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- r revised
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- E use with caution
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# Waiting time for medical specialist consultations in Canada, 2007

by Gisèle Carrière and Claudia Sanmartin

## Abstract

### Background

Waiting for specialist consultations can represent a substantial component of overall waiting time in the continuum of care. However, relatively little is known about the factors associated with how long patients wait for an initial specialist consultation.

### Data and methods

The analysis is based on a subsample of 5,515 respondents aged 15 or older to the 2007 Canadian Community Health Survey who had consulted a specialist about a new condition in the previous 12 months and reported a waiting time. Multivariate logistic regression models were used to identify patient- and provider-related factors associated with waiting time.

### Results

Female patients were less likely than male patients to see a specialist within a month. The nature of the new condition and the source of referral were significantly associated with waiting time. Compared with those referred by a family physician, patients referred by another specialist or a health care provider other than a physician, or who did not require a referral, were more likely to have a shorter waiting time. For men, but not women, household income and immigrant status were associated with waiting time.

### Interpretation

This analysis suggests that factors beyond medical need are associated with how long patients wait to see a specialist. More research could usefully explore decision-making and communication processes between primary care physicians and specialists to better understand how urgency is assessed, how patients are triaged for specialist consultations, and how these patterns differ among various groups of patients.

## Keywords

access to care, specialists, immigrant, socio-economic

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Accessibility is fundamental to the quality of health care. In Canada, waiting time has been identified as a key measure of access and the major barrier among those who experienced difficulties obtaining care.<sup>1,2</sup> In 2005, approximately 20% of Canadians reported adverse effects as a result of waiting for health care, including worry and stress and pain.<sup>2</sup>

Recently, numerous initiatives across Canada have endeavored to reduce waiting time for specialized health services,<sup>1,3-5</sup> particularly for non-emergency procedures in five priority areas identified in the 2004 Health Accord.<sup>6</sup> While waiting times for surgery and other procedures can be a significant barrier to care, they represent only one of the waiting periods experienced across the continuum of care.<sup>7</sup> Interest is now shifting “upstream” toward waits that occur earlier in the delivery of health care, including waiting for specialist consultations, which can account for a significant component of overall waiting time. For example, in 2005, among Canadians who had had a joint replacement, waits for an initial orthopedic specialist consultation made up nearly 30% of total waiting time.<sup>5</sup>

Despite growing interest in access to specialists, little is known about patient- and provider-related factors associated with shorter versus longer waiting times for initial consultations. Access to

specialists, like other types of health care services, may be associated with a range of factors.<sup>8</sup> Patients’ socio-economic characteristics have been related to the use of specialist services,<sup>9-13</sup> but it is not known if these characteristics are also associated with *waiting time* for specialist consultations. Provider-related variables,<sup>13,14</sup> including physicians’ decision processes in assessing urgency,<sup>15</sup> have also been related to who gets referred to specialists. But again, it is unclear if these factors are associated with how long patients wait.

Based on information from the 2007 Canadian Community Health Survey, this study examines associations between patient- and provider-related factors and the length of time patients wait to consult a specialist about a new illness or condition.

## Methods

### Data source

The data are from a subsample of respondents aged 15 or older in the 10 provinces, to whom the “Access to Care” and “Waiting Times” modules of the 2007 Canadian Community Health Survey were administered. These modules, formerly the Health Services Access Survey, were incorporated into the Canadian Community Health Survey in 2003.

The survey response rate was 75.7%. Residents of institutions, the three territories, Indian reserves, Crown lands and certain remote regions and full-time members of the Canadian Forces were excluded from the survey. Proxy responses were not permitted. Since respondents in this analysis are a subsample, the multiple sample frames of the parent survey apply. More information about the Canadian Community Health Survey is available in other reports<sup>16,17</sup> and on Statistics Canada’s website: <http://www.statcan.gc.ca/cgi-bin/imdb/p2SV.pl?Function=getSurvey&SDDS=3226&lang=en&db=imdb&adm=8&dis=2>.

The study pertains to 5,515 respondents who reported that they had consulted a specialist about a new illness or health condition in the previous 12 months and who reported a waiting time.

### Analytical techniques

Factors associated with waiting times for specialist consultations were determined with multivariate logistic regression analyses in total cohort and sex-specific models. The outcome of interest was waiting time for the initial specialist consultation, expressed as a dichotomous variable, indicating whether patients waited: 1) less than one month, or 2) longer. This cut-off was chosen based on the median waiting time (4.3 weeks). To account for the complex survey design, standard errors, coefficients of variation and 95% confidence intervals were estimated using the bootstrap technique.<sup>18,19</sup> Differences between estimates were tested for statistical

significance, established at the level of  $p < 0.05$ .

The patient-related factors hypothesized to be associated with waiting time for a specialist consultation were sex, age, education, household income, immigrant status and rural/urban residence.

Immigrants were defined as respondents who were born outside of Canada and were not Canadian citizens by birth. They were categorized according to their duration of residence in Canada: less than 10 years, or 10 or more years before the survey date.

Based on a national distribution of total household income (adjusted for household size), respondents were classified into household income quintiles.

Education is the highest level of personal educational attainment.

Waiting time for an initial specialist consultation has been shown to be related to the nature of the underlying health condition.<sup>5</sup> Therefore, adjustment was made for the type of new condition reported and the presence of chronic conditions. The chronic conditions were asthma, arthritis, cancer, diabetes, chronic obstructive pulmonary disease, heart disease, and mood disorders (depression, bipolar disorder, mania and dysthymia).

People with chronic conditions, particularly those with multiple comorbidities, often experience poorer health. This may affect the severity of the condition for which they seek care, and in turn, waiting time. To partially adjust for this possibility, respondents were classified according to the number of selected chronic conditions they reported: none, one, or two or more. In addition, respondents were identified as having (or not having) high blood pressure.

Provider-related factors were represented by two variables: having a regular doctor and the source of the specialist referral (family doctor, another specialist, another health care provider, or did not require a referral).

The multivariate models initially included province of residence, but the results did not differ from those not adjusted for province. Therefore, because of the limited sample size, province was removed from the final models to preserve statistical power.

All independent variables in the models were tested for multicollinearity.

## Results

### Characteristics of patients consulting specialists

In 2007, an estimated 3 million patients aged 15 or older reported having consulted a specialist about a new condition in the previous year (Table 1). Almost 60% of these patients were female. More than half of the patients were aged 45 or older. Men consulting specialists were slightly older than women, averaging 50 years versus 47 years (data not shown). The educational attainment and household income of patients tended to be slightly higher than those of the population overall (data not shown). Approximately 20% were immigrants, just under three-quarters of whom had been in Canada more than a decade.

The top three conditions about which specialists were consulted were gynecological conditions (12%), heart/stroke (9%), and cancer (7%), though of course, this varied by sex. Fully 21% of the women had consulted a specialist about a new gynecological condition (data not shown). Men were more likely than women to have consulted a specialist because of a new heart condition/stroke (13% versus 7%).

Slightly fewer than half the patients also had at least one chronic condition, and 17% reported multiple comorbidities.

Most of the patients (91%) who had seen a specialist had a regular doctor. Over two-thirds (68%) of the patients had been referred to the specialist by their family doctor, 11% by another specialist, 12% by another health care provider, and 9% reported that they had not needed a referral. The most common sources of referral varied by province, especially in Quebec, where almost 20% of patients

**Table 1**  
**Characteristics of patients who consulted specialist about new condition, household population aged 15 or older, Canada excluding territories, 2007**

	Sample count	Weighted estimate ('000)	Column (%)
<b>Total aged 15 or older</b>	<b>5,515</b>	<b>3,043</b>	<b>100.0</b>
<b>Sex</b>			
Male	2,035	1,226	40.3
Female	3,480	1,816	59.7
<b>Age group</b>			
15 to 34	1,138	746	24.5
35 to 44	877	588	19.3
45 to 64	2,099	1,148	37.7
65 or older	1,401	560	18.4
<b>Education</b>			
Less than secondary graduation	1,015	469	15.5
Secondary graduation	801	418	13.8
Some postsecondary	423	248	8.2
Postsecondary graduation	3,250	1,894	62.5
<b>Household income quintile</b>			
1 (lowest)	1,004	532	17.5
2	962	478	15.7
3	983	605	19.9
4	1,000	537	17.7
5 (highest)	984	580	19.1
Missing	582	311	10.2
<b>Immigrant status</b>			
Immigrant (0 to 10 years in Canada)	148	173	5.7
Immigrant (more than 10 years in Canada)	659	446	14.7
Canadian-born	4,688	2,412	79.6
<b>Residence</b>			
Urban core	3,290	2,179	71.6
Urban fringe	149	79	2.6
Urban area outside Census Metropolitan Area/ Census Agglomeration	427	130	4.3
Secondary urban core	60	46 <sup>E</sup>	1.5 <sup>E</sup>
Mix of urban and rural	815	254	8.3
Rural	774	355	11.7
<b>New condition</b>			
Gynecological condition	598	372	12.2
Heart condition/Stroke	530	279	9.2
Cancer	373	212	7.0
Skin condition	323	180	5.9
Cataract or other eye condition	320	164	5.4
Arthritis/Rheumatism	196	93	3.1
Mental health disorder	183	103	3.4
Asthma or other breathing condition	126	66	2.2
Other	2,852	1,567	51.5
<b>High blood pressure<sup>†</sup></b>			
No	4,046	2,381	78.4
Yes	1,459	657	21.7
<b>Number of selected chronic conditions<sup>‡</sup></b>			
None	2,603	1,602	53.2
One	1,775	903	30.0
2 or more	1,076	504	16.8
<b>Has regular family doctor</b>			
Yes	5,132	2,766	90.9
No	382	275	9.1
<b>Source of specialist referral</b>			
Family doctor	4,012	2,061	67.9
Other specialist	570	339	11.1
Other health care provider	571	372	12.2
Did not require referral	352	263	8.7

<sup>†</sup> excluded from count of chronic conditions

<sup>‡</sup> selected chronic conditions were asthma, arthritis, cancer, chronic obstructive pulmonary disease, diabetes, heart disease, mood disorders (depression, bipolar disorder, mania, dysthymia)

<sup>E</sup> use with caution (coefficient of variation 16.6% to 33.3%)

**Notes:** Estimates are based on population who completed initial consultation with medical specialist in previous 12 months and provided information about waiting time. Except for total household income, analyses exclude non-response ("don't know," "not stated," "refusal").

**Source:** 2007 Canadian Community Health Survey.

reported that they had been referred by a health care provider who was not their family doctor or another specialist, and 17% had not required a referral (Table 2).

### Distribution of waiting times

Nearly half (46%) of the patients had waited less than a month for their initial specialist consultation (Table 2). An additional 40% waited one to three months, and 14% waited more than three months. The percentage who saw the specialist within a month varied from 37% in Newfoundland and Labrador and Manitoba to 51% in Quebec. Just under half (49%) of those who required a consultation for a new mental health condition waited less than a month.

The length of the wait depended on the nature of the new condition. Not surprisingly, patients with potentially life-threatening illnesses were the most likely to have seen a specialist within a month. Almost 60% of those with a heart condition/stroke or cancer waited less than a month for their initial consultation, compared with 29% of those with arthritis/rheumatism (Table 3). Just under half (49%) of those who required a consultation for a new mental health condition waited less than a month.

Overall, 51% of male patients with a new condition waited less than a month for their initial consultation. However, 63% of men with a new heart condition/stroke saw a specialist within a month, as did 56% of those with cancer, 55% with eye conditions, and 52% with mental disorders.

Compared with men, a lower percentage (42%) of female patients had their first specialist consultation within a month. Again, the likelihood of a short wait varied with the condition. More than half of those with cancer (57%) or a heart condition/stroke (55%) had their first consultation within a month. On the other hand, relatively small percentages with gynecological conditions (39%), skin conditions (39%) or arthritis/rheumatism (25%) waited less than a month.

Table 2

Unadjusted percentage distribution of waiting times and of referral sources to consult specialist about new condition, by province, household population aged 15 or older, Canada excluding territories, 2007

Province	Sample count	Weighted estimate	Waiting time				Waited longer than median	Referral source			
			Less than 1 month	1 to 3 months	3 month or longer	Family doctor		Other specialist	Other health care provider	Did not require referral	
			Number	'000	%						
<b>Total</b>	<b>5,515</b>	<b>3,043</b>	<b>45.6</b>	<b>40.5</b>	<b>13.9</b>	<b>39.1</b>	<b>67.9</b>	<b>11.2</b>	<b>12.2</b>	<b>8.7</b>	
Newfoundland and Labrador	217	49	37.0*	41.7	21.4*	49.3*	69.0	12.1 <sup>E</sup>	11.0 <sup>E</sup>	F	
Prince Edward Island	173	13	44.6	44.3	11.1 <sup>E</sup>	41.7	77.8*	8.8 <sup>E</sup>	9.1 <sup>E</sup>	F	
Nova Scotia	322	99	47.6	37.6	14.8 <sup>E</sup>	39.7	78.7*	10.2 <sup>E</sup>	4.5 <sup>E*</sup>	6.6 <sup>E</sup>	
New Brunswick	284	76	44.3	37.9	17.8 <sup>E</sup>	45.2	73.6	8.8 <sup>E</sup>	9.5 <sup>E</sup>	8.1 <sup>E</sup>	
Quebec	520	711	51.0*	36.9	12.2	33.3*	46.2*	17.5*	19.8*	16.5*	
Ontario	2,391	1,195	44.7	40.7	14.5	40.2	72.4*	10.2	11.0	6.4*	
Manitoba	365	108	37.2*	48.8*	14.0 <sup>E</sup>	47.2*	76.7*	6.8 <sup>E*</sup>	9.2 <sup>E</sup>	7.4 <sup>E</sup>	
Saskatchewan	363	81	46.3	38.8	15.0 <sup>E</sup>	43.3	78.1*	10.8 <sup>E</sup>	7.9 <sup>E*</sup>	F	
Alberta	403	314	41.8	45.9	12.4 <sup>E</sup>	40.8	75.4*	8.1 <sup>E</sup>	9.1 <sup>E</sup>	7.4 <sup>E</sup>	
British Columbia	477	396	44.4	41.1	14.6	39.5	78.5*	7.1 <sup>E*</sup>	9.5 <sup>E</sup>	4.9 <sup>E*</sup>	

\* significantly different from estimate for "rest of Canada" which represents all respondents not in province indicated ( $p < 0.05$ )

<sup>E</sup> use with caution (coefficient of variation 16.6% to 33.3%)

F too unreliable to be published (coefficient of variation greater than 33.3%)

Notes: Estimates are based on population who completed initial consultation with medical specialist in previous 12 months and provided information about waiting time. Analyses exclude non-response ("don't know," "not stated," and "refusal").

Source: 2007 Canadian Community Health Survey.

Table 3

Unadjusted percentage distribution of waiting times to consult specialist about new condition, by nature of new condition, household population aged 15 or older, Canada excluding territories, 2007

New condition	Waiting time			Less than 1 month	
	Less than 1 month	1 to 3 months	3 month or longer	Males	Females
	<b>Total</b>	<b>45.6</b>	<b>40.5</b>	<b>13.9</b>	<b>51.0</b>
Heart condition/Stroke <sup>†</sup>	59.3	33.3	7.4 <sup>E</sup>	63.3	54.5
Cancer	56.8	30.5	12.7 <sup>E</sup>	56.3	57.2
Mental health disorder	48.7	36.6	14.7 <sup>E</sup>	51.5	47.2 <sup>E</sup>
Cataract or other eye condition	46.4*	39.6	14.1 <sup>E*</sup>	54.6	41.8
Asthma or other breathing condition	45.0*	45.6	9.5 <sup>E</sup>	x	43.7 <sup>E</sup>
Other	44.4*	41.7*	13.9*	48.7*	40.6*
Skin condition	42.2*	42.6	15.2 <sup>E*</sup>	45.4*	39.0*
Gynecological condition	39.1*	46.3*	14.6*	...	39.1*
Arthritis/Rheumatism	28.9*	40.1	31.0*	x	24.6 <sup>E*</sup>

<sup>†</sup> reference group

\* significantly different from estimate for reference group ( $p < 0.05$ )

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Notes: Estimates are based on population who completed initial consultation with medical specialist in previous 12 months and provided information about waiting time. Analyses exclude non-response ("don't know," "not stated," and "refusal").

Source: 2007 Canadian Community Health Survey.

### Unadjusted bivariate results

Unadjusted analyses for the entire subsample suggest that, in addition to gender and the nature of the new condition, several other factors were

associated with waiting time for specialist consultations (Table 4).

People with high blood pressure were less likely than those not afflicted to be seen within a month. Comparatively high percentages of patients without a

regular medical doctor and those who were referred by someone other than a family doctor or who did not need a referral waited less than a month.

Unadjusted sex-specific analyses show that among female patients, waiting less than a month was significantly associated with only two variables: the nature of the new condition and referral source. However, among male patients, in addition to the nature of the condition and referral source, not having high blood pressure or a regular family doctor and being an immigrant were associated with waiting less than a month.

### Multivariate logistic regression results

Results from the full model indicate that even when the influence of the other variables was controlled, female patients were significantly less likely than male patients to see a specialist in less than a month. And as expected, for both sexes, the nature of the new condition was significantly associated with waiting time: compared with those who had a new heart condition/stroke, the odds of seeing a specialist within a month were



## ***What is already known on this subject?***

- Waiting time for an initial consultation with a specialist can constitute a substantial part of the continuum of care.
- Little known about factors associated with waiting time for specialist consultations.

## ***What does this study add?***

- This study identifies factors associated with shorter versus longer waiting times for specialist consultations.
- As might be expected, the nature of the health condition prompting the consultation was significantly associated with how long patients waited.
- Women tended to wait longer than men.
- For both sexes, waiting time varied significantly depending on the source of referral.
- For men only, household income and immigrant status were significant factors in waiting time.

significantly lower for men and women with skin and eye conditions and arthritis/rheumatism. As well, men with asthma or other breathing conditions and women with gynecological conditions had lower odds of consulting a specialist within a month.

The sex-specific multivariate results also confirm the importance of referral source in waiting times for both male and female patients. Compared with patients referred by their family doctor, those referred by another specialist or another health care provider had about twice the odds of seeing a specialist within a month. And among patients who indicated no referral was required,

the odds of seeing a specialist within a month were five times higher for men and almost four times higher for women, compared with those referred by their family doctor.

For men, but not women, several other factors were significantly associated with waiting time to see a specialist. Among male patients, the odds of seeing a specialist within a month were twice as high for those who had immigrated more than 10 years earlier than for those who were Canadian-born. As well, male patients reporting high blood pressure had significantly low odds of seeing a specialist within a month, compared with those without high blood pressure. Household income was also significant for male patients. Compared with men in the top income quintile, those in the lowest were less likely to see a specialist within a month. Yet this was also true for men in the second-highest quintile.

## **Discussion**

This national study identifies patient- and provider-related factors associated with waiting time for an initial specialist consultation about a new condition. Not surprisingly, waiting time varied with the nature of that condition, with generally shorter waits for those that were potentially life-threatening. But even when the influence of this variable was taken into account, the results highlight significant differences in waiting times by sex, source of referral, and for male patients, household income and immigration status.

Women were significantly less likely than men to see a specialist within a month. This could result from systemic gender biases in access to health care services, evidence of which has previously been demonstrated. For example, gender differences in access to primary care for heart disease have been reported,<sup>20-22</sup> including physicians' diagnostic and management practices.<sup>22</sup> Differential access to specialized cardiovascular care based on non-clinical patient attributes, such as social status, has also been reported.<sup>23</sup>

However, the disparity between male and female patients in waiting time may reflect differences in the severity of the condition that prompted the specialist consultation. Because information about the patients' health status before the visit is limited, and no measure of the severity of the new condition is available, it was not possible to fully adjust for health status. It may be that men's shorter waiting time for specialist consultations was attributable to more advanced conditions. Men are less likely than women to use physician services or to have a regular family doctor,<sup>12,24</sup> and consequently, may have less continuity of primary care. As a result, men may present at more advanced stages of disease and require expedited specialist consultations.

Differences in specialist waiting time by immigration status among male patients could also reflect greater severity of the emergent health condition. This is consistent with well-known associations between immigration status and changes to health over time, as well as differences in the use of and access to care among the immigrant population. Immigrants tend to have lower health literacy,<sup>25</sup> which may contribute to less use of preventive care. For example, significantly lower rates of cancer screening have been found among visible minorities, a large proportion of whom are immigrants.<sup>26</sup> And although recent immigrants tend to be in better health than the Canadian-born population, over time they are more likely to report health deterioration.<sup>27</sup> Therefore, the differences among men in waiting time for specialist consultations by immigrant status may be attributable to medical need.

Finally, the results of this study demonstrate the importance of the referral source in specialist waiting time. There may be several explanations. First, the referral source may indicate the point at which a patient is located in the pathway of diagnosis and treatment. The question on the Canadian Community Health Survey pertained to waiting time for a specialist consultation in the previous 12 months, but the specific visit

about which the respondent answered might have resulted from prior visits to other specialists to confirm a diagnosis. This process may have yielded greater diagnostic certainty, and perhaps, influenced assessed urgency. General practitioners often use referrals to obtain assistance with diagnoses or advice about therapy.<sup>28</sup> Therefore, diagnostic uncertainty may be involved when a family physician is the referral source, and may affect assessed urgency. As well, suboptimal communication between general practitioners and specialists has been cited as a difficulty in the referral process.<sup>29</sup> Recently, referral tools have been developed to improve and standardize communications between general practitioners and specialists.<sup>15</sup>

Respondents who reported not needing a referral had much higher odds of seeing the specialist within a month, compared with those referred by a family doctor. To some extent, this may be attributable to provincial variations in how services are organized, especially in Quebec. Relatively high percentages of Quebec residents reported referral sources other than family doctors or self-referrals. According to recent data,<sup>24</sup> Quebec residents are less likely than people in other provinces to have a regular family doctor, and so may rely on nurses<sup>30</sup> or other health care professionals working in primary health care teams in community health centres. This, in turn, may facilitate referral to specialists.

### **Limitations**

The distribution of waiting times reported to the Canadian Community Health Survey was skewed. To attempt to preserve the continuous nature of the data, a logarithmically transformed, continuous dependent variable using linear regression was employed. But because respondents could report waiting times in days, weeks or months, and because they tended to round responses, especially for longer waits, these models were difficult to fit. Consequently, a dichotomous outcome was derived, and logistic regression analyses were used.

The study is based on self-reported data that were not clinically validated and may be subject to recall bias.

As well, if respondents interpreted the question, "In the past 12 months, did you require a visit to the specialist for a diagnosis or consultation for a new illness or condition?" to mean that both the occurrence of the new illness and the consultation arose within the past 12 months, some respondents with long waiting times may not have been captured.

Clinical need is a crucial indicator of waiting time for health care services, so it was expected that those in greater need would wait less time for a specialist consultation. However, it was not possible to fully adjust for the need for

services because information about the severity of the new or existing conditions is not available from these data.

### **Conclusion**

Waiting time for specialist services represents a key indicator of access to health care in Canada. Data from the Canadian Community Health Survey provide a unique opportunity to explore factors associated with how long patients wait for specialist care.

The results of this study suggest that, in addition to the nature of the new condition, gender and referral source are associated with obtaining a consultation within a month. And for males, household income and immigration status are also significant.

This is only a preliminary examination of factors related to waiting time for specialist consultations; more research is obviously required. In particular, given the apparent importance of the source of referral, future analyses might focus on decision-making and communication processes to determine how urgency is assessed and how patients are triaged for specialist consultations. The findings from this and subsequent research may be relevant to a better understanding of the role of different health care providers in accessing specialists and how these processes vary across patient groups. ■

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# Blood pressure in Canadian children and adolescents

by Gilles Paradis, Mark S. Tremblay, Ian Janssen, Arnaud Chiolero and Tracey Bushnik

## Abstract

### Background

Because blood pressure (BP) tracks from childhood to adulthood, assessing levels in youth is relevant. There are no recent BP data for Canadian children and adolescents, and past studies have used a variety of design and measurement devices.

### Data and methods

With a clinically validated oscillometric device, resting BP was measured in 2,079 respondents aged 6 to 19 years from the Canadian Health Measures Survey. The average of the last five of six BP measures taken one minute apart at a single visit was used in this report. Borderline or elevated BP was defined as greater than or equal to the 90th percentile of US reference values for participants aged 6 to 17 years. Borderline or elevated BP for 18- to 19-year-olds was defined as equal to or greater than 120 systolic BP or equal to or greater than 80 diastolic BP. Participants of any age who reported taking antihypertensive medication in the past month were also defined as having elevated BP.

### Results

At ages 6 to 11 years, mean (standard error) systolic/diastolic blood pressure was 93(0)/61(1) in boys and 93(0)/60(0) mmHg in girls, and at ages 12 to 19 years, 101(1)/63(1) and 98(1)/63(1) mmHg, respectively. An estimated 2.1% (95% confidence interval 1.3% to 3.0%) of Canadian children and youth had borderline levels; 0.8% (0.4% to 1.4%) had elevated BP.

### Interpretation

Despite the prevalence of obesity among young people, BP levels were lower than reported in provincial samples, which may, in part, reflect differences in methodologies and measurement instruments.

## Keywords

diastolic pressure, hypertension, obesity, overweight, survey, systolic pressure

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No nationally representative blood pressure (BP) data for Canadian children and adolescents have been collected since the 1978 Canada Health Survey.<sup>1</sup> With the results of the 2007-2009 Canadian Health Measures Survey (CHMS), launched by Statistics Canada in partnership with Health Canada and the Public Health Agency of Canada, it is possible to address this data gap.<sup>2-5</sup> The CHMS is the most comprehensive direct health measures survey ever conducted in Canada. In addition to a detailed health interview, the survey involves direct measurement of indicators and of risk factors for chronic diseases, infectious diseases, environmental exposures, nutritional status, physical activity and physical fitness.<sup>2-5</sup>

Elevated BP is one of the most important causes of death and disability worldwide,<sup>6</sup> accounting for 7.6 million premature deaths and 92 million disability-adjusted life years annually. In adolescence, hypertension is associated with increased left ventricular mass, diastolic dysfunction,<sup>7</sup> fatty streaks and fibrous plaques in the coronary arteries and the aorta,<sup>8</sup> and arterial wall thickening.<sup>9</sup> BP levels track from childhood to adulthood,<sup>10,11</sup> indicating that elevated BP at young ages is a risk factor for the development of hypertension in

adulthood. The strength of BP tracking increases with body mass index (BMI), such that tracking is strongest in overweight and obese youth.<sup>12,13</sup>

Population information about BP levels in children and adolescents can be useful from a public health and clinical perspective to guide prevention planning, help establish norms, and monitor trends over time. However, Quebec is the only Canadian province to have relatively recent measures for youth: in 1999, 12% to 23% of youth aged 9, 13 and 16 years had high-normal or elevated

BP.<sup>9</sup> A 2004 study of BP levels among American youth found that from 1988-1994 to 1999-2000, mean systolic blood pressure (SBP) increased 1.4 mmHg, and mean diastolic blood pressure (DBP) increased 3.3 mmHg.<sup>15</sup> A longer-term review of trends in American youth from 1963 to 2002 also demonstrated a slight upturn in the prevalence of elevated BP in the last decade.<sup>16</sup> But such findings have not been consistent. For example, a study of 15-year-old Russian adolescents between 1995 and 2004 found a significant decrease in DBP among boys, and a significant decrease in SBP among both sexes.<sup>17</sup> As well, comparisons of results from past studies are complicated by different survey methods, including different measurement devices.

Based on data from the 2007-2009 CHMS, this study presents BP distributions and estimates of elevated BP for a representative sample of Canadian children and adolescents aged 6 to 19 years.

## Methods

### Data source

Data are from cycle 1 of the Canadian Health Measures Survey (CHMS), which collected information at 15 sites from March 2007 through February 2009. The CHMS covered the population aged 6 to 79 years living in private households. Residents of Indian Reserves or Crown lands, institutions and certain remote regions and full-time members of the regular Canadian Forces were excluded. Approximately 96.3% of Canadians were represented.<sup>18</sup>

Health Canada's Research Ethics Board gave ethics approval to conduct the survey. Informed written consent was obtained from respondents aged 14 years or older. For younger children, a parent or legal guardian provided written consent, in addition to written assent from the child. Participation was voluntary; respondents could opt out of any part of the survey at any time.

The response rate for households selected for inclusion in the CHMS was 69.6%—meaning that in 69.6% of

selected households, the sex and date of birth of all household members were provided by a household resident. In each responding household, one or two members were chosen to participate; 88.5% of selected 6- to 19-year-olds completed the household questionnaire, and 86.9% of those who completed the questionnaire participated in the subsequent examination centre component. The final response rate for 6- to 19-year-olds, after adjusting for the sampling strategy, was 53.5%. This article is based on 2,079 examination centre respondents aged 6 to 19 years (after removing 8 with missing BP data) (Appendix Table A).

### Measures

At the respondent's home, an interviewer administered a questionnaire covering socio-demographic characteristics, medical history, current health status and lifestyle behaviours (Table 1). In the chronic conditions component of the questionnaire, respondents aged 12 years or older were asked if they had high BP (diagnosed by a health professional and expected to last or had already lasted six months or more) and if they had taken "medicine for high blood pressure" in the past month.

One day to six weeks after the home interview, the respondent visited a mobile examination centre for a battery of physical measurements, including anthropometry, BP, heart rate, spirometry, physical fitness, oral health and biospecimen collection.<sup>4</sup> BMI was calculated as weight in kilograms divided by height in meters squared ( $\text{kg}/\text{m}^2$ ), and respondents were classified as overweight, obese, or neither.<sup>19,20</sup> BP was measured after urine collection, but before blood collection and fitness testing.<sup>4</sup>

BP and heart rate were measured with the BpTRU™ BP-300 (BpTRU Medical Devices Ltd., Coquitlam, British Columbia). The BpTRU™, an automated electronic monitor, automatically inflates and deflates the upper-arm cuff and uses an oscillometric technique to calculate

SBP and DBP. It has passed international validation protocols for accuracy.<sup>21,22</sup>

An advantage of an automated device is that it enables BP to be measured in the absence of another person, thereby eliminating observer errors such as digit bias, zero preference and incorrect deflation rates, and reducing "white-coat hypertension" (a rise in BP associated with the presence of the health care professional and the measurement procedures).<sup>23</sup> For more detailed information on the procedures and protocol, including staff training, equipment calibration, and quality assurance and control, see *Resting blood pressure and heart rate measurement in the Canadian Health Measures Survey cycle 1*.<sup>24</sup>

### Definitions

Measures of SBP and DBP were calculated as the average of the first set (last five of six measures taken one minute apart) of valid BP measurements.<sup>24</sup> For those aged 6 to 17 years, based on age and sex, each respondent's height and average SBP and DBP were converted to z-scores, which were used to calculate individual BP percentiles as per the equations in Appendix B of the fourth report of the National High Blood Pressure Education Program Working Group on High Blood Pressure in Children and Adolescents (NHBPEP4).<sup>25</sup> With these calculated percentiles, children and youth in this age group were classified into BP categories. As well, respondents who reported taking medicine for high BP in the past month were classified as having "elevated" BP, regardless of their BP percentile value (fewer than 10 respondents). The seventh report of the Joint National Committee on Prevention, Detection, Evaluation and Treatment of High Blood Pressure (JNC7) was used to classify youth aged 18 or 19 years.<sup>26</sup> The NHBPEP4 classification parallels that of the JNC7.

*Normal BP* for respondents aged 6 to 17 years was defined as a calculated SBP percentile and DBP percentile less than the 90<sup>th</sup> percentile. For respondents

aged 18 or 19 years, it was defined as a measured mean SBP less than 120 mmHg and a measured mean DBP less than 80 mmHg. This corresponds to the “normal” category proposed by the NHBPEP4 and JNC7.

**Borderline BP** for respondents aged 6 to 17 years was defined as a calculated SBP percentile or DBP percentile greater than or equal to the 90<sup>th</sup> percentile, but less than the 95<sup>th</sup> percentile, or a measured SBP/DBP greater than 120/80 mmHg, even if less than the 90<sup>th</sup> percentile. For respondents aged 18 or 19 years, it was defined as a measured mean SBP of 120 to 139 mmHg and a measured mean DBP of 80 to 89 mmHg; or SBP of 120 to 139 mmHg and DBP lower than 80 mmHg; or SBP lower than 120 mmHg and DBP 80 to 89 mmHg. This corresponds to the “prehypertension” category proposed by the NHBPEP4 and JNC7.

**Elevated BP** for respondents aged 6 to 17 years was defined as a calculated SBP percentile or DBP percentile greater than or equal to the 95<sup>th</sup> percentile, or the respondent’s report of using BP medication in the past month. For respondents aged 18 or 19 years, elevated BP was defined as a measured mean

SBP/DBP of 140/90 mm Hg or higher, or the respondent’s report of BP medication use in the past month. This corresponds to the “Stage 1 or Stage 2 hypertension” category proposed by the NHBPEP4 and JNC7.

**Analytical techniques**

Weighted data were analyzed separately by sex and age. Estimates of proportions, means, standard errors, and percentiles were produced. Standard errors, coefficients of variation and 95% confidence intervals (CI) were estimated using bootstrap weights to account for the complex survey design of the CHMS.<sup>27,28</sup> Gender differences in SBP and DBP were tested using t-tests. Analyses were conducted with SUDAAN.

**Results**

Mean SBP (standard error) rose with age from 91(1) mmHg among boys aged 6 to 7 years to 104(1) mmHg at 18 to 19 years; for girls, the increase was from 92(1) to 99(1) mmHg (Table 2). Mean SBP was similar in boys and girls from ages 6 to 7 through 10 to 11 years, and also at 14 to 15 years. However, at 12

to 13 years and 16 through 19 years, mean SBP was higher in boys (p<0.01). Median SBP was very close to the mean in all age/sex categories.

The sample size was too small to obtain percentile values by single-year-of-age or 95<sup>th</sup> percentile values for most two-year age groups. At ages 6 to 11 years, the 95<sup>th</sup> percentile (95% CI) for SBP was 105 (102 to 107) mmHg among boys and 106 (104 to 108) mmHg among girls; at ages 12 to 19 years, the 95<sup>th</sup> percentile for SBP was 116 (113 to 119) mmHg among boys and 111 (108 to 114) mmHg among girls.

Mean DBP also rose with age, but not as much as SBP (Table 3). From ages 6 to 7 to 18 to 19 years, mean DBP increased from 59(1) to 65(1) mmHg among boys and from 60(1) to 64(1) among girls. Mean DBP was similar in both sexes. Median DBP was very close to the mean in all age/sex groups.

In 2007-2009, few Canadian children and adolescents had borderline or elevated BP: 3.7% (2.3% to 6.0%) at ages 6 to 11 years and 2.2% (1.2% to 4.0%) at 12 to 19 years (Table 4).

Mean SBP was higher among children and adolescents who were overweight or

**Table 1**  
**Selected characteristics of sample (weighted), by age group and sex, household population aged 6 to 19 years, Canada, March 2007 to February 2009**

	Age group (years)											
	6 to 11					12 to 19						
	Boys	95% confidence interval		Girls	95% confidence interval		Boys	95% confidence interval		Girls	95% confidence interval	
from		to	from		to	from		to	from		to	
Mean age (years)	8.6	8.2	9.0	8.7	8.5	8.9	15.2	15.0	15.5	15.7	15.5	16.0
Measured body mass index (kg/m <sup>2</sup> )	17.9	17.5	18.2	17.7	17.2	18.1	22.6	21.6	23.6	22.4	21.7	23.0
Overweight† (%)	17.3	13.5	21.9	16.3	11.6	22.4	18.0	14.6	21.9	17.6	13.5	22.7
Obese† (%)	7.1	5.1	9.8	5.8 <sup>E</sup>	3.2	10.1	12.3 <sup>E</sup>	6.6	21.7	8.3	5.8	11.6
Smoke daily (%)	...	...	...	...	...	...	8.0 <sup>E</sup>	4.0	15.2	6.8 <sup>E</sup>	3.3	13.4
Physically active†† (%)	84.5	80.8	87.6	82.5	79.0	85.6	77.4	69.3	83.9	65.0	59.5	70.2
Immediate family history of high blood pressure (%)	12.6	8.8	17.7	15.9	12.0	20.8	25.8	20.3	32.2	22.1	16.3	29.3
Household education more than secondary graduation (%)	88.5	84.6	91.5	85.3	79.1	89.9	86.6	83.4	89.2	83.0	74.2	89.2
Household type - couple with children (%)	82.6	77.1	87.1	79.4	72.9	84.6	72.5	65.7	78.4	76.3	68.5	82.7
Low household income††† (%)	7.7 <sup>E</sup>	4.4	12.9	6.5 <sup>E</sup>	3.8	11.1	5.4 <sup>E</sup>	3.0	9.6	11.2 <sup>E</sup>	7.1	17.2
Born in Canada (%)	92.4	81.8	97.0	92.0	81.8	96.7	90.5	77.5	96.4	88.3	80.2	93.3

† 18- to 19-year-olds classified as overweight (BMI 25 to 29.9 kg/m<sup>2</sup>) or obese (BMI 30 kg/m<sup>2</sup> or more)(Source: Health Canada. *Canadian Guidelines for Body Weight Classification in Adults* (Catalogue H49-179) Ottawa: Health Canada, 2003); 6- to 17-year-olds classified as overweight or obese based on definitions proposed by International Obesity Task Force (Source: Cole TJ, Bellizzi MC, Flegal KM, et al. Establishing a standard definition for child overweight and obesity worldwide: international survey. *British Medical Journal* 2000; 320(7244): 1240-3).

†† for ages 6 to 11, physically active for at least 60 minutes 4 or more days in typical week; for ages 12 to 19, categorized as “active” or “moderately active according to Physical Activity Index

††† based on household size and income range; denominator is 1,920 respondents with valid household income value

<sup>E</sup> interpret with caution (coefficient of variation 16.6% to 33.3%)

... not applicable

Source: 2007 to 2009 Canadian Health Measures Survey.



**Table 4**  
Percentage distribution of measured blood pressure status, by sex and age group, household population aged 6 to 19 years, Canada, March 2007 to February 2009

	Sample size	%	95% confidence interval	
			from	to
<b>Total</b>				
Normal	2,019	97.2	96.1	98.0
Borderline	47	2.1 <sup>E</sup>	1.3	3.1
Elevated	13	0.8 <sup>E</sup>	0.4	1.4
<b>Boys</b>				
Normal	1,019	96.9	95.7	97.7
Borderline or elevated	32	3.1	2.3	4.3
<b>Girls</b>				
Normal	1,000	97.6	95.9	98.6
Borderline or elevated	28	2.4 <sup>E</sup>	1.4	4.1
<b>6 to 11 years</b>				
Normal	1,029	96.3	94.0	97.7
Borderline or elevated	38	3.7 <sup>E</sup>	2.3	6.0
<b>12 to 19 years</b>				
Normal	990	97.8	96.0	98.8
Borderline or elevated	22	2.2 <sup>E</sup>	1.2	4.0

<sup>E</sup> interpret with caution (coefficient of variation 16.6% to 33.3%)

**Notes:** For respondents aged 6 to 17 years, blood pressure status was derived using the methodology outlined in Appendix B of The Fourth Report on the Diagnosis, Evaluation, and Treatment of High Blood Pressure in Children and Adolescents, *Pediatrics* 2004; for respondents aged 18 to 19, the classification in the seventh report of the *Joint National Committee on Prevention, Detection, Evaluation and Treatment of High Blood Pressure* was used.

**Source:** 2007 to 2009 Canadian Health Measures Survey.

obese (Table 5). The SBP differences between BMI categories reached statistical significance among boys aged 12 to 19 years, girls aged 6 to 11 years, and in both age groups when the genders were combined. Differences in DBP by BMI category were less apparent, reaching statistical significance only among obese boys aged 12 to 19 years.

## Discussion

The main finding of this analysis is the remarkably low overall prevalence of borderline or elevated BP among Canadian children and adolescents.

However, echoing the results of other studies,<sup>14,15</sup> mean SBP was significantly higher among boys aged 12 to 19 years and girls aged 6 to 11 years who were overweight or obese. Excess weight is believed to influence BP through increased sympathetic nervous system activation, which is associated with SBP. The association of weight with DBP was much less pronounced.

The generally low levels of BP obtained from the CHMS appear inconsistent with the rise of childhood and adolescent obesity in Canada.<sup>29,30</sup> And despite a trend toward excess weight among youth in other countries, BP levels have not shown consistent increases.<sup>31</sup>

Hence, population-level increases in BP may not necessarily be a consequence of rising weight. More research is required to explain this apparent paradox.

For each age and sex category, mean child and adolescent SBP in Canada was about 10 mmHg lower than the most recent United States National Health and Nutrition Examination Survey (NHANES) data.<sup>32</sup> The only other recent BP data from a large, representative sample of youth in Canada were collected in 1999 by the Quebec Child and Adolescent Health and Social Survey (QCAHS) from respondents aged 9, 13 and 16 years.<sup>14</sup> Compared with the results of the QCAHS, mean SBP at these ages in the CHMS was 9, 16 and 20 mmHg lower in boys, and 8, 17 and 16 mmHg lower in girls.

CHMS values for DBP generally exceeded the NHANES results, with a mean difference of 5 mmHg higher in boys and 2 mmHg higher in girls. And compared with the QCAHS, the CHMS values were 8, 7 and 7 mmHg higher in boys aged 9, 13 and 16 years, respectively, and 9, 5 and 7 mmHg higher among girls of the same ages.<sup>14</sup>

Differences in measurement instruments and procedures may, in part, explain the disparities in BP levels in the three surveys. The CHMS used

**Table 5**  
Mean measured value of systolic (SBP) (mm/Hg) and diastolic blood pressure (DBP) (mm/Hg), by age group, sex and body mass index (BMI) category, household population aged 6 to 19 years, Canada, March 2007 to February 2009

	Systolic blood pressure								Diastolic blood pressure							
	6 to 11 years				12 to 19 years				6 to 11 years				12 to 19 years			
	Sample size	Mean	95% confidence interval		Sample size	Mean	95% confidence interval		Sample size	Mean	95% confidence interval		Sample size	Mean	95% confidence interval	
		from	to			from	to			from	to			from	to	
<b>Total</b>																
Neither overweight nor obese <sup>†</sup>	836	92	91	93	751	98	96	99	836	60	59	61	751	63	61	64
Overweight	159	97*	93	100	180	101*	99	104	159	62	58	65	180	63	61	65
Obese	71	97*	94	101	77	106*	103	109	71	62	59	65	77	65	62	68
<b>Boys</b>																
Neither overweight nor obese <sup>†</sup>	413	92	91	93	378	99	97	100	413	60	59	61	378	62	61	63
Overweight	86	97	92	102	94	104*	100	107	86	62	57	68	94	64	61	67
Obese	38	97	91	102	40	108*	104	112	38	63	58	68	40	66*	63	70
<b>Girls</b>																
Neither overweight nor obese <sup>†</sup>	423	92	91	93	373	97	95	98	423	60	59	61	373	63	61	65
Overweight	73	97*	94	99	86	99	96	102	73	61	58	63	86	63	60	65
Obese	33	98*	95	101	37	103	98	107	33	61	58	64	37	64	60	68

<sup>†</sup> reference category

\* significantly different from reference category p<.025 (Bonferroni corrected)

**Notes:** BMI categories for ages 6 to 17 are based on the Cole cut-points. BMI categories for ages 18 and 19 years are based on the World Health Organization cut-points.

**Source:** 2007-2009 Canadian Health Measures Survey.

the BpTRU™ device; QCAHS used the DINAMAP (Critikon Co, FL) device; and NHANES used mercury sphygmomanometers. The last has been the gold standard for BP assessment for many years, but its use in children is decreasing because mercury-containing instruments are being removed from pediatric environments, and because

auscultatory methods are subject to various biases (digit preference, rounding, white coat hypertension, etc.). The substantial differences between the CHMS and QCAHS may be due to opposing systematic differences between BP measured by mercury manometers and by the DINAMAP and the BpTRU. The DINAMAP has been reported to overestimate SBP by about 10 mmHg and slightly underestimate DBP, whereas the BpTRU may slightly underestimate DBP (by 2.1 mmHg), compared with the mercury manometer.<sup>33</sup> Most cases of borderline or elevated BP among CHMS participants had diastolic rather than systolic elevation, whereas clinically, most reported cases of pediatric hypertension are the result of an increase in SBP, thought to reflect, at least in part, hyperactivity of the sympathetic nervous system. Counterintuitively, children aged 6 to 11 years were somewhat more likely to have borderline or elevated BP than were adolescents aged 12 to 19 years.

The CHMS procedures may also have contributed to lower mean SBP. Measurement in a quiet room and in the absence of staff may have been conducive to maximal subject relaxation, which could decrease sympathetic activation and lower SBP. By contrast, the QCAHS measurements took place in school settings, usually a room where other survey-related measures were going on and in the presence of a staff member recording BP readings.<sup>14,34</sup>

### Limitations

The overall CHMS response rate was slightly above 50%. Although survey weights were adjusted to the socio-demographic characteristics of the Canadian population, it was not possible to adjust for many factors that could be associated with BP levels. Selection bias would be present if the BP levels of non-participants differed systematically from those of participants. In addition, the

logistical and cost constraints associated with the use of mobile examination centres restricted the number of collection sites to 15.<sup>18</sup> Whether this sampling strategy affected the results is unknown.

### Conclusion

A small percentage of Canadians aged 6 to 19 years have borderline or elevated BP. More research is required to improve our understanding of BP levels and their determinants in order to help maintain healthy levels over the life-course. ■

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### *What is already known on this subject?*

- Elevated blood pressure (BP) is an important cause of disability and death worldwide.
- Elevated BP at young ages is a risk factor for the development of hypertension in adulthood.
- The strength of BP tracking increases with body mass index.
- No nationally representative BP data for Canadian children and adolescents have been collected since the 1978 Canada Health Survey.

### *What does this study add?*

- Based on data from the 2007-2009 Canadian Health Measures Survey, an estimated 0.8% of Canadians aged 6 to 19 had elevated BP, and 2.1% had borderline levels.
- The differences in mean systolic BP between BMI categories reached statistical significance among boys aged 12 to 19 years, girls aged 6 to 11 years, and in both age groups when the genders were combined.
- Differences in mean diastolic BP by BMI category reached statistical significance only among obese boys aged 12 to 19 years.

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**Appendix****Table A**  
**Sample sizes for selected characteristics, by sex and age group, household population aged 6 to 19 years, Canada, March 2007 to February 2009**

	Age group (years)			
	6 to 11		12 to 19	
	Boys	Girls	Boys	Girls
Blood pressure status	538	529	513	499
Measured body mass index (kg/m <sup>2</sup> )	537	529	512	496
Current smoking	...	...	507	497
Physical activity	538	528	507	497
Immediate family history of high blood pressure	530	518	481	470
Household education	524	518	498	483
Household type	538	529	513	499
Household income	524	513	457	426
Country of birth	538	529	513	499

... not applicable

**Source:** 2007-2009 Canadian Health Measures Survey.



# Using population data to measure outcomes of care: The case of hip and knee replacements

by Claudia Sanmartin, Kimberlyn McGrail, Mike Dunbar and Eric Bohm

## Abstract

### Background

Accumulating evidence points to overall improvements in health-related quality of life after joint replacement for osteoarthritis. Some patients, however, do not appear to benefit from joint replacement. This study investigates health outcomes of patients who underwent hip or knee replacement surgery.

### Methods

Linked survey and administrative data were used to compare the health-related quality of life of individuals who underwent surgery (surgical group) with that of their contemporaries who did not (comparison group), adjusting for other determinants of health. Weighted multivariate linear regression analyses were conducted.

### Results

When the results were adjusted for other covariates known to be associated with health, the surgical group reported lower functional health (post-operative) than did the comparison group. Differences ranged from 6% lower functional health among hip replacement patients diagnosed with osteoarthritis to 21% lower functional health for those with hip fractures. Among surgical patients with osteoarthritis, co-morbid conditions and being underweight were associated with lower post-operative functional health.

### Interpretation

This study is a unique application of linked data to the study of health outcomes of joint replacement at the population level. Outcomes of joint replacement differed by the initial diagnosis or reason for the surgery. For patients with osteoarthritis, poorer post-operative health outcomes were associated with co-morbidities and with being underweight.

### Keywords

arthroplasty, databases, data collection, health status, hip fractures, hospital records, osteoarthritis

### Authors

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Joint (hip and knee) replacement can provide substantial relief to people suffering from pain and limited mobility. In Canada, approximately 23,000 hip replacements and 38,400 knee replacements were conducted in 2006/2007.<sup>1</sup> The rate at which these procedures were performed more than doubled between 1995/1996 and 2005/2006, with even sharper increases between 2004/2005 and 2006/2007.<sup>2</sup> The rising rate is partially a reflection of an aging population; the recent acceleration is likely related to the identification of joint replacement among the five priority areas selected for meaningful reductions in waiting times.<sup>3</sup>

Accumulating evidence points to the health benefits of joint replacement for *osteoarthritis*, including reduced pain and greater mobility, which improve health-related quality of life.<sup>4-9</sup> But despite generally positive results, some patients do not appear to benefit from these procedures.<sup>10</sup> Recent reviews by Jones et al. indicated that 15% to 30% of arthroplasty patients reported little or no improvement in health-related quality of life after surgery.<sup>11,12</sup> However, the generalizability of most outcome studies is limited, as they were based on selected samples representing specific geographic regions, institutions, clinical sites, and/or providers.

The evidence is less clear about the effectiveness of hip replacement for *hip fracture* patients. Considerable disagreement remains about the best course of treatment, depending on factors such as age, type of fracture and condition of the hip.<sup>13-15</sup> While surgery is almost always indicated for such patients, the indications for type of surgery are less clear for some subtypes of hip fracture.<sup>15</sup> Some studies report higher rates of infection and mortality after hip replacement, compared with alternative procedures such as internal fixation.<sup>16-18</sup> Other studies report lower rates of re-operation and comparable hip function and health-related quality of life in the long term.<sup>18,19</sup>

A population approach to health outcomes yields information about the results of care obtained in various settings, representing a wide range of patients, providers and health care institutions. Most previous research in this area has relied either on survey data, which offer only limited information about health care services received, or on administrative data, which often lack information about health outcomes and about patient characteristics that may explain why some fare better than others.

This study takes an innovative, population-based approach to the analysis of health outcomes using linked survey and administrative data. Responses to the 2000/2001 Canadian Community Health Survey (CCHS) were linked with administrative data from the Hospital Morbidity Database (HMDB) on the use of inpatient acute-care services. Linkage of these two datasets makes it possible to take advantage of the strengths of each.

The primary objective is to study patients' health outcomes after hip and knee replacement: specifically, whether those who have these procedures (surgical group) return to the average health status of their peers (comparison group). Combining patient-based information from the CCHS and from the HMDB allows for an investigation of a wide range of factors hypothesized to be associated with outcomes of care, as identified in the Health Outcome Framework developed by Statistics Canada and the Canadian Institute for Health Information.<sup>20</sup>

The second, more data-driven, objective is to examine the potential of linked data for the analysis of health outcomes of specific surgical interventions. This will provide some policy perspective on gains to be made in future data investments, for example, surveys of patients who have undergone surgical interventions.

## Methods

### Data source

The data are from the Canadian Community Health Survey (CCHS)

and the Hospital Morbidity Database (HMDB). The CCHS is a nationally representative cross-sectional survey that collects information about Canadians' health status and use of health care. Cycle 1.1 was conducted in 2000/2001 with a sample size of 131,535.<sup>21</sup> The survey covers approximately 98% of the population aged 15 or older living in private dwellings.

The HMDB is a national administrative database representing all inpatient acute hospital admissions. It contains information on dates of admission and separation, up to sixteen ICD-9 diagnoses identifying the reason(s) for the stay, and up to ten procedure codes (based on ICD-9/-10 codes<sup>22</sup>) indicating interventions during the stay.

### Study sample

To identify the "surgical group" (those who had joint replacement surgery), data from cycle 1.1 of the CCHS were linked to HMDB data covering the five years before the survey (1995/1996 to 2000/2001) using probabilistic data linkage techniques based on health insurance number, sex, date of birth and postal code.<sup>23,24</sup> The analyses included only respondents who agreed to have their survey information linked to administrative data. The Statistics Canada Policy Committee approved the linkage. To address potential bias introduced by non-linkers, new survey weights were derived. The analyses excluded CCHS

respondents from Quebec, because data provided to Statistics Canada by Quebec for the HMDB have scrambled health insurance numbers, which make it impossible to link administrative records and survey responses.

Hospital stays were included in the analysis only if they were coded with a first surgical intervention indicating hip or knee replacement (Table 1). Some individuals had more than one acute inpatient admission with the relevant procedure codes. In these cases, the hospital event closest to the survey date was retained for analysis; subsequent admissions were dropped. No attempt was made to differentiate revisions from primary replacements; individuals (n=16) who stayed in hospital for these surgeries both before and after their CCHS interview were excluded. As well, hospital stays that occurred within the six months before the CCHS interview were excluded, because in these cases, answers to the survey questions about health status would reflect the post-operative recovery/rehabilitation period rather than full recovery. The sample was limited to CCHS respondents aged 40 or older because joint replacement at younger ages is rare and generally has different precursors and causes.

The "comparison group" consisted of CCHS respondents aged 40 years or older who had not had joint replacement in the five years before their interview (n=58,667).

### Analytical techniques

Univariate analyses and weighted multivariate linear regression were used to compare the health status of individuals who had joint replacement surgery ("surgical group") with those who did not ("comparison group"), controlling for factors associated with post-operative health status. The same variables were then modelled to identify factors associated with health status among surgical patients diagnosed with osteoarthritis. Small sample sizes prevented similar analyses for the other diagnostic groups. Analyses were conducted with Stata software using the

**Table 1**  
**Procedure and diagnosis codes used to identify surgery groups**

Surgery group	Procedure code	Diagnosis code
Hip replacement with osteoarthritis	935, 936	715
Hip replacement with fracture	935, 936	820, 821
Knee replacement with osteoarthritis	934 (ICD-9)	715
Complications of surgery (hip/knee)	934, 935, 936	996, 997, 998, 999
Other diagnoses (hip/knee)	934, 935, 936	All other diagnoses

xi: regression procedure. Special linkage weights were developed by Statistics Canada to adjust the linked data for those who did not consent to link and those who could not be linked because the information required for linkage was insufficient.

**Variables**

*Health outcome measure*

The primary health outcome measure is the health utility index (HUI), a multidimensional preference-based measure of health status<sup>25,26</sup> that has been used in studies of population health<sup>27-29</sup> and in clinical settings,<sup>30</sup> including among joint replacement patients. The HUI has a theoretical range between -0.3 (living in a state worse than death) and 1 (perfect health). It is intended to capture an individual’s functional health status across eight dimensions: vision, hearing, speech, dexterity, cognition, emotion, mobility and pain. The two latter dimensions are particularly relevant for individuals undergoing hip and knee replacement surgery. A difference of 0.03 in the HUI is considered clinically significant.<sup>29</sup>

*Independent variables*

The CCHS includes demographic information (age, sex, marital status, province of residence), socio-economic variables (household income, education), and risk factors that are hypothesized to be related to health status (presence of chronic conditions, body mass index, smoking). Education refers to the highest level attained by the respondent: less than secondary graduation; secondary graduation or some postsecondary, and postsecondary graduation. Household income, adjusted for household size, was measured in quintiles.

The CCHS collects information about chronic conditions including arthritis, diabetes, chronic obstructive pulmonary disease, asthma, hypertension, stroke, heart conditions, chronic pain, cancer and depression. Individuals were classified by the number chronic conditions they reported as diagnosed by a health professional and lasting

more than six months. Body mass index (BMI) was based on self-reported height and weight (weight in kilograms/height in metres squared). Smoking status was categorized as never smoked, former smoker, or current smoker based on self-reported smoking habits.

The surgical cohort was divided into diagnostic groups according to the reason for joint replacement as indicated by the most responsible diagnosis code on the hospital separation record for the surgical procedure: osteoarthritis, fracture (hip replacements), complications (specific ICD codes indicating complications of a surgical intervention), or other (for example, cancer, rheumatoid arthritis). This classification reflects the hypothesis that post-operative recovery differs depending on the reason for the surgery. Individuals undergoing joint replacement due to fractures, for example, experience a different trajectory of care and outcomes, given that the surgery is in response to an acute event.<sup>31</sup>

**Results**

**Descriptive**

A total of 598 individuals had a hip or knee replacement sometime between six months and five years before their CCHS cycle 1.1 interview (Table 2).

**Table 2**  
**Distribution of surgery groups, by surgical procedure and diagnosis, respondents aged 40 or older to 2000/2001 Canadian Community Health Survey, Canada excluding Quebec**

Surgical procedure and diagnosis	Number	%
<b>Total</b>	<b>598</b>	<b>100.0</b>
<b>Hip replacement</b>		
Osteoarthritis	177	29.5
Fracture	52	8.7
<b>Knee replacement (osteoarthritis)</b>	239	40.0
<b>Hip or knee replacement with/resulting from complications</b>	63	10.5
<b>Hip or knee replacement with other diagnoses (for example, cancer, arthritis)</b>	67	11.2

Sources: 2000/2001 Canadian Community Health Survey; Hospital Morbidity Database.

***What is already known on this subject?***

- The rate at which hip and knee replacements are performed has increased sharply since 1995/1996.
- Despite generally positive results, some patients report little or no improvement in health-related quality of life after joint replacement.

***What does this study add?***

- This study is the first population-based analysis of the health outcomes of joint replacement using linked survey and administrative data at the national level in Canada.
- People aged 40 to 79 who underwent joint replacement reported lower post-operative functional health than did the comparison group.
- Among surgical patients with osteoarthritis, co-morbid conditions and being underweight were associated with lower post-operative functional health.
- Linked survey and administrative data show promise for assessing outcomes of health care interventions.

Osteoarthritis was the most common diagnosis among both hip and knee replacement patients: 29.5% and 40.0%, respectively. Hip fractures accounted for 8.7% of the cohort. Almost equal percentages had a joint replaced with or resulting from complications (10.5%), or with other diagnoses such as cancer or rheumatoid arthritis (11.2%).

The surgical group was, on average, older than the comparison group (47.3% versus 10.3% were aged 75 or older) and more likely to be female (63.4% versus 51.6%) and to have co-morbidities (89.7% versus 52.4%) (Table 3).

Average (unadjusted) health status, measured by the HUI, was 0.615 for

**Table 3**  
Selected characteristics of surgery and comparison groups, respondents aged 40 or older to 2000/2001 Canadian Community Health Survey, Canada excluding Quebec

Characteristic	Surgery group		Comparison group	
	Number	%	Number	%
<b>Total</b>	<b>598</b>	<b>100.0</b>	<b>57,493</b>	<b>100.0</b>
<b>Demographic</b>				
<b>Age group</b>				
40 to 64	116	19.4	42,881	74.6
65 to 74	199	33.3	8,699	15.1
75 or older	283	47.3	5,912	10.3
<b>Sex</b>				
Men	219	36.6	27,820	48.4
Women	379	63.4	29,673	51.6
<b>Marital status</b>				
Married/Common-law	377	63.0	42,448	73.8
Widowed	163	27.2	5,221	9.1
Separated/Divorced	28	4.6	5,608	9.8
Never married	31	5.2	4,155	7.2
<b>Region</b>				
Newfoundland and Labrador, Prince Edward Island, Nova Scotia, New Brunswick	60	10.0	6,104	10.6
Ontario	307	51.3	29,063	50.6
Manitoba, Saskatchewan	55	9.2	5,127	8.9
Alberta, British Columbia	176	29.5	17,200	29.9
<b>Socio-economic</b>				
<b>Education</b>				
Less than secondary graduation	280	46.9	14,717	25.6
Secondary graduation/Some postsecondary	121	20.3	15,351	26.7
Postsecondary graduation	190	31.7	26,791	46.6
<b>Household income quintile</b>				
Lowest	20	3.4	1,797	3.1
Lower-middle	52	8.7	3,577	6.2
Middle	190	31.8	10,933	19.0
Upper-middle	180	30.2	17,659	30.7
Highest	78	13.1	17,118	29.8
<b>Health/Lifestyle</b>				
<b>Number of chronic conditions</b>				
None	62	10.4	27,369	47.6
One	155	26.0	15,837	27.5
Two	172	28.8	8,831	15.4
Three	124	20.8	3,794	6.6
Four	50	8.4	1,319	2.3
Five	31	5.2	276	0.5
Six or more	F	F	53	0.1
<b>Body mass index (BMI)</b>				
Underweight	33	5.6	3,268	5.7
Normal	188	31.4	22,305	38.8
Overweight	219	36.7	20,920	36.4
Obese	145	24.2	9,708	16.9
<b>Smoking</b>				
Never	236	39.4	18,420	32.0
Former	309	51.7	26,100	45.4
Current	52	8.7	12,828	22.3
<b>Mean Health Utility Index</b>	<b>0.615</b>	<b>...</b>	<b>0.844</b>	<b>...</b>

... not applicable

F too unreliable to be published (coefficient of variation 16.6% to 33.3%)

Source: 2000/2001 Canadian Community Health Survey; Hospital Morbidity Database.

**Table 4**  
Adjusted<sup>†</sup> difference in Health Utility Index between surgical and comparison groups, by surgical procedure and diagnosis, respondents aged 40 or older to 2000/2001 Canadian Community Health Survey, Canada excluding Quebec

Surgical procedure (diagnosis)	Coefficient	95% confidence interval	
		from	to
Hip (osteoarthritis)	-0.056*	-0.086	-0.025
Hip (fracture)	-0.209*	-0.265	-0.153
Knee (osteoarthritis)	-0.089*	-0.115	-0.063
Hip or knee (complications)	-0.075*	-0.126	-0.024
Hip or knee (other)	-0.164*	-0.214	-0.115
No surgery	...	...	...

<sup>†</sup> adjusted for demographic, socio-economic and health/life-style characteristics

\* significantly different from "no surgery" (p<0.01)

... not applicable

Sources: 2000/2001 Canadian Community Health Survey; Hospital Morbidity Database.

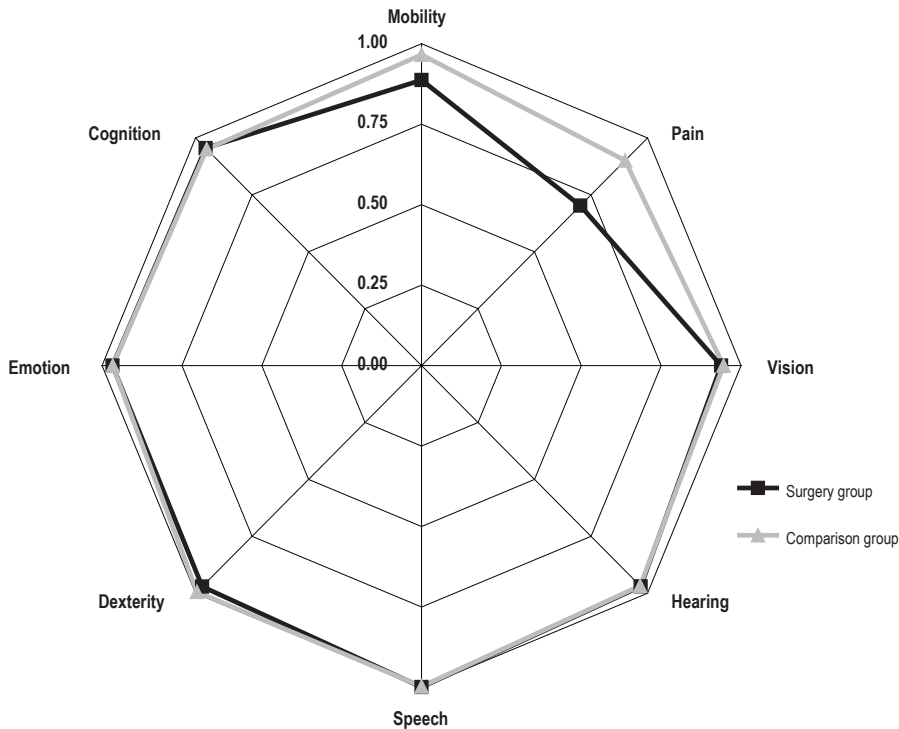
the surgical group and 0.844 for the comparison group (Table 3). The differences were mostly in the dimensions of mobility and pain, as shown, for example, on a radar plot for those age 65 to 74 (Figure 1). The pattern was similar for the other age groups and when the fracture group was removed from the analysis (data not shown).

### Multivariate regression analysis

Overall, the surgical group reported lower functional health than did the comparison group, when the results were adjusted for other covariates hypothesized to be associated with health (Table 4). The results, however, varied by diagnosis. Joint replacement patients with a primary diagnosis of osteoarthritis "regained" more health, reporting 6% (hip replacement) and 9% (knee replacement) less functional health compared with the control group, whereas the hip fracture group reported 21% less functional health.

Among joint replacement patients with *osteoarthritis*, several other factors were significantly associated with post-operative health status (Table 5). Their functional health decreased with each

**Figure 1**  
**Mean (unadjusted) Health Utility Index scores, by attribute, for surgery and comparison groups, aged 65 to 74, to 2000/2001 Canadian Community Health Survey, Canada excluding Quebec**



Source: 2000/2001 Canadian Community Health Survey; Hospital Morbidity Database.

additional chronic condition (13% less). Those who were underweight reported 24% less functional health, compared with “normal” weight individuals. Former smokers reported more functional health (7%), compared with those who never smoked.

## Discussion

This is the first population-based analysis of health outcomes of joint replacement using linked survey and administrative data at the national level in Canada. Unlike studies based solely on administrative health data, the availability of health-related quality of life information (HUI) in the survey data allowed a more direct assessment of health outcomes on a range of patients, in a variety of care settings and providers.

On average, individuals who underwent joint replacement surgery were not restored to a level of functional level compared with a similar population group. As expected, the results varied by type of diagnosis, from 6% (hip replacement) and 9% (knee replacement) lower functional health among those with a diagnosis of osteoarthritis to 21% lower functional health among the hip fracture group. After surgery, patients with fractures do not “regain” health to the same degree as the osteoarthritis group. This finding supports evidence about the outcomes of treatment for hip fractures. Hip fracture has been associated with excess mortality, compared with the general population<sup>32</sup> and compared with other hip replacement recipients.<sup>33</sup> As previously observed, the evidence about the effectiveness of joint replacement for hip fracture patients is mixed. Other

consequences of hip fractures may adversely affect patients’ health-related quality of life. It is likely that the fracture itself has a negative impact on their health trajectory; for example, the hospital stay itself can result in changes in functional status.<sup>34-36</sup> Fractures among the elderly are as much a cause as a consequence of frailty, representing a closer to terminal event in the process of health decline.<sup>37,38</sup>

The linked database made it possible to explore a range of factors associated with health outcomes of joint replacement among a nationally representative population. The results indicate that, among people with osteoarthritis who underwent joint replacement, being underweight and having co-morbid conditions were associated with poorer post-operative health. Although sex, age and marital status also seemed to be associated with poorer health, the results did not attain statistical significance, likely because of the small sample size. These results are consistent with other findings that point to a variety of factors associated with outcomes of joint replacement,<sup>39,40</sup> including co-morbid conditions<sup>41</sup> and lack of social support.<sup>42</sup> These associations may indicate the expected effectiveness of joint replacement, in terms of health status, for individuals with osteoarthritis.

The better health of former smokers, compared with those who never smoked, was unanticipated. However, former smokers include both recent and long-time quitters, the latter of whom often achieve health status and adopt health care practices similar to those of non-smokers.<sup>43,44</sup> In fact, some evidence suggests that long-time quitters are more likely than non-smokers to believe in the efficacy of modifying other risk factors.<sup>45</sup> It is possible, then, that former smokers (at least, long-time quitters) have adopted other healthy lifestyles, such as greater physical activity, that improve their overall health.

## Limitations

This study has several limitations. First, the sample size is small—the analysis pertains only to joint replacement patients

**Table 5**  
**Linear regression coefficients relating selected characteristics to Health Utility Index, joint replacement patients with osteoarthritis, respondents aged 40 or older to 2000/2001 Canadian Community Health Survey, Canada excluding Quebec**

Characteristic	Coefficient	95% confidence interval	
		from	to
<b>Demographic</b>			
<b>Age group</b>			
40 to 64 <sup>†</sup>	...	...	...
65 to 74	0.064	-0.016	0.143
75 or older	-0.078	-0.163	0.007
<b>Sex</b>			
Men <sup>†</sup>	...	...	...
Women	-0.055	-0.117	0.007
<b>Marital status</b>			
Married/Common-law <sup>†</sup>	...	...	...
Widowed	0.055	-0.015	0.125
Separated/Divorced	0.074	-0.069	0.217
Never married	-0.136	-0.282	0.010
<b>Region</b>			
Newfoundland and Labrador, Prince Edward Island, Nova Scotia, New Brunswick	0.094	-0.007	0.195
Ontario	-0.007	-0.071	0.058
Manitoba, Saskatchewan	0.041	-0.068	0.150
Alberta, British Columbia <sup>†</sup>	...	...	...
<b>Socio-economic</b>			
<b>Education</b>			
Less than secondary graduation	0.000	-0.070	0.070
Secondary graduation/Some postsecondary	0.034	-0.054	0.122
Postsecondary graduation <sup>†</sup>	...	...	...
<b>Household income</b>			
Lowest	-0.105	-0.325	0.115
Lower-middle	-0.129	-0.260	0.002
Middle	-0.042	-0.137	0.053
Upper-middle	-0.072	-0.165	0.021
Highest <sup>†</sup>	...	...	...
<b>Health/Lifestyle</b>			
<b>Number of chronic conditions</b>	-0.134*	-0.157	-0.112
<b>Body Mass Index (BMI)</b>			
Underweight	-0.243*	-0.429	-0.057
Normal <sup>†</sup>	...	...	...
Overweight	0.047	-0.028	0.122
Obese	0.024	-0.056	0.105
<b>Smoking</b>			
Never <sup>†</sup>	...	...	...
Former	0.074*	0.015	0.133
Current	0.011	-0.119	0.141

<sup>†</sup> reference category

\* significantly different from "no surgery" (p<0.05)

... not applicable

Sources: 2000/2001 Canadian Community Health Survey; Hospital Morbidity Database.

who were respondents to the 2000/2001 CCHS. Subsequent studies may benefit from ongoing efforts at Statistics Canada to link several waves of the CCHS to hospital administrative data. This limitation, however, is counterbalanced by gains in generalizability—the data represent the Canadian population, not a single hospital or a single health insurance provider or even a single province.

