Comparison of the estimated prevalence of mood and/or anxiety disorders in Canada between self-report and administrative data

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Background. To compare trends in the estimated prevalence of mood and/or anxiety disorders identified from two data sources (self-report and administrative). Reviewing, synthesising and interpreting data from these two sources will help identify potential factors that underlie the observed estimates and inform public health action.

Method. We used self-reported, diagnosed mood and/or anxiety disorder cases from the Canadian Community Health Survey (CCHS) across a 5-year span (from 2003 to 2009) to estimate the prevalence among the Canadian population aged ≥ 15 years. We also estimated the prevalence of mood and/or anxiety disorders using the Canadian Chronic Disease Surveillance System (CCDSS), which identified cases using ICD-9/-10-CA codes from physician billing claims and hospital discharge records during the same time period. The prevalence rates for mood and/or anxiety disorders were compared across the CCHS and CCDSS by age and sex for all available years of data from 2003 to 2009. Summary rates were age-standardised to the Canadian population as of 1 October 1991.

Results. In 2009, the prevalence of mood and/or anxiety disorders was 9.4% using self-reported data *v.* 11.3% using administrative data. Prevalence rates obtained from administrative data were consistently higher than those from self-report for both men and women. However, due to an increase in the prevalence of self-reported cases, these differences decreased over time (rate ratios for both sexes: 1.6–1.2). Prevalence estimates were consistently higher among females compared with males irrespective of data source. While differences in the prevalence estimates between the two data sources were evident across all age groups, the reduction of these differences was greater among adolescent, young and middle-aged adults compared with those 70 years and older.

Conclusions. The overall narrowing of differences over time reflects a convergence of information regarding the prevalence of mood and/or anxiety disorders trends between self-report and administrative data sources. While the administrative data-based prevalences remained relatively stable, the self-reported prevalences increased over time. These observations may reflect positive societal changes in the perceptions of mental health (declining stigma) and/or increasing mental health literacy. Additional research using non-ecological data is required to further our understanding of the observed findings and trends, including a data linkage exercise permitting a comparison of prevalence estimates and population characteristics from these two data sources both separately and merged.

Received 22 September 2014; Revised 1 May 2015; Accepted 5 May 2015; First published online 17 June 2015

Key words: Administrative data, epidemiology, mood and/or anxiