseases or populations. This approach could limit the potential reach and effect of self-management. Creating policies that identify self-management as a key element in a total population approach could lead to improved care for Canadians living with chronic diseases.

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# Cancer in Canada Fact Sheet Series #1

## Thyroid cancer in Canada

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This article has been peer reviewed.

- The incidence of thyroid cancer is increasing more rapidly than that of any other cancer in Canada, while mortality has remained low and stable
- In the last 10 years the number of thyroid cancer cases has increased 144% from 1709 to 4172 cases per year
- Thyroid cancer is three times more common in females than males
- 40% of thyroid cancers are diagnosed in Canadians under 45 years of age
- Some of the apparent increase in incidence is likely due to improved and more widely available diagnostic techniques

Thyroid cancer is a cancer that forms in the thyroid gland (an organ at the base of the throat that makes hormones that help control heart rate, blood pressure, body temperature and weight).<sup>\*</sup> Although thyroid cancer is a relatively rare tumour, it is the most common endocrine malignancy worldwide<sup>1</sup> and the tenth most common cancer in Canada.<sup>2</sup>

More than 4000 Canadians were diagnosed with thyroid cancer in 2007, or nearly 12 per 100 000, accounting for approximately 2.5% of all malignant tumours.<sup>†</sup> Unlike most cancers, thyroid cancer is three times more common in females than males and is generally diagnosed at a younger age<sup>2,3</sup> (Figure 1). Nearly 40% of all thyroid cancers are diagnosed before 45 years of age and three-quarters before age 60. Thyroid cancer ranks second in Canadians aged 15 to 44 years (Figure 2) and is the most common cancer diagnosis in those aged 15 to 29 years (Figure 3). The large majority of thyroid cancers are papillary carcinomas (86%), while others include follicular (6%), medullary (2%), anaplastic (1%) and other/unknown (5%).

\* See The Canadian Cancer Society ([www.cancer.ca](http://www.cancer.ca)) for more details on thyroid cancer biology and clinical treatment.

† Data definitions and statistical methods used in this analysis are outlined in the Canadian Cancer Statistics Annual Report.<sup>2</sup>

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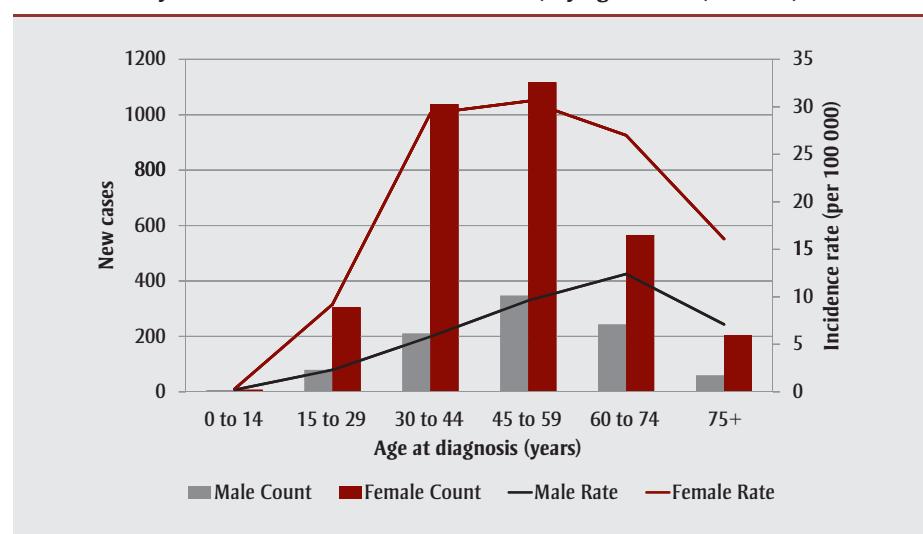
from 2.0 to 5.2 per 100 000, and 7.3% per year in females, from 6.8 to 17.9 per 100 000 (Figure 4). The highest increase, 8.2% per year, was found in women aged 30 to 59 years. The increase in thyroid cancers has been particularly rapid in the last 10 years as the number of new cases diagnosed in Canada increased by 144%, from 1709 in 1998 to 4172 in 2007. Similar increases took place in Europe, North and South America, Oceania and parts of Asia.<sup>1,3,6-8</sup> However, rates vary considerably between and within continents and are not consistently higher or lower in any region of the world except in Africa where rates are generally low.