Second, because the sample is restricted to the household population, it does not represent outcomes of joint replacement among residents of institutions such as long-term care facilities.

Finally, the study does not directly measure the change in health status before and after surgery. Rather, it compares the post-operative health status of surgical patients to a population comparison group. This approach assumes that the surgery was intended to restore patients to a level of health similar to that of their contemporaries. However, a negative finding does not necessarily signal the absence of a gain in health-related quality of life as a result of the surgery.

## Conclusion

This study is a unique application of linked data to the study of health outcomes after a health care intervention, namely, joint replacement. The data allow for a population approach to the assessment of health outcomes, taking into account a range of factors. The outcomes of joint replacement differ depending on the initial diagnosis or reason for the surgery. In particular, patients with osteoarthritis who are underweight or have co-morbid conditions may be susceptible to poorer outcomes. Linked data show promise for studying outcomes of health care interventions, especially interventions that are common and are well-documented in administrative records. ■

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# Weight gain during pregnancy: Adherence to Health Canada's guidelines

by *Hélène Lowell and Doris C. Miller*

## Abstract

The 2006 Maternity Experiences Survey provides information about women's weight before, during and after pregnancy. Using these data, this study assessed Canadian women's adherence to the 1999 gestational weight gain guidelines. Women with a higher pre-pregnancy body mass index were more likely than normal or underweight women to gain more than recommended. Compared with older mothers, a higher percentage of young mothers gained more than recommended. Women who gave birth for the first time were more likely than those who had had more than one birth to gain more than recommended. A lower level of education was associated with weight gain exceeding the recommendations. Aboriginal women were more likely than non-Aboriginal women to gain more than recommended. Women who gained more than recommended while they were pregnant retained more weight five to nine months post-partum, compared with those who gained less than or within the amount recommended.

## Keywords

birth weight, body mass index, behaviour, body weight changes, health surveys, pregnancy outcomes

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Canadian women's adherence to Health Canada's gestational weight gain guidelines has not been assessed since the recommendations were released in 1999.<sup>1</sup> Observational studies in countries with similar guidelines have shown that women tend to gain more weight than recommended while they are pregnant.<sup>2-5</sup> The release of perinatal health data<sup>6</sup> for a representative sample of Canadian women provides an opportunity to determine if women in Canada also gain more weight than is recommended.

This article describes Canadian women's adherence to Health Canada's 1999 gestational weight gain guidelines, based on an analysis of data from the 2006 Maternity Experiences Survey (see *The data*). These guidelines for singleton pregnancies vary according to the mother's pre-pregnancy body mass index (BMI). At the time of the survey, the recommended weight gain ranges were:

- 12.5 to 18.0 kilograms for women with a pre-pregnancy BMI less than 20;
- 11.5 to 16.0 kilograms for women with a pre-pregnancy BMI of 20 to 27; and
- 7.0 to 11.5 kilograms for women with a pre-pregnancy BMI greater than 27.<sup>1</sup>

The ranges were adapted from the 1990 Institute of Medicine gestational weight gain recommendations,<sup>7</sup> which were under review at the time of the analysis.<sup>8</sup>

The findings are reported according to whether the gestational weight gain was below, within or above the recommendations, by selected socio-demographic and maternity characteristics of the mother: pre-pregnancy BMI; age; parity (number of times the woman had given birth, including stillbirths); education; household income; Aboriginal status; country of birth; and region of residence.

Results are also presented for two health outcomes—post-partum weight retention and infant birth weight—for the three gestational weight gain categories.

## The data

The 2006 Maternity Experiences Survey collected information about the experiences during pregnancy, birth and the early post-partum months of women aged 15 or older at the time of their baby's singleton live birth in Canada during the three-month period before the 2006 Census. They had to be living with their infant at the time of the survey, which, for 96.9% of the mothers, was conducted five to nine months post-partum. Mothers living in institutions or on reserves were excluded from the survey. The survey was carried out by Statistics Canada on behalf of the Public Health Agency of Canada as an initiative of the Canadian Perinatal Surveillance System. Detailed descriptions of the survey design and methods are available in a published report.<sup>9</sup> The complete questionnaire is available online.<sup>10</sup>

A total of 6,421 women completed the survey, representing an estimated 76,508 women who gave birth during the target period, for a response rate of 78%. Only those who gave birth to a full-term baby (37 to 41 weeks' gestation) were included in this analysis; this excluded 474 women. As well, 24 women whose self-reported pre-pregnancy weight, gestational weight gain and post-pregnancy weight could not be reconciled were excluded; these were women who may have reported their pregnancy weight instead of their weight gain, or who had a large relative difference between their pre-pregnancy and post-pregnancy weights. Women with missing values for length of gestation or pre-pregnancy BMI were also excluded. A total of 5,554 women remained in the analysis.

To take account of the complex survey design, the bootstrap method<sup>11,12</sup> was used to estimate standard deviations, coefficients of variation and confidence intervals. The significance level was set at  $p < 0.05$ . The Bonferroni correction<sup>13</sup> was used for multiple comparisons.

In addition to descriptive statistics, a separate logistic regression was performed to identify significant associations between socio-demographic/maternal characteristics (pre-pregnancy BMI, mother's age, parity, education, household income, born in Canada by Aboriginal status or born outside of Canada, and region of residence) and gaining more weight than recommended, compared with gaining within the recommendations.

The mother's *pre-pregnancy BMI* was obtained from self-reported height and weight. The mothers were also asked about their gestational weight gain and their weight at the time of interview:

- "How tall are you without shoes on?"
- "Just before your pregnancy with (your baby), how much did you weigh?"
- "How much weight did you gain during your pregnancy with (your baby)?"
- "How much do you weigh now?"

For *parity*, women were defined as either primiparous (their first live birth with no previous stillbirths), or multiparous (had previous live births or stillbirths).

The mother's *highest level of education* was categorized into four levels: less secondary, secondary graduation, some postsecondary/diploma/certificate, and university degree.<sup>14</sup>

The variable for *household income* was similar to a derived variable for income in the 2000/2001 (cycle 1.1) Canadian Community Health Survey,<sup>15</sup> based on total household income and the number of people living in the household, collapsed into three categories: lowest/lower-middle, middle, and upper-middle/highest.

Mothers were asked their *country of birth*. For those who were foreign-born, no adjustment was made for how long they had lived in Canada. Although *Aboriginal status* was asked of respondents who were born in Canada, the United States and Greenland, in this analysis, Aboriginal was defined as those who self-identified as Aboriginal and were born in Canada.

One of the main limitations of the data is that height and weight were self-reported. However, the percentage distribution of pre-pregnancy BMIs among the weight classification categories<sup>16</sup> of women aged 18 to 50 in this analysis and that based on self-reported height and weight of non-pregnant women aged 18 to 50 in the 2005 Canadian Community Health Survey were similar<sup>17</sup> (5.8% versus 5.5% underweight; 60.3% versus 59.4% normal weight; 21.0% versus 22.4% overweight; and 13.0% versus 12.7% obese).<sup>18</sup> This similarity provides additional assurance that the findings presented here can be generalized to Canadian women of child-bearing age.

A systematic review of studies that compared directly measured with self-reported height, weight and BMI concluded that self-reported weight and BMI were underestimated, and height was overestimated.<sup>19</sup> Using data from the 2005 Canadian Community Survey, Shields et al<sup>20</sup> quantified the bias associated with self-reported height, weight and BMI. Females' average BMI was 1.2 kg/m<sup>2</sup> less when calculated with self-reported height and weight, compared with measured height and weight, and as weight increased so did the difference between self-reported and measured BMI. If BMI was underestimated in the 2006 Maternity Experiences Survey, some women might actually be in a higher BMI category; that is, rather than being in the "less than recommendations" group, they should be in the "within recommendations" group, or in the "more than recommendations" group rather than the "within recommendations" group. This implies that the percentages "within recommendations" and "more than recommendations" could be underestimated for women whose pre-pregnancy BMI was 20 to 27 or more than 27.

Mothers in Nunavut, the Northwest Territories and Yukon were included in the sample, although they were interviewed nine to 14 months post-partum rather than five to nine months. As a result of the inclusion of these women, the data on average weight retention by pre-pregnancy BMI may be an underestimation of weight retention at five to nine months post-partum.

Factors that were not controlled for in the logistic regression (such as mother's height, smoking status and alcohol use)<sup>8</sup> may also predict gestational weight gain.

### Factors associated with gestational weight gain

According to the 1990 Institute of Medicine report, a woman's pre-pregnancy weight is a primary determinant of how much weight she will gain while she is pregnant.<sup>7</sup> Indeed, results from the Maternity Experiences Survey show that 55% of overweight women gained more than recommended while they were pregnant, compared with 41% of those who were in the normal range and 26% of those who were underweight (Figure 1). However, in addition to pre-pregnancy weight, factors such as age, parity, education and income have also been identified as potential predictors of weight gain during pregnancy.<sup>21,22</sup>

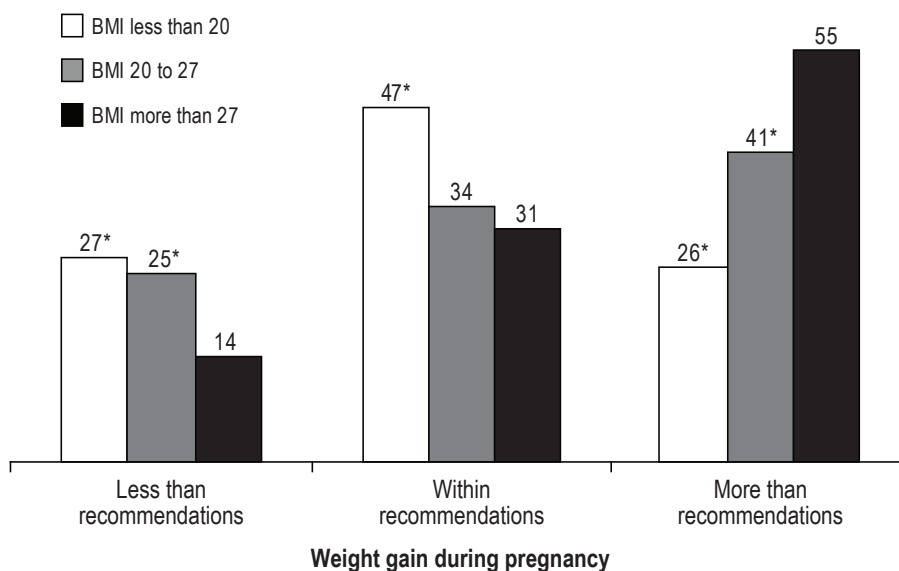
The percentage who gained more weight than recommended declined at older ages, from 56% of 15- to 19-year-old mothers to 35% of those aged 35 to 39 (Table 1).

Women giving birth for the first time (primiparous) were more likely than those who had previously given birth (multiparous) to gain more than recommended: 47% versus 37%. This difference persisted when other variables, including age, were taken into account. Primiparous women's adjusted odds of exceeding rather than being within the weight gain recommendations were 1.5 (95% CI of 1.3 to 1.7) times those of multiparous women (data not shown).

The likelihood of gaining more weight than recommended during pregnancy was greater among women with less than secondary education (53%), compared with those who had some postsecondary education (43%) or a university degree (38%). This difference held when other factors were taken into account. The adjusted odds that women with less than secondary education would exceed rather than be within the weight gain recommendations were 2.1 (95% CI of 1.6 to 3.0) times those of women with a university degree (data not shown).

On the other hand, women with a low household income were no different from those with a high household income in terms of gaining more weight than

**Figure 1**  
Percentage of women who gained less than, within and more than Health Canada's gestational weight gain guidelines, by pre-pregnancy body mass index (BMI), female household population aged 15 or older who gave birth during three months before 2006 Census, Canada



\* significantly different from corresponding estimate for BMI more than 27 (p<0.05)

Source: 2006 Maternity Experiences Survey.

recommended (43% versus 41%) during pregnancy. However, a higher percentage of women with a low household income gained less than recommended, compared with women who had a high household income (27% versus 21%).

Women who self-identified as Aboriginal were more likely than non-Aboriginal women to gain more than recommended: 55% versus 44%. And owing to post-partum weight retention, excess weight gain during pregnancy has the potential of further exacerbating the current high prevalence of overweight and obesity among Aboriginal women<sup>23</sup> living off-reserve.

A higher percentage of women born in Canada (44%) gained more weight than recommended during their pregnancy, compared with women not born in Canada (33%).

Among the six regions, Ontario's percentage distribution of weight gain during pregnancy in relation to the Health Canada recommendations was very close to the distribution for Canadian

women overall. And compared with Ontario, only in the Atlantic region did a significantly higher percentage of women gain more weight than recommended while they were pregnant.

### Gestational weight gain and health outcomes

The weight gain guidelines reflect observations of healthy pregnancy outcomes.<sup>7</sup> Gaining insufficient weight has been associated with low birth weight (less than 2,500 grams), while gaining too much weight has been associated with both high birth weight (more than 4,000 grams) and post-partum weight retention.<sup>24</sup>

According to the Maternity Experiences Survey, women who gained less weight than recommended when they were pregnant were more likely to have an infant weighing less than 2,500 grams than a normal weight full-term infant: 44% versus 24% (Table 2). On the other hand, the majority (58%) of women who gained more weight than

**Table 1**  
**Percentage of women who gained less than, within and more than Health Canada's gestational weight gain guidelines, by selected characteristics, female household population aged 15 or older who gave birth during three months before 2006 Census, Canada**

Characteristics	Weight gain during pregnancy								
	Less than recommendations			Within recommendations			More than recommendations		
	%	95% confidence interval		%	95% confidence interval		%	95% confidence interval	
		from	to		from	to		from	to
<b>Age at delivery</b>									
15 to 19	20	14	26	24*	19	30	56*	49	62
20 to 24	22	18	25	29*	25	32	50*	46	54
25 to 29	21	19	23	35	33	37	44*	41	46
30 to 34	23	21	25	38	36	41	39	37	42
35 to 39†	26	23	30	38	35	42	35	32	39
40 or older	24	17	31	40	32	49	36	28	44
<b>Parity</b>									
Primiparous	19*	18	21	33*	31	35	47*	45	50
Multiparous†	25	24	27	38	36	39	37	35	39
<b>Highest level of education</b>									
Less than secondary†	21	17	25	26	22	31	53	48	58
Secondary graduation	25	22	28	30	26	33	45	41	49
Some postsecondary/diploma/certificate	22	20	24	36*	34	38	43*	40	45
University degree	22	20	24	40*	37	42	38*	35	40
<b>Household income</b>									
Low†	27	23	31	30	26	34	43	39	47
Medium	23	21	24	35*	34	37	42	40	44
High	21*	19	23	38*	36	40	41	39	44
<b>Aboriginal status</b>									
Non-Aboriginal	21	19	22	36*	34	37	44*	42	45
Aboriginal†	16	12	20	29	23	35	55	49	61
<b>Country of birth</b>									
Canada	21*	19	22	35	34	37	44*	43	46
Other†	29	26	32	38	35	41	33	30	36
<b>Region</b>									
Canada	22	21	24	36	34	37	42	40	43
Atlantic	15	13	18	35	32	37	50*	47	53
Quebec	22	20	25	39	36	42	39	36	41
Ontario†	23	21	25	35	32	37	42	40	44
Prairies	22	20	25	34	31	37	44	41	47
British Columbia	24	20	27	35	31	39	41	37	45
Territories	29	25	33	34	29	38	37	33	42

† reference category

\* significantly different from estimate for reference category ( $p < 0.05$ )

Source: 2006 Maternity Experiences Survey.

recommended gave birth to an infant weighing 4,000 grams or more. These findings mirror results from a systematic review by Viswanathan et al,<sup>24</sup> who found moderate-to-strong evidence of an association between gestational weight gains below the 1990 Institute of Medicine recommendations and low birth weight, and strong evidence to support an association between gains above the recommendations and high birth weight.

Five to nine months after they had given birth, women who gained more weight than recommended during their pregnancy retained more weight (an average of 4.5 kg) than did women who gained within or less than the recommendations (averages of 2.0 kg and 0.5 kg, respectively) (Table 3). Viswanathan et al<sup>24</sup> also found moderate evidence supporting an association between weight gain above the Institute of Medicine recommendations and post-partum weight retention three months to three years later.

## Conclusion

Information from the 2006 Maternity Experiences Survey suggests that relatively high percentages of women who are young, primiparous, less educated or Aboriginal gain more weight than recommended while they are pregnant. ■

**Table 2**  
**Percentage of women who gained less than, within and more than Health Canada's gestational weight gain guidelines, by baby's birth weight, female household population aged 15 or older who gave birth during three months before 2006 Census, Canada**

Baby's birth weight (grams)	Weight gain during pregnancy								
	Less than recommendations			Within recommendations			More than recommendations		
	%	95% confidence interval		%	95% confidence interval		%	95% confidence interval	
		from	to		from	to		from	to
Low (less than 2,500)	44*	33	55	F	...	...	F	...	...
Normal (2,500 to less than 4,000)	24*	22	25	37*	35	38	40*	38	41
High (4,000 or more) <sup>†</sup>	12	9	14	30	27	34	58	54	62

<sup>†</sup> reference category

\* significantly different from estimate for reference category (p<0.05)

F too unreliable to be published (coefficient of variation more than 33.3%)

... not applicable

Source: 2006 Maternity Experiences Survey.