The ASIR of thyroid cancer has increased in every province and territory in Canada over the last 16 years, but percent change

### Trends in incidence and mortality

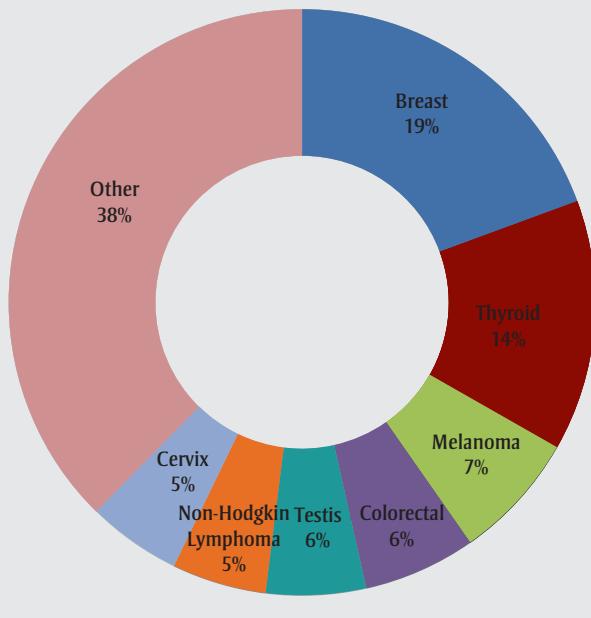
The incidence rate of thyroid cancer is increasing more rapidly than any other cancer in Canada.<sup>2,4,5</sup> Between 1992 and 2007, the age-standardized incidence rate (ASIR) increased 5.7% per year in males,

**FIGURE 1**  
New thyroid cancer cases and incidence rates, by age and sex, Canada, 2007



Source: The Canadian Cancer Registry database at Statistics Canada;<sup>23</sup> Canadian population estimates provided by Statistics Canada.<sup>24</sup>

**FIGURE 2**  
**Distribution of new cancer cases, aged 15–44 years, males and females, Canada, 2007 (N = 11 746)**

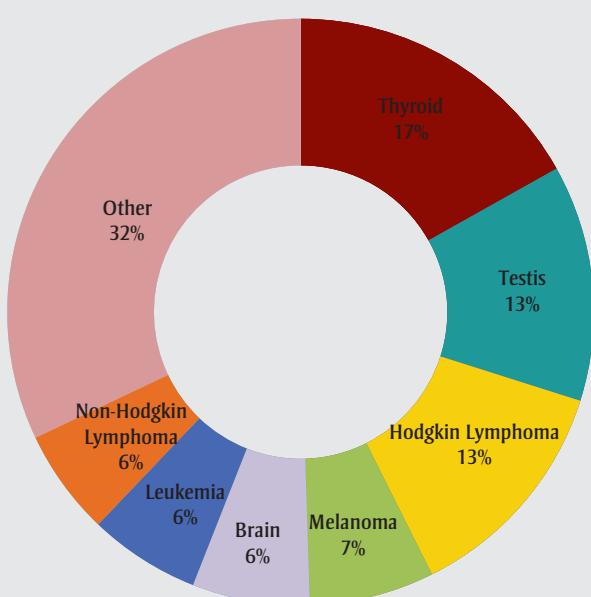


Source: The Canadian Cancer Registry database at Statistics Canada.<sup>23</sup>

and rates vary widely across the country (Figure 5). In 2007, ASIR were highest in the most populous province, Ontario, at 15.2 per 100 000, and lowest in

Saskatchewan (5.2), British Columbia (5.8) and Manitoba (8.5). These rates were significantly different ( $p < .05$ ) than the average Canadian ASIR of 11.6 per 100 000.