**Table 3**  
**Average weight retention of women who gained less than, within and more than Health Canada's gestational weight gain guidelines, by pre-pregnancy body mass index, 5 to 9 months postpartum, female household population aged 15 or older who gave birth during three months before 2006 Census, Canada**

Pre-pregnancy body mass index	Weight gain during pregnancy								
	Less than recommendations			Within recommendations			More than recommendations		
	Mean weight retention (kg)	95% confidence interval		Mean weight retention (kg)	95% confidence interval		Mean weight retention (kg)	95% confidence interval	
		from	to		from	to		from	to
Total	0.5 <sup>E</sup>	0.2	0.8	2.0	1.8	2.3	4.5	4.3	4.8
Less than 20	1.8	1.3	2.3	3.0	2.6	3.4	5.8	5.1	6.5
20 to 27	1.0 <sup>E</sup>	0.6	1.3	2.2	1.9	2.5	5.0	4.7	5.3
More than 27	-3.7	-4.7	-2.6	F	...	...	3.2	2.6	3.9

<sup>E</sup> interpret with caution (coefficient of variation 16.6% to 33.3%)

F too unreliable to be published (coefficient of variation more than 33.3%)

... not applicable

Source: 2006 Maternity Experiences Survey.

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# The Manitoba Human Papillomavirus vaccine surveillance and evaluation system

by Erich V. Kliewer, Alain A. Demers, Marc Brisson, Alberto Severini, Robert Lotocki, Brenda Elias, Gregory Hammond, George Wurtak and the Manitoba HPV Research Group

## Abstract

### Background

With the recent introduction of a human papillomavirus (HPV) vaccine in Canada, it is important to establish surveillance and evaluation programs that not only track the uptake of the vaccine, but also assess its safety and its impact on: distribution of HPV type, cervical cancer screening programs, the incidence of anogenital warts, precancerous lesions and various cancers, and sexual behaviour.

### Data sources and methods

Administrative databases, registries and questionnaire information are being linked to identify people receiving the HPV vaccine and to develop an evaluation system.

### Interpretation

The availability of extensive linkable databases in Manitoba allows for the development of a comprehensive HPV vaccine surveillance and evaluation system that can address many of the questions related to the HPV vaccine. Aspects of the Manitoba surveillance and evaluation system could be implemented in other provinces that have similar databases.

## Keywords

human papillomavirus vaccine, surveillance, evaluation, record linkage

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A quadrivalent human papillomavirus (HPV) vaccine was approved for sale in Canada in July 2006 for females aged 9 to 26 years. This vaccine protects against infection from HPV types 6, 11, 16 and 18. Types 16 and 18 are responsible for approximately 70% of all cervical cancers, while types 6 and 11 are responsible for over 90% of anogenital warts.<sup>1-4</sup> Clinical trials have shown that the vaccine is effective in preventing anogenital warts and precancerous cervical, vulvar and vaginal lesions.<sup>5-9</sup> A bivalent (types 16 and 18) HPV vaccine is currently going through the Canadian regulatory approval process, and other HPV vaccines that protect against an increased number of HPV genotypes are being evaluated.

Because most provinces and territories have implemented voluntary school-based vaccination, it is important to establish a surveillance and evaluation program that not only tracks uptake of the vaccine, but also assesses its safety and its impact on the distribution of HPV type, on cervical cancer screening, on the incidence of anogenital warts, precancerous lesions and various cancers, and on sexual behaviour.

The Canadian National Advisory Committee on Immunization statement

on HPV vaccine noted an infrastructure gap in Canada, and that to evaluate the vaccine's effectiveness and impact, databases and registries must be developed and linked.<sup>10</sup> Others have also recognized the potential of linkable databases for evaluating vaccines.<sup>11-15</sup> Such databases allow for evaluation at a population level, as opposed to the restrictive setting of clinical trials. Through partnerships with Manitoba Health, CancerCare Manitoba and the Public Health Agency of Canada's

National Microbiology Laboratory, and with access to extensive linkable data resources, Manitoba is well-positioned to develop such a surveillance and evaluation system.

This paper describes specific aspects of the surveillance and evaluation system (Figure 1) that is being implemented in Manitoba (population 1.15 million).

### HPV immunization registry

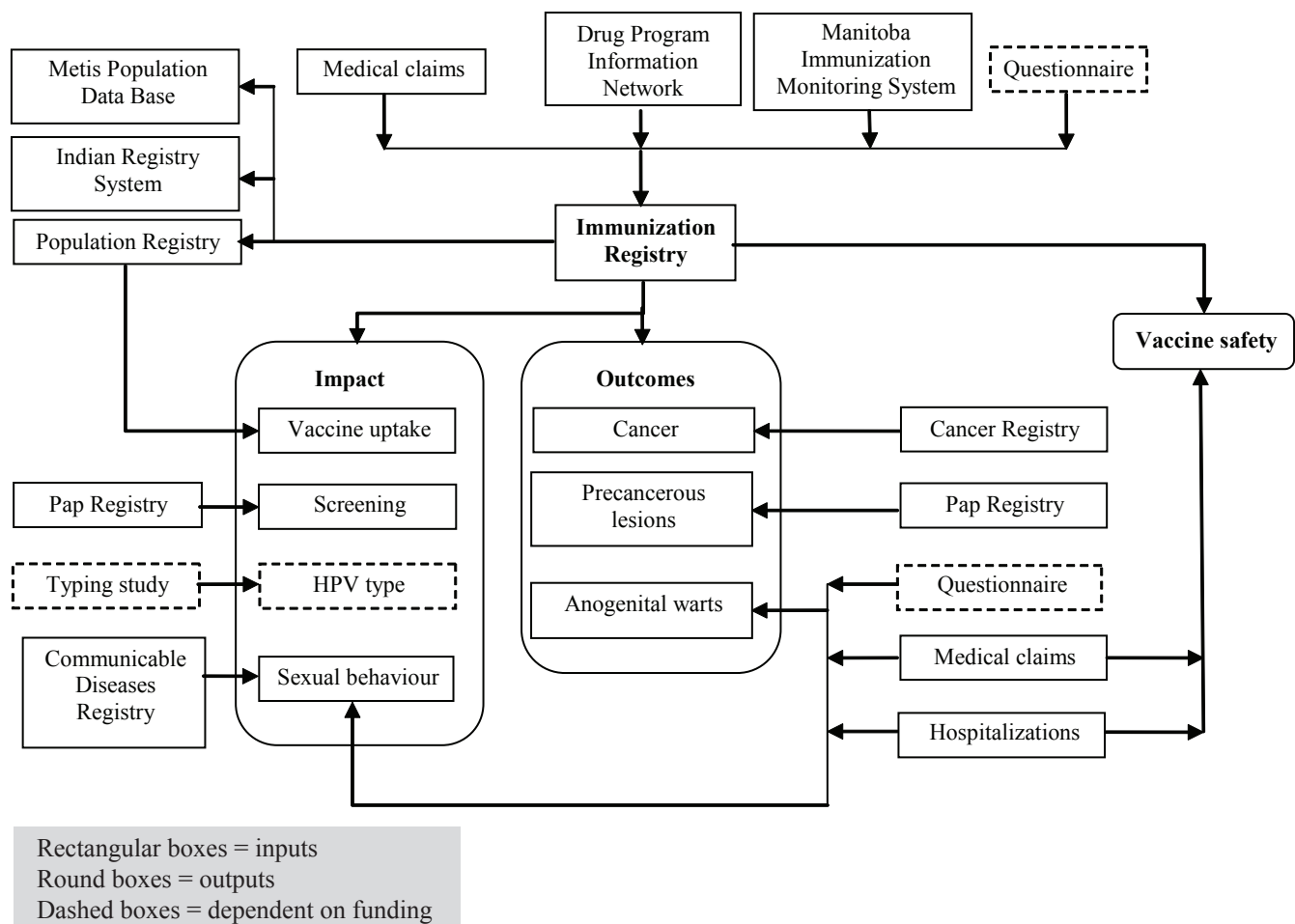
The backbone of any vaccine surveillance and evaluation program is an immunization registry. In Manitoba, such a registry is being developed from information in the Manitoba

Immunization Monitoring System (MIMS - see [www.gov.mb.ca/health/publichealth/cdc/surveillance/mims07.pdf](http://www.gov.mb.ca/health/publichealth/cdc/surveillance/mims07.pdf)), the Drug Program Information Network (DPIN), and medical claims. Females receiving the HPV vaccine through the school-based program are captured in MIMS. Those obtaining the vaccine outside the school-based program usually require a physician's prescription; the DPIN database includes most prescriptions filled in the province. This database allows for the identification of those who filled a prescription for the vaccine, but it is not possible to determine if they were

actually vaccinated. However, given the cost of the vaccine (approximately \$400 for three doses), it is unlikely that those who purchased it did not use it.

Anecdotal reports suggest that some Manitoba physicians provide the vaccine to their patients without a prescription. A potential source for identifying these patients is the medical claims database, which includes records of all claims submitted to Manitoba Health by physicians for payment for services. The tariff (billing) code 8891 has been specifically assigned to the HPV vaccine, although this code was not implemented until late 2008. Before that, physicians

**Figure 1**  
**Human papillomavirus (HPV) vaccine surveillance and evaluation system**





could use 8800, which is a billable tariff code for any immunization. Physicians could indicate in the claim's comment field that the HPV vaccine was administered, but not all may have done so. Thus, the immunization registry will miss individuals whose physician gave them the vaccine without a prescription and submitted a claim with tariff code 8800, but did not specify HPV.

The immunization registry contains only non-identifying information such as the scrambled unique personal health identification number, date of birth, region of residence, date the prescription was filled, and date the vaccine was administered.

Aside from being essential for an effective evaluation of the vaccine, the registry will also be a means of contacting vaccinated individuals if safety issues arise or if booster doses are required. This is more effective than relying on the media or health professionals.<sup>10</sup>

### Non-vaccinated females

The Manitoba surveillance system allows for the follow-up and comparison of outcomes in vaccinated and non-vaccinated females. All residents covered by the provincial health insurance are included in the Manitoba Population Registry (MPR), which is maintained by Manitoba Health to administer the insurance program. Since health insurance is provided free of charge, it covers more than 99% of the population. By linking the HPV immunization registry to the MPR, it is possible to identify females who have not been vaccinated. Loss of follow-up can be determined for both vaccinated and non-vaccinated females, as the MPR contains dates of termination of coverage through emigration or death.

### Aboriginal peoples

Although HPV infection rates<sup>16-18</sup> and cervical cancer incidence and mortality rates<sup>19-21</sup> are higher in Aboriginal than non-Aboriginal females, little is known about the epidemiology of HPV among Aboriginal peoples. The uptake and

impact of the vaccine may be different in Aboriginal populations.<sup>22</sup>

#### *First Nations*

As part of a Health Disparity Research Program at the Manitoba First Nations Centre for Aboriginal Health Research at the University of Manitoba, permission has been received from the federal Department of Indian and Northern Affairs to link the Indian Registry System (IRS) to the MPR. The IRS contains information on all registered First Nations as defined by the Indian Act, including reinstated First Nations under federal Bill C-31 legislation. With this link it is possible to undertake studies on vaccinated and non-vaccinated cohorts that include Registered First Nation status. However, approval must first be obtained from Manitoba's institutional review boards, which include First Nations ethical and health information decision-making bodies. To date, permission has been received to investigate HPV vaccine uptake, comparing Registered First Nations in Manitoba and all Manitobans, and permissions will be sought to examine broader aspects of the HPV vaccine surveillance program.

#### *Métis*

The Manitoba Metis Federation (MMF) Health and Wellness Department, in partnership with the Manitoba Centre for Health Policy and Manitoba Health, produced a province-wide Metis Health Status and Health Services Utilization study that created a large permanent updatable Metis Population Data Base (MPDB). The MPDB identifies the Manitoba Metis and exists under MMF ownership, control, access and stewardship. It is, in principle, possible to link the MPDB with the MPR to undertake a Metis-specific HPV vaccine surveillance and evaluation program. However, an agreement outlining the details of the program and authority from the MMF would be required, along with ethics and privacy approvals.

### Vaccine uptake

With the development of the immunization registry, uptake of the vaccine in Manitoba is being tracked on a population basis. Specific questions that are being examined include:

- What are the overall and age-specific vaccination rates?
- How has uptake changed over time?
- What percentage of females receive fewer than the three recommended doses?
- Is uptake highest in areas of greatest need (for example, with the highest cervical cancer rates or lowest screening rates)?
- Does uptake vary by income quintile?

Among individuals with lower income, cervical cancer screening rates tend to be lower,<sup>23-26</sup> and cervical cancer incidence and mortality rates higher.<sup>27,28</sup> Cost is an important determinant of women's attitudes about receiving the vaccine, and household income has been associated with uptake.<sup>29-31</sup> Given the high cost, it would be expected that vaccination rates outside the school-based program would be lower among individuals with low income. Such inequity in access may well widen the difference between low- and high-income women in rates of anogenital warts and cervical abnormalities.

### Vaccine impact

#### *Cervical screening program*

Some vaccinated females may develop a false sense of protection that could result in their no longer seeking screening.<sup>32-34</sup> Although the vaccine targets the oncogenic HPV types 16 and 18, it is essential that vaccinated females continue to be screened, as only about 70% of cervical cancers are caused by these two HPV types.<sup>1-3</sup> And some females may have been infected by these two types before vaccination or infected by other types of oncogenic HPV.

The Manitoba Cervical Cancer Screening Program was established in

January 2000, and the reporting of all cervical cancer screening tests to the program was mandated by law in 2001. A registry was established that contains demographic information for all women aged 18 to 69, and all Pap test, colposcopy and biopsy results. The registry also includes results for females outside the program's age range. By linking the immunization registry to the Pap registry, it will be possible to determine the impact of the vaccine on screening, in particular, whether screening rates of vaccinated and non-vaccinated women differ.

If females receiving the vaccine are those who would have been screened regularly, the vaccine will have less impact on reducing rates of cervical cancer.<sup>35</sup> Because a substantial number of Manitoba women aged 18 or older are being vaccinated, this possibility can be investigated by using the linked databases to examine the screening history of vaccinated and non-vaccinated women.

The vaccine will likely reduce the prevalence of cytological abnormalities, which, in turn, will lead to a decrease of the positive predictive value of Pap cytology.<sup>33,36</sup> Research is needed to evaluate the performance of cytology and HPV testing among vaccinated and non-vaccinated women, although because of ethical concerns, randomized trials may not be possible.<sup>37</sup> As described in the next section, a province-wide survey of HPV type was undertaken in Manitoba, the results of which will be included in the Pap registry. If such surveys continue, the accuracy of cytology versus HPV testing in vaccinated and non-vaccinated women can be determined by linking the immunization registry to the Pap registry. It would also be possible to determine if the HPV type is changing over time in women with lesions.

#### *HPV type*

A pilot study conducted in Winnipeg in 2007 and a larger province-wide study in 2008 collected HPV samples from approximately 900 women. HPV type is being determined by the Public Health Agency of Canada's National

Microbiology Laboratory and the Cadham Provincial Laboratory of Manitoba Health. The results of the HPV tests are being entered into the Pap registry. Participants also completed a questionnaire on demographic, socio-economic, reproductive and lifestyle characteristics ([http://www.cancercare.mb.ca/resource/File/Epi-Cancer\\_Registry/Questionnaire\\_For\\_Risk\\_Factors\\_Associated\\_With\\_Cervical\\_Cancer.pdf](http://www.cancercare.mb.ca/resource/File/Epi-Cancer_Registry/Questionnaire_For_Risk_Factors_Associated_With_Cervical_Cancer.pdf)).

These studies will provide preliminary estimates of the prevalence of HPV types in Manitoba before widespread HPV vaccination. The intention is to repeat the survey periodically, although the frequency will depend on funding. These surveys will make it possible to determine whether the vaccine alters the infection rate and distribution of other HPV types, particularly other oncogenic types.<sup>38</sup> Based on the questionnaire information, differences in HPV type by the personal characteristics of survey participants will be examined.

#### *Sexual behaviour*

Concern has been expressed that HPV vaccination may lead to an increase in premature sexual activity and risky sexual behaviour.<sup>33,39,40</sup> The questionnaire for the Manitoba HPV typing study, which asks about sexual behaviour, could provide information on the sexual behaviour of vaccinated versus non-vaccinated females.

Although the impact of the vaccine on sexual behaviour cannot be directly assessed using the Manitoba databases, differences in pregnancy or birth rates between vaccinated and non-vaccinated women may be an indirect measure. Because virtually all births occur in hospital, linked immunization registry and hospital data can be used to determine birth rates in the two cohorts of women. And by including information from medical claims, pregnancy rates could also be estimated, although this would be less accurate than the data for births.

Differences between vaccinated and non-vaccinated women in the incidence of notifiable sexually transmitted

infections may also provide indirect evidence of how the vaccine affected sexual behaviour. This information will be derived by linking the vaccine registry to the Manitoba communicable diseases registry.

If a sufficient number of older women are vaccinated, it will be possible to compare these indicators of sexual behaviour before and after vaccination.

## **Vaccine outcomes**

### *Cancer*

The Manitoba cancer registry was established in the 1930s and has been population-based since 1956. Because cancer is a notifiable disease and multiple sources of ascertainment are used, completeness in the recording of cases is considered to be very high.