**FIGURE 3**  
**Distribution of new cancer cases, aged 15–29 years, males and females, Canada, 2007 (N = 2265)**



Source: The Canadian Cancer Registry database at Statistics Canada.<sup>23</sup>

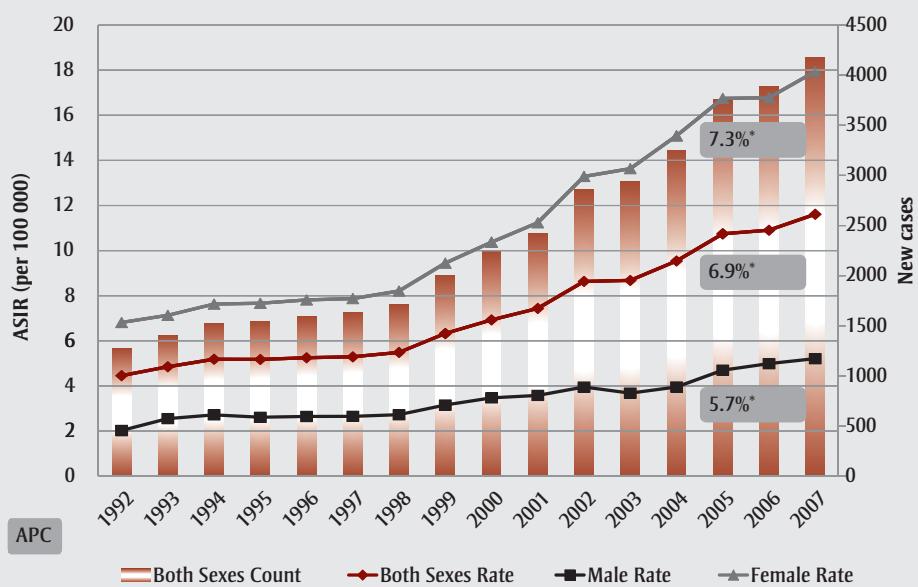
In contrast to incidence, mortality from thyroid cancer has remained exceptionally low and stable. Between 1992 and 2007 there was an average 142 deaths due to thyroid cancer each year in Canada and the age-standardized mortality rate (ASMR) decreased, on average, by less than 1% per year from 0.5 per 100 000 in 1992 to 0.4 per 100 000 in 2007 (Figure 6). The low and stable rate of thyroid cancer mortality in Canada is consistent with rates found in the US, Europe, Oceania and Asia.<sup>1,3</sup> Accordingly, thyroid cancer has the highest five-year relative survival rate of all cancers in Canada, at 97% for the period 2001 to 2003.<sup>9</sup>

## Risk factors

The most well-established risk factor for thyroid cancer is ionizing radiation from therapeutic radiation treatment or nuclear accidents/fallout.<sup>10</sup> However, at a population level, this accounts for very few cases. The risk of developing thyroid cancer is also increased in those with benign thyroid conditions, such as goitre and thyroid nodules, and in those with a family history of thyroid cancer or some genetic conditions.<sup>10</sup> Female reproductive factors, body mass index and iodine consumption have shown some association with thyroid cancer but results are inconsistent.<sup>11–13</sup> The association between thyroid cancer risk and exposure to endocrine-disrupting chemicals is inconclusive, although research is limited.<sup>14–17</sup>

Some of the increase in incidence of thyroid cancer is likely due to better detection as a result of improved and more widely available diagnostic techniques (primarily ultrasound and fine needle aspiration).<sup>4,6</sup> A number of studies have shown the increase to be primarily restricted to small, asymptomatic tumours that may have had little clinical significance,<sup>4,6,7,18</sup> which is supported by the fact that mortality from thyroid cancer has remained low and stable. However, other studies have found increased rates in all tumour sizes and across sex and racial/ethnic groups, suggesting a true increase in incidence.<sup>19–22</sup> In addition, rates have not plateaued, which is what would be expected after new or improved diagnostic

**FIGURE 4**  
New thyroid cancer cases, age-standardized incidence rates and annual percent change, Canada, 1992–2007



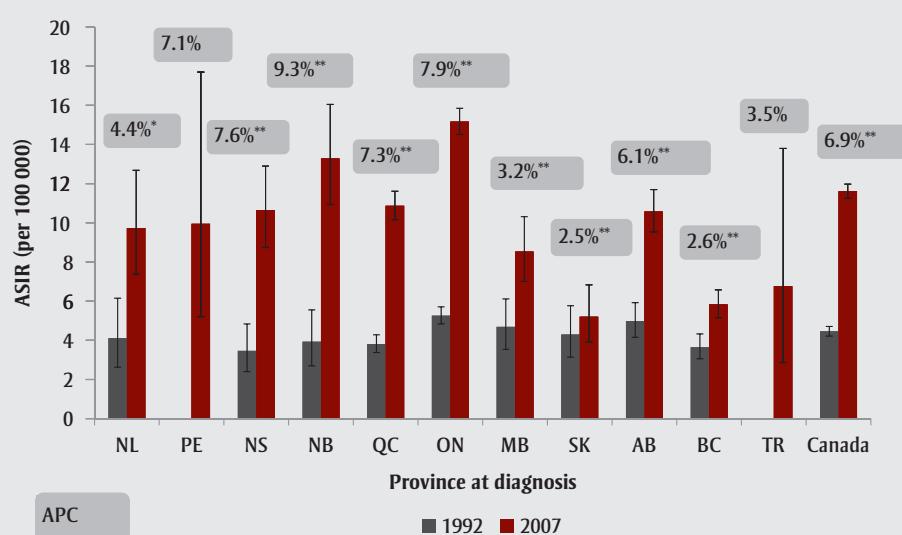
**Source:** The Canadian Cancer Registry database at Statistics Canada.<sup>23</sup>

**Abbreviations:** APC, annual percent change; ASIR, age-standardized incidence rates.

**Note:** Rates are age-standardized to the 1991 Canadian population estimates provided by Statistics Canada.

\* $p < .01$

**FIGURE 5**  
Thyroid cancer age-standardized incidence rates,<sup>a</sup> 95% confidence intervals<sup>b</sup> and annual percent change, by province, 1992 and 2007, Canada



**Source:** The Canadian Cancer Registry database at Statistics Canada.<sup>23</sup>

**Abbreviations:** AB, Alberta; APC, annual percent change; ASIR, age-standardized incidence rates; BC, British Columbia; MB, Manitoba; NB, New Brunswick; NL, Newfoundland and Labrador; NS, Nova Scotia; ON, Ontario; PE, Prince Edward Island; QC, Quebec; SK, Saskatchewan; TR, territories i.e. Yukon, North West Territory and Nunavut.

**Note:** Rates are age-standardized to the 1991 Canadian population estimates provided by Statistics Canada.

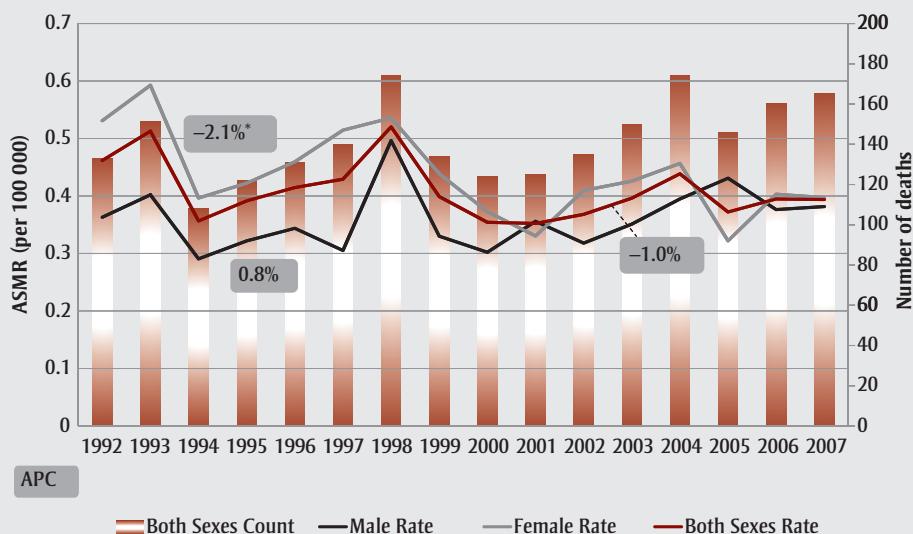
<sup>a</sup> ASIR for PE and TR suppressed for 1992 due to small numbers.

<sup>b</sup> 95% confidence intervals calculated using bootstrap variance estimates.

\* $p < .05$

\*\* $p < .01$

**FIGURE 6**  
**Thyroid cancer deaths, age-standardized mortality rates and annual percent change, 1992–2007, Canada**



**Source:** Canadian Vital Statistics Death database at Statistics Canada.<sup>25</sup>

**Abbreviations:** APC, annual percent change; ASMR, age-standardized mortality rates.

**Note:** Rates are age-standardized to the 1991 Canadian population estimates provided by Statistics Canada.

\* $p < .05$

techniques have identified the prevalent cases in the population.

## Summary

The incidence of thyroid cancer is increasing more rapidly than that of any other in Canada. The number of Canadians diagnosed with thyroid cancer has more than doubled over the past 10 years, particularly in young to middle-aged females. Part of the increase may be due to improved detection of small, indolent tumours, which is leading to the treatment of previously untreated or undiagnosed cases. Other potential risk factors, or a combination of factors, may also be associated with the rising rates. Further in-depth investigations are needed to elucidate the causes of this rapidly increasing cancer.

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# Book review

## ***Community-based Prevention: Reducing the Risk of Cancer and Chronic Disease***

**D. P. Rao, MSc**

**Authors:** David McLean, Dan Williams, Sonia Lamont, Hans Krueger

**Publisher:** University of Toronto Press, Scholarly Publishing Division

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The escalating impact of cancer and chronic disease on morbidity and mortality affect quality of life, and their impact on health care expenditures highlight the need for long-term and sustainable solutions. In “Community-based Prevention: Reducing the Risk of Cancer and Chronic Disease,” the authors explore health promotion-based programs as a solution for individual- and population-level improvements in health. Using as a template the community-based prevention educator (CPE)-led program delivered by the British Columbia Cancer Agency (BCCA), the authors analyze and compare six programs identified as having community engagement, professional leadership, regional deployment and a generalist prevention agenda at their foundation.