In addition to causing most cervical cancer, HPV 16 and 18 are responsible for 80% to 90% of anal cancers. As well, varying proportions of vulvar, vaginal, urethral and head and neck cancers contain oncogenic HPV types.<sup>33</sup> Risk for these cancers can be determined by linking the Manitoba cancer registry to the cohorts of vaccinated and non-vaccinated females. However, given the rarity of these diseases, the cohorts must be followed for a substantial period before enough cases have occurred to test for differences. On the other hand, Manitoba may be able to contribute data to existing efficacy trials, such as the Nordic HPV vaccine trials, for a possible pooled analysis.<sup>41</sup>

### *Precancerous cervical lesions*

While vaccination should, in the long-term, lead to a decrease in cervical cancer caused by HPV 16 and 18, in the short-term, a reduction in atypical squamous cells of undetermined significance and squamous intraepithelial lesions would be expected because of the shorter latency between HPV infection and development of these abnormalities.<sup>36</sup> Because the Pap registry includes cytological results for all Pap tests undertaken in Manitoba and colposcopy and histological information, abnormality rates among the vaccinated and non-vaccinated can be calculated.

## ***What is already known on this subject?***

- A quadrivalent HPV vaccine was approved for sale in Canada in July 2006.
- Most provinces and territories have implemented school-based vaccination programs.
- Questions remain about the vaccine's safety and its impact on anogenital warts, cervical abnormalities, cervical cancer screening, HPV type, and sexual behaviour.

## ***What does this study add?***

- This article explains how linkable databases and registries available in Manitoba and other Canadian provinces and territories can be used to address questions about the HPV vaccine.

### *Anogenital warts*

Given the short time between exposure to HPV and the development of anogenital warts, they are one of the first indicators of the success of a vaccination program.<sup>42</sup> For the 1985 to 2004 period, medical claims and hospitalization records were linked to identify men and women with anogenital warts for a study of incidence and prevalence trends in Manitoba.<sup>43</sup> The methodology developed in that study will be employed to create an on-going registry of cases of anogenital warts. This registry will be employed to document the impact of the vaccine on the incidence and prevalence of anogenital warts, and by linking it to the immunization registry, to determine the effectiveness of the vaccine in preventing anogenital warts. Although the vaccine has not been recommended for males, an anogenital warts registry will make it possible to determine if vaccinating females reduces the incidence of anogenital warts in males.

### **Vaccine safety**

After reviewing data on events occurring up to six years after vaccination, the World Health Organization concluded that the evidence for the safety of the HPV vaccines was “reassuring.”<sup>44,45</sup> However, “long-term safety data are essential for an HPV vaccine, since it will likely target hundreds of millions of young, healthy individuals worldwide who are otherwise not subject to epidemiological surveillance...”<sup>38</sup> Furthermore, the safety results to date are based on carefully controlled clinical trials, the participants in which are subjected to strict eligibility criteria. Studies that examine the safety of the vaccine in real world population-based settings are required.

Because many vaccinated females will be in, or about to enter, their reproductive years, it is important to determine if the vaccine results in reproductive toxicities or increases the risk of adverse pregnancy outcomes.<sup>33,38</sup> It has been suggested that the vaccine may have a positive impact on pregnancy outcomes by reducing the number of women treated for precancerous cervical lesions.<sup>33</sup> Procedures used to treat these lesions, such as loop electrosurgical excision and cold knife conization, have been associated with preterm delivery, low birth weight, caesarean section, and premature rupture of membranes.<sup>46</sup>

Canada, like many other countries, has a surveillance system that tracks adverse events following vaccination.<sup>12</sup> A recent report<sup>47</sup> based on the American system found that, except for syncope and venous thromboembolic events, the rates of adverse events after receiving the HPV vaccine were no greater than those for other vaccines. However, these results tend to be based on voluntary notification and underestimate the actual number of events. And because no information is available for a comparative non-vaccinated cohort, determining causality is difficult. By linking medical and hospitalizations records to the immunization registry, as has been called for by Brotherton et al.,<sup>48</sup> it will be possible to undertake a long-term follow-

up on a population basis to determine if the vaccinated group is at increased risk for any medical conditions. A similar method is being used in the Nordic trials.<sup>41</sup>

### **Mathematical modeling**

Mathematical models, such as those developed by Brisson and colleagues,<sup>49,50</sup> are currently part of the overall evidence base used to inform decision-making about HPV vaccination and cervical cancer screening programs in Canada.<sup>22</sup> Models can also be an intrinsic part of an ongoing HPV vaccine surveillance program, particularly the long-term impact of the vaccine. An individual-based dynamic model of HPV transmission, infection and disease, including screening and vaccination, can be developed with data from the various Manitoba databases and registries. Integration of models and surveillance will allow:

- better understanding of emerging epidemiologic trends after vaccination (for example, changes in age at infection, waning effectiveness, herd-immunity, HPV type replacement).
- improved predictions of the effectiveness and cost-effectiveness of HPV vaccination and cervical cancer screening (for example, projections based on up-to-date data).
- adjustment and optimization of HPV vaccination and cervical cancer screening strategies (for example, reduce number of doses, change vaccine schedule, revisit screening paradigms).

### **Conclusion**

Surveillance of vaccine coverage and safety is critical for a successful immunization program.<sup>51</sup> Erickson et al. have outlined the requirements for an evaluation of an immunization program, which include the availability of information systems to measure coverage, reduction of disease incidence, complications, sequelae and mortality,

and adverse events associated with vaccination, and to link health outcomes databases, immunization registries and population registries.<sup>14</sup> The essential role of linked databases in evaluating the HPV vaccine's effectiveness has also been noted by others in Canada and elsewhere.<sup>10-13,22,52,53</sup> The participants in the Canadian HPV Vaccine Research Priorities Workshop rated the importance of such linkages as high, but they considered feasibility to be low.

Manitoba has a long history of record linkage, facilitated by the inclusion of a unique Personal Health Identification Number in most databases. The Manitoba databases are as comprehensive as those being used in the Phase III and IV Nordic trials. Information arising from the

surveillance and evaluation system will provide data on many questions related to the vaccines' uptake, impact and safety. Aspects of the Manitoba surveillance and evaluation system could be implemented in other provinces that have similar databases. Also, policy makers and/or researchers who have questions about the HPV vaccine that are not being addressed by the current surveillance system and evaluation program could, with the appropriate local ethics and privacy approvals, obtain access to the necessary information from the registries and databases that form the basis of the Manitoba surveillance system. ■

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# Evaluating the Hyperactivity/Inattention Subscale of the National Longitudinal Survey of Children and Youth

by Alice Charach, Elizabeth Lin and Teresa To

## Abstract

### Background

High scores on the National Longitudinal Survey of Children and Youth Hyperactivity/Inattention Subscale (NLSCY H/I Scale) have been used to indicate severe inattention and overactivity representing Attention Deficit/Hyperactivity Disorder (ADHD) symptoms. However, a threshold on the scale has not been identified for use as an epidemiological marker for clinically significant disorder.

### Data and methods

The NLSCY H/I Scale is evaluated in a subsample of the cycle 1 NLSCY population (n=10,498), weighted to represent 2.36 million children aged 6 to 11 in 1994/1995. Logistic regression measured the association of scores on the scale against three potential criteria, adjusting for age, sex and socio-economic status: 1) current methylphenidate use, 2) diagnosed emotional disorder, and 3) functional impairment. Sensitivity analyses identified threshold scores where false positives and false negatives were most nearly equivalent. The preferred criterion provides the greatest area under the Receiver Operating Characteristic (ROC) curve and the highest specificity at the identified threshold.

### Results

Current methylphenidate use and diagnosed emotional disorder yielded essentially identical models, with thresholds of 14 or more and nearly overlapping ROC curves. High scores on the NLSCY H/I Scale are associated with current methylphenidate use and diagnosed emotional disorder.

### Interpretation

The parent-reported NLSCY H/I Scale can be used in population studies as a highly specific indicator of clinically significant ADHD symptoms.

## Keywords

Attention Deficit/Hyperactivity Disorder, epidemiology, hyperactivity, inattention, National Longitudinal Survey of Children and Youth

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The National Longitudinal Survey of Children and Youth (NLSCY) is a federally sponsored, national prospective study designed to measure the well-being, health and development of Canadian children from birth through young adulthood. The survey began in 1994/1995, and data collection has occurred at two-year intervals since then. As part of the interview, the parent (usually the biological mother) was asked to describe the child's behaviour using the Children's Behaviour Scale.

The entire scale is composed of several subscales, one of which, the Hyperactivity/Inattention Subscale (H/I Scale), is designed to identify hyperactive, inattentive and impulsive behaviours in children aged 4 to 11 in large, population-based studies. The items were taken from the Ontario Child Health Study<sup>1</sup> and the Montreal Longitudinal Study.<sup>2</sup>

Several researchers have used high scores on this scale as a proxy for clinically significant symptoms often identified with Attention Deficit Hyperactivity Disorder (ADHD).<sup>3-5</sup> However, comparisons across studies are hampered by the lack of consistency in classifying children likely to have a clinically significant disorder such as

ADHD. Two studies where the scale has been dichotomized to distinguish children with significant difficulties used thresholds of 1.5 standard deviations above the population mean,<sup>3,5</sup> and another used the top 10%.<sup>4</sup>

This article evaluates the parent-reported NLSCY H/I Scale with data from cycle 1 (1994/1995) of the survey. The NLSCY H/I Scale is based on the Ontario Child Health Study Survey Diagnostic Instrument (OCHS SDI)<sup>1</sup> hyperactivity scale, which was validated against *Diagnostic and Statistical Manual of Mental Disorders, Third Edition* (DSM-III) diagnosis of ADHD, and used a combination of parent- and teacher-reports for case identification. However, DSM criteria for ADHD have

been substantially revised since DSM-III was published.<sup>6</sup> Nonetheless, since DSM-II,<sup>7</sup> the underlying conceptualization has remained a long-standing childhood disorder characterized by detrimental levels of overactivity, impulsiveness and distractibility, and a short attention span.

In addition to changes in diagnostic criteria over time, another reason for evaluating how well the parent-reported NLSCY H/I Scale identifies children at risk of ADHD is that 52% of the teacher-reported information was missing in cycle 1.<sup>8</sup> To determine whether the child showed symptomatic behaviours in more than one context (at home and at school), the OCHS SDI required that both parent and teacher rate the child. However, the lack of teacher responses for slightly more than half the NLSCY participants substantially undermines this method of identifying cases in the NLSCY data.

The method in the present study is based on the work of Boyle et al.,<sup>9</sup> who recommended that survey instruments designed for population studies incorporate “elements of distress, impairment and therapeutic concern” in defining a case, rather than simply applying a threshold number of symptoms.<sup>9</sup> In 1999, Goodman demonstrated that a measure of child “impact” that combined “distress” and “social impairment” improved case identification, compared with parent and teacher ratings alone.<sup>10</sup>

The NLSCY database contains two variables that represent these elements: current use of methylphenidate (Ritalin), which is used almost exclusively to treat childhood ADHD,<sup>11,12</sup> and previous diagnosis of emotional, psychological or nervous disorder. In each instance, the child’s parent would have sought professional assistance. In the first, before prescribing methylphenidate, a physician concurred that the child required treatment, and in the second, for the child to have a *diagnosed* emotional disorder, a health professional perceived enough impairment to warrant diagnosis and treatment

To some extent, the groups of children that these two variables

identify may overlap. However, one represents a narrow, and the other, a broad, conceptualization of disorder. In 1994/1995, methylphenidate accounted for the vast majority of stimulant medications prescribed to children,<sup>11,12</sup> and was likely to be a marker for ADHD, but not for other disorders. In addition, the NLSCY question specified *current* medication use.<sup>13</sup> By contrast, a diagnosis of emotional, mental or nervous disorder could apply to several conditions, only one of which might be ADHD. As well, the diagnosis was not specific to the time of the interview.

The NLSCY includes items about functional impairment (academic performance, getting along with peers, and getting along with parents), the third element identified by Boyle et al. As was done by Boyle et al., this study combined these items to indicate impaired functioning in at least one domain.<sup>9</sup>

Another consideration in developing a model to evaluate the H/I Scale is the sensitivity and specificity of the threshold for case identification. Sensitivity is the percentage of cases that the threshold identifies as positive that truly have the disorder (true positives/true positives + false negatives). Specificity is the percentage of cases that the threshold identifies as negative that do not have the disorder (true negatives/true negatives + false positives).<sup>14</sup> For diagnostic screening, the ideal threshold maximizes both sensitivity and specificity, although false positives and false negatives may be common. But when a scale is used to determine the prevalence of a relatively rare disorder in a large non-clinical population, priority should go to minimizing the error rate.<sup>15</sup>

Like other measures designed for use in population samples, the NLSCY H/I Scale is abbreviated. Such scales are highly sensitive, but not very specific. A threshold chosen to balance sensitivity and specificity would yield excessively high rates of false positives in population samples. The overall error rate is lowest when the threshold is set where the numbers of false positives and false negatives are closest to equivalent.

This results in greater specificity and less sensitivity, the strategy chosen for this study because of the relatively low prevalence of ADHD in the population.

The goal is to develop a model for evaluating the NLSCY H/I Scale so that it can be used to identify children with clinically significant ADHD symptoms in large population-based studies. The model is tested with 1994/1995 data, the cycle with the most complete information and that has not been subject to attrition over time. The objectives are to: 1) evaluate the strength of the association between scores on the NLSCY H/I Scale and each of three potential criteria for ADHD: current methylphenidate use, diagnosis of an emotional disorder, and functional impairment; 2) identify the criterion with the strongest association, adjusting for age, sex and socio-economic status; and 3) identify the threshold with the most nearly equal false negatives and false positives. The point prevalence of clinically significant ADHD symptoms among Canadian children is also estimated.

## Methods

### Sample

The NLSCY used a random sampling frame of households with clusters within age groups and large geographic areas to be representative of children in the 10 provinces. Children in highly mobile, transient or homeless families were under-represented. Children living in institutions and on Aboriginal reserves were excluded. A full description of the NLSCY is available elsewhere.<sup>16</sup>

In each household, Statistics Canada interviewers administered a standardized questionnaire to the person most knowledgeable about the child (the biological mother in 89.9% of cases). (In this study, the term “mother” or “parent” is used rather than person most knowledgeable because the NLSCY H/I Scale was designed to be parent-reported.) The overall response rate was 87%. The population analysed is the subset of the NLSCY sample consisting of children aged 6 to 11 in 1994/1995 whose parent

**Table 1**  
**Selected characteristics of training sample and National Longitudinal Survey of Children and Youth (NLSCY) sample, household population aged 6 to 11, Canada excluding territories, 1994/1995**

Characteristics	Training sample			NLSCY sample		
	%	99% confidence interval		%	99% confidence interval	
		from	to		from	to
Male sex	51.3	48.8	53.7	51.3	48.0	53.7
Low maternal education	16.7	15.1	18.3	17.1	15.4	18.7
Low household income	16.3	14.7	17.9	17.0	15.4	18.7
Current methylphenidate use	2.0	1.3	2.6	1.9	1.4	2.5
Diagnosed emotional disorder <sup>†</sup>	1.9	1.3	2.4	1.7	1.1	2.3
Impairment in academic, social or family functioning	4.9	4.0	5.8	4.7	3.7	5.7

<sup>†</sup> emotional, psychological or nervous disorder

**Notes:** Determined using cross-sectional weights from Statistics Canada, normalized for missing values. Training sample = 10,370 observations, representing 2,354,000; NLSCY sample = 10,498 observations, representing 2,360,300.

**Source:** 1994/1995 National Longitudinal Survey of Children and Youth.

responded to the interview—a total of 10,498, representing 2.36 million children across Canada.

The statistical models were developed based on a training sample derived using a replicate sampling with replacement strategy,<sup>17,18</sup> followed by testing the statistical model in the NLSCY sample. A random half-sample for model development was not feasible because of confidentiality constraints imposed by the small number of respondents scoring positive for the clinical indicators. The training sample was produced by aggregating 10 replicate random samples, each equivalent to 10% of the NLSCY sample, a strategy similar to a simplified bootstrap<sup>17,18</sup> procedure. The resulting sample is comparable to the NLSCY sample (Table 1). The final models reported here are those evaluated in the NLSCY sample, specifically the NLSCY cycle 1 subsample of children whose parents answered the interview questions.

**Measures**

The Hyperactivity/Inattention Subscale of the parent-reported NLSCY Children’s Behavior Scale consists of 8 items (can’t sit still, distractible, fidgets, impulsive, difficulty sitting still, cannot settle for long, can’t concentrate, inattentive) scored as 0 (not true), 1 (sometimes true) or 2 (often true), resulting in a continuous scale with scores from 0 to 16. Internal

consistency on factor analysis is good (Cronbach’s  $\alpha = 0.86$ ).<sup>8</sup>

The *covariates* are the child’s age and sex, low maternal education (did not complete secondary school) and low household income, based on Statistics Canada’s derived variable of household size and income (below the 1995 low income cut-off).<sup>19</sup>

Three clinical indicators reported by the parent were evaluated as potential criteria for validity:

*Current methylphenidate use:* “Does ... (your child) ... take any of the following medications on a regular basis ... Ritalin?” (Yes/No)

*Previous diagnosis of emotional disorder:* “ Does ... (your child) ... have any of the following long-term conditions that have been diagnosed by a health professional? ... Emotional, psychological or nervous disorder?” (Yes/No)

*Impairment in academic, social or family functioning:*

- “Based on your knowledge of his/her school work, including report cards, ... how is he/she doing overall?”
- “During the past six months, how well has ... (your child) ... gotten along with other kids such as friends or classmates (excluding brothers or sisters)?”
- “How well has ... (your child) ... gotten along with his/her parents?”

Parents evaluated each of the three areas on a 5-point scale; scores of 4 or more (poor or very poor functioning) on any of the three scales indicated functional impairment in one or more areas.<sup>9</sup>

**Data analysis**

The research design is a retrospective cross-sectional analysis. Logistic regression analysis using backward selection was applied to the training sample to measure the association of the H/I Scale against each of the potential criterion variables, adjusted for age, sex, low maternal education and low household income. The regression models included cross-sectional population weights.<sup>8,20,21</sup> Only independent variables with a statistical significance of  $p \leq 0.01$  were retained in the final models. Best-fit statistical models were chosen using the –2 Log Likelihood statistic and the Hosmer-Lemeshow goodness-of-fit test. Receiver Operating Characteristic (ROC) curves were examined to identify the model with the greatest area under the curve. Sensitivity analyses throughout the full range of scores were used to identify the threshold scores with the most nearly equivalent false negatives and false positives. Frequency estimates were normalized to adjust for missing values, and reported with cross-sectional population weights and variance estimates.<sup>8,20</sup> The criterion variable of choice was the one with the greatest area under the ROC curve, with the largest *beta*, and whose threshold has the highest specificity.

After the preferred criterion variable(s) were determined, the statistical models were tested in the NLSCY sample. Using the threshold score identified during model development, the association of the binary NLSCY H/I Scale was measured against the chosen criteria in the NLSCY sample (including cross-sectional population weights) to understand the properties of case identification. In addition, an estimate of the population prevalence of clinically significant ADHD symptoms was generated. All analyses were performed using SAS version 8.2.<sup>22</sup>

**Table 2**

**Logistic regression models of current methylphenidate use, diagnosed emotional disorder and functional impairment, household population aged 6 to 11, Canada excluding territories, 1994/1995**

Characteristics	Current methylphenidate use			Diagnosed emotional disorder			Impairment in academic, social or family functioning		
	beta <sup>†</sup>	Standard deviation	P value	beta <sup>†</sup>	Standard deviation	P value	beta <sup>†</sup>	Standard deviation	P value
<b>Hyperactivity/Inattention Scale (continuous)</b>	<b>0.30</b>	<b>0.02</b>	<b>&lt; 0.0001</b>	<b>0.31</b>	<b>0.02</b>	<b>&lt; 0.0001</b>	<b>0.29</b>	<b>0.01</b>	<b>&lt; 0.0001</b>
Male sex	0.52	0.10	< 0.0001	...	...	...	...	...	...
Age (years)	0.13	0.04	0.0046	0.26	0.05	< 0.0001	0.16	0.03	< 0.0001
Low household income	...	...	...	0.32	0.09	0.0002	0.39	0.05	< 0.0001

<sup>†</sup> beta coefficient of parameter

... not applicable

**Notes:** Multivariable regression models chosen by backwards selection. Model chosen using backwards selection with  $p < 0.01$  to stay and  $p < 0.10$  to go. Best model chosen using -2 Log Likelihood statistic and Hosmer/Lemeshow Goodness-of-Fit tests.

**Source:** 1994/1995 National Longitudinal Survey of Children and Youth.

**Table 3**

**Sensitivity and specificity values for threshold on National Longitudinal Survey of Children and Youth Hyperactivity/Inattention Subscale, by current methylphenidate use, diagnosed emotional disorder and functional impairment, household population aged 6 to 11, Canada excluding territories, 1994/1995**

Threshold	True		False		Sensitivity	Specificity
	positives	negatives	positives	negatives		
<b>Current methylphenidate use</b>						
7 or more	33,110	1,674,677	592,445	11,738	74	74
8 or more	30,901	1,823,860	443,262	13,947	69	80
9 or more	28,100	1,961,000	306,100	16,800	63	86
10 or more	26,100	2,056,900	210,200	18,700	58	91
11 or more	20,900	2,121,000	146,100	23,900	47	94
12 or more	16,400 <sup>E</sup>	2,169,000	98,100	28,400	37	96
13 or more	13,700 <sup>E</sup>	2,201,500	65,600	31,200	31	97
<b>14 or more*</b>	<b>11,200<sup>E</sup></b>	<b>2,230,200</b>	<b>36,900</b>	<b>33,600</b>	<b>25</b>	<b>98</b>
15 or more	8,000 <sup>E</sup>	2,247,800	19,300	36,900	18	99
<b>Diagnosed emotional disorder</b>						
7 or more	28,932	1,674,227	596,623	10,692	73	74
8 or more	27,644	1,824,331	446,519	11,980	70	80
9 or more	24,200	1,960,900	309,900	15,400	61	86
10 or more	21,800	2,056,300	214,600	17,900	55	91
11 or more	17,800	2,121,600	149,200	21,800	45	93
12 or more	14,800 <sup>E</sup>	2,171,100	99,700	24,900	37	96
13 or more	11,700 <sup>E</sup>	2,203,200	67,700	28,000	29	97
<b>14 or more*</b>	<b>8,900<sup>E</sup></b>	<b>2,231,700</b>	<b>39,200</b>	<b>30,700</b>	<b>23</b>	<b>98</b>
15 or more	6,400 <sup>E</sup>	2,250,000	20,900	33,200	16	99
<b>Impairment in academic, social or family functioning</b>						
9 or more	59,300	1,927,700	274,800	49,900	54	88
10 or more	48,800	2,015,000	187,500	60,400	45	91
11 or more	39,600	2,075,100	127,500	69,700	36	94
<b>12 or more*</b>	<b>31,200</b>	<b>2,119,300</b>	<b>83,300</b>	<b>78,000</b>	<b>29</b>	<b>96</b>
13 or more	25,307	2,148,500	54,000	83,900	23	98
14 or more	17,700	2,172,100	30,400	91,600	16	99

\* threshold value with most nearly equivalent false positives and false negatives

<sup>E</sup> interpret with caution (coefficient of variation 16.6% to 33.3%)

**Note:** Normalized weighted population frequencies; N=2,312,000 for current methylphenidate use; N=3,210,500 for diagnosed emotional disorder; N=2,311,800 for impairment in academic, social or family functioning.

**Source:** 1994/1995 National Longitudinal Survey of Children and Youth.

## Results

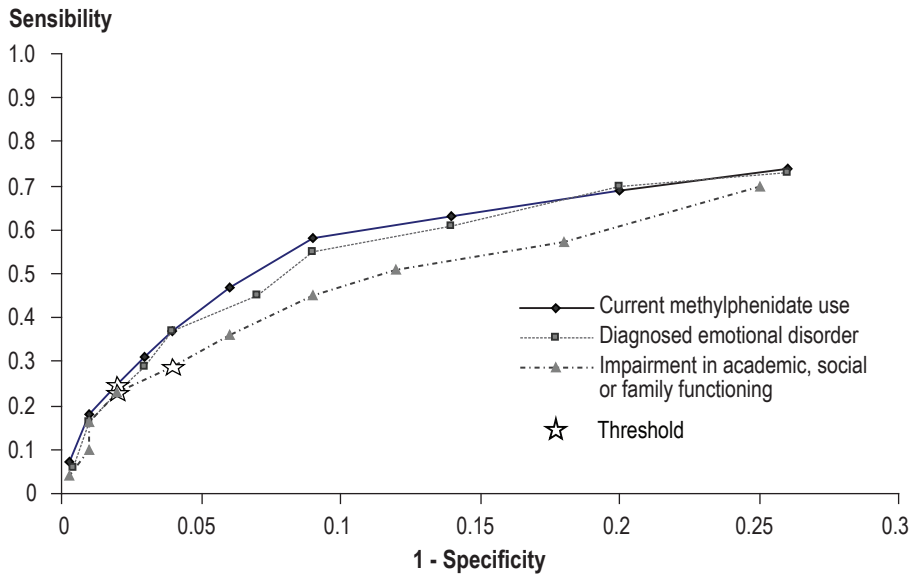
Scores on the parent-reported NLSCY H/I Scale was associated with each of the three clinical indicators: current methylphenidate use; previous diagnosis of emotional disorder; and impaired functioning in academic, social or family domains among children aged 6 to 11 (Table 2). Statistical overlap among the three models was substantial, with beta values ranging narrowly from 0.29 (SE = 0.01) for impaired functioning to 0.31 (SE = 0.02) for emotional disorder.

The sensitivity analyses and resulting ROC curves show that *methylphenidate use* and *emotional disorder* produced essentially the same statistical model—that is, a model with a greater area under the ROC curve and higher specificity at the identified threshold compared with impaired functioning (Table 3, Figure 1). With either methylphenidate use or emotional disorder as the criterion, a H/I Scale threshold of 14 or more out of 16 distinguished cases from non-cases. With methylphenidate use as the criterion, sensitivity = 0.25 and specificity = 0.98; with emotional disorder, sensitivity = 0.23 and specificity = 0.98. This threshold resulted in highly specific, but not very sensitive, case identification.

The logistic regression models for the continuous scale highlight similarities and differences between the models (Table 2). If methylphenidate use is the criterion, the best-fit model for the



**Figure 1**  
**Receiver Operating Characteristic (ROC) curves from sensitivity analyses for National Longitudinal Survey of Children and Youth Hyperactivity/Inattention Subscale plotted against current methylphenidate use, diagnosed emotional disorder and functional impairment, household population aged 6 to 11, Canada excluding territories, 1994/1995**



Source: 1994/1995 National Longitudinal Survey of Children and Youth.

continuous H/I Scale includes age and sex as modifiers, with older children and boys more likely to be taking methylphenidate. If emotional disorder is the criterion, the best-fit model for the continuous H/I Scale includes age and low household income, with older children and those from low-income households more likely to have been diagnosed.

To better understand the properties of case identification using the H/I Scale, the association of the binary variable with methylphenidate use and with emotional disorder was examined (data not shown). Children using methylphenidate were more likely to: show high rather than low levels of parent-reported hyperactivity and inattention (OR = 16.2; 99% CI = 11.2 to 23.5); be boys rather than girls (OR = 3.8; 99% CI = 2.6 to 5.4); and be near the older end of the 6 to 11 age range (OR = 1.1; CI = 1.0 to 1.2). Children with a previous diagnosis of emotional, psychological or nervous disorder were more likely to: show high

levels of parent-reported hyperactivity and inattention (OR = 16.9; CI = 11.3 to 25.2); come from households with a low income (OR = 2.2; CI = 1.6 to 3.1), and be near the older end of the age range (OR = 1.3; CI = 1.2 to 1.4).

Based on a threshold of 14 or more on the NLSCY H/I Scale, an estimated 2.1% (99% CI = 1.5 to 2.7) of Canadian children aged 6 to 11 had clinically significant ADHD symptoms.

## Discussion

The current study demonstrates that the NLSCY Hyperactivity/Inattention Subscale was associated with two clinical indicators of ADHD in Canadian children aged 6 to 11 in 1994/1995: methylphenidate use, adjusted for age and sex, and previous diagnosis of emotional disorder, adjusted for age and household income. Earlier studies based on the NLSCY have shown an association between high levels of parent-reported hyperactivity and methylphenidate use

among school-aged boys,<sup>3,5</sup> but this is the first to examine the association of hyperactivity with emotional disorder, and to develop a model to determine a threshold for use as a marker for identifying children with ADHD.

Although there is no clear statistical advantage to choosing either current methylphenidate use or previous diagnosis of emotional disorder as the criterion for evaluating the NLSCY H/I Scale, there may be broad conceptual value in choosing the latter. While it is no surprise that methylphenidate use can be a criterion for ADHD, it is somewhat more novel that a history of emotional disorder can be used as a criterion as well. The ROC curves for methylphenidate use and for emotional disorder appear to be essentially the same statistical model. This is consistent with the likelihood that children taking methylphenidate were diagnosed before they began taking it. That is, the basic construct of “caseness” is met—a child came to the attention of a health professional because of parental concern, and that professional agreed that therapeutic attention was warranted. However, diagnosis of emotional disorder represents a wide array of potential disorders. As such, it could be considered for use as a criterion to evaluate other subscales of the NLSCY Children’s Behaviour Scale as potential measures of mental health disorders.

The similarity in the statistical models raises the question of whether methylphenidate use and diagnosed emotional disorder represent the same children. As noted earlier, the two groups may overlap, but only partially. For example, boys were more likely than girls to use methylphenidate, but sex was not significantly associated with diagnosed emotional disorder. And while children in low-income households were more likely to have been diagnosed with an emotional disorder, household income was not associated with methylphenidate use. The lack of overlap may be attributable to several factors. The NLSCY question about emotional disorder asked if the child had ever received a diagnosis. Therefore,

## ***What is already known on this subject?***

- The parent-reported Hyperactivity/Inattention Subscale in the National Longitudinal Survey of Children and Youth was designed to identify children with severe symptoms of hyperactivity and inattention.
- A threshold score on the scale that identifies children likely to have clinically significant disorder has not been determined.
- Previous studies using the Scale have not been consistent in how children with high levels of hyperactivity were defined.

## ***What does this study add?***

- Variables collected by the NLSCY that represent therapeutic concern by parents and health professionals—methylphenidate use and diagnosis of emotional disorder—can be used as criteria to evaluate the Hyperactivity/Inattention Scale and set a threshold that identifies clinical “cases” requiring intervention.
- The threshold where false positives and false negatives are nearly equivalent is a highly specific, but not very sensitive, marker of clinical “caseness.”

a child may have been diagnosed with ADHD in the past, but was not taking medication at the time of the interview. As well, parent reports that a professional had diagnosed the child with an emotional disorder could refer to a wide range of conditions, including cognitive and learning problems identified by educators, and other behaviour disorders for which medication is not the treatment of choice.

The prevalence estimate of 2.1% for ADHD among 6- to 11-year-olds in Canada is low compared with other estimates. The Ontario Child Health

Study reported 6.1% among children aged 4 to 16,<sup>23</sup> and the Quebec Child Mental Health Survey, 5.4% among children aged 6 to 14.<sup>24</sup> These two estimates were based on combined parent and teacher information about symptoms and a measure of impairment. In a systematic review of studies using this combination of case identification methods, Waddell et al. generated a summary prevalence estimate of childhood ADHD of 4.8% (95% CI: 2.7 to 7.3).<sup>25</sup>

The low estimate from the NLSCY H/I Scale may reflect the use of only parent information. However, it may also reflect the input of clinical professionals. In 2000, British researchers, Goodman et al., estimated that 2.4 % of children aged 5 to 15 had ADHD according to DSM-IV criteria.<sup>26</sup> Their method for identifying cases included parent and teacher reports and measures of impairment, but in addition, a clinician reviewed all material to decide if the child met diagnostic criteria. Health professionals examine children with behavioural problems to find explanations other than ADHD, a judgment not available from surveys, and one that could influence rates of case identification.<sup>27</sup> Therefore, an alternative explanation for the low NLSCY estimate is that it may reflect the practice of Canadian health professionals in 1994/1995. For instance, in 1995/1996, administrative data from Manitoba identified 2.9% of children aged 7 to 9 and 2.2% of children aged 10 to 13 with ADHD, a rate similar to that of the NLSCY.<sup>27</sup>

## **Limitations**

An important question raised by this study is whether parent-reported clinical case markers are the “gold standard” for identification of childhood ADHD. A strong argument can be made that parent reports introduce multiple sources of potential error. Waddell et al.<sup>25</sup> recommended independent professional input for population-based studies. The original design of the NLSCY would have offered the opportunity to use

this method, but missing teacher data preclude this option.

The issue is how best to take advantage of the strengths of NLSCY data to examine predictors and consequences of severe childhood hyperactivity and inattention. The clinical markers are useful target criteria for severe behaviour problems. Specifically, parent-reported history of emotional disorder can be used to set thresholds for the children’s behaviour questionnaire subscales in the NLSCY.

The replicate sampling strategy with replacement rather than a random half sample to create the development set could be a limitation, because individual participants might appear in the dataset more than once. Although this may seem to interfere with the independence of observations (and potentially bias derived estimates), the strategy is a simplified version of the bootstrapping procedure used to provide reliable variance estimates and confidence intervals around values derived in population samples.<sup>17,18</sup> In fact, estimates from the development sample were highly comparable to estimates in the NLSCY parent sample (Table 1).

Some researchers have suggested that NLSCY data can be used without population weights for studies where population estimates are not the primary focus. While the methodological gap addressed here may appear to be such a study, it is important to consider the likelihood of geographic variability. Differences in rates of ADHD diagnosis and psychostimulant prescriptions in administrative data suggest that Canadian children experience differential access to specialists and differences in clinical practice.<sup>27,28</sup> For the current study, the prevalence of clinical markers is too low to generate provincial estimates. Statistics Canada’s cross-sectional population weighting strategies were used to resolve the population distribution issues and provide a national estimate.

An additional limitation is that the scale was developed to elicit information about children aged 4 to 11, but previous diagnosis of emotional disorder and

impairment in school functioning were asked only for children aged 6 to 11. Also, the sample size was not large enough to perform separate sensitivity analyses by sex and age, which are both known modifiers of hyperactivity and attention span. It is plausible that separate threshold values should be set by sex or by age. Finally, the small number of children reported as using methylphenidate or having been diagnosed with an emotional disorder introduces uncertainty. However, a conservative approach was used in the regression analyses, retaining only variables with statistical significance  $\leq 0.01$  and thereby increasing confidence in the results.

### **Future directions**

With the method described in this paper, the parent-reported NLSCY H/I Scale can be used to identify clinically significant ADHD symptoms in Canadian children aged 6 to 11, either as an outcome measure for investigating developmental antecedents of such symptoms, or as an independent variable predicting adolescent and adult outcomes in the NLSCY sample. Even without teacher information, a score of 14 or more on the scale identifies children likely to have clinically significant difficulties. As well, previous diagnosis of emotional

disorder can be used as a target criterion to evaluate other subscales of the NLSCY children's behaviour questionnaire. With a common method of using the behaviour subscales as clinical markers, NLSCY data can be applied to the study of childhood mental health disorders. ■

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