To convince public health policy planners to consider a prevention strategy similar to the CPE program, the authors discuss the need for upstream investments in the context of current chronic disease management requirements in Part A of the book. They then explain BCCA’s CPE-led program so that readers can understand the concepts that guided its development and implementation. Following a review of the program’s vision and purpose, organizational structure, key roles and responsibilities and approach towards

secondary prevention and special populations, the authors show how this CPE program fosters supportive environments to help individuals and populations make healthy life choices. While this bottom-up program was designed with the goal of preventing cancer, the authors recognize that cancer prevention efforts correspond with those required for broader chronic disease by virtue of their similar modifiable risk factors.

To consider which components of the BCCA program have contributed to its success and to gain insight from the achievements of similar models globally, the authors undertake case study research in Part B of their book. They analyzed six programs from five jurisdictions—two European countries, two American states and one Canadian province—starting with Finland’s North Karelia project, which was ahead of its time when implemented in the 1970s. Poverty, social and political issues, and an unhealthy diet all contributed to the region having one of the highest coronary heart disease mortality rates in the world. This robust project achieved great success and has since served as an important example for health planners.

The Health Promotion Officers from Northern Ireland’s Action Cancer charity

is the next CPE-type program the authors describe in their book. In addition to early detection initiatives and mobile screening activities, this private charity has the freedom to endorse and fundraise for initiatives, opportunities that may not always be available to public organizations.

Kentucky’s Health Education through Extension Leadership (HEEL) program and the Kentucky Cancer Program both profited from a close collaboration with the University of Kentucky. The authors observe that this allowed for two-way communication about up-to-date knowledge and evidence-informed interventions between researchers and community workers. The HEEL program’s acknowledgment of the roles that social determinants of health and sustained community ownership play in health promotion underscores the socioecological underpinnings of many health promotion programs as well as the application of diffusion and innovations theory to achieve positive outcomes. This commitment to action on the social determinants of health is paralleled in North Carolina’s Community Health Ambassador Program (CHAP), which was developed to eliminate health disparities. By recruiting community leaders to serve as health ambassadors, the program’s message is shared through

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established and trusted relationships within the community. The authors lastly discuss Health Promotion Co-ordinators from Manitoba's Chronic Disease Prevention Initiative. Given the geopolitcal barriers in this province, this project was a testament to the value of teamwork between regional health authorities and communities to, for example, provide locally adapted risk factor prevention support for First Nations communities.

Throughout Parts A and B of the book, the authors draw readers in to make them feel connected with the message of health promotion and how it can be applied in various contexts. Part B specifically focuses on the parallels and contrasts of each case study with BCCA's program and highlights any insights that may be gained. Part C then expands upon these lessons to further encourage the reader to consider the value of each insight. This section also offers a synopsis of various lessons learned and serves as a powerful resource for health planners seeking to be comprehensive in the design of their health promotion efforts. The importance of local knowledge and connections, intensive staff-to-population ratios, scalability, primary and secondary prevention efforts, university affiliation, and more are all discussed in compelling detail.

This book may have a much wider audience than the public health planners the authors identify. The book's message is relevant to public health practitioners, primary care physicians, policy experts, social workers and others. This book reinforces many of the lessons taught in population health, reinforcing the scientific foundations in an appealing format. For example, the book is very clear about the value of theory and conceptual frameworks in helping organize thinking about programs so that they may be developed in a systematic way. On the other end of the program cycle is the role of evaluation and dissemination, which are also both discussed in great detail. The authors advise for ongoing evaluation and collection of both qualitative and quantitative metrics so as to guide program delivery and assess their outcomes. The utility of evaluation in assessing efficacy, as well as in considering possible confounding

effects of secular trends, are all discussed in substantial detail.

"Community-based Prevention: Reducing the Risk of Cancer and Chronic Disease" is persuasive in its argument for CPE-type programs and provides the reader with ample opportunity to learn from various insights and extrapolate to their own planning. While the authors do present several alternate routes a planner might take, they reinforce the benefits of their approach by illustrating how disease latency and the slow onset of chronic disease make CPE-type programs a long-term investment that can leverage often modest health promotion budgets to effect far-reaching success.

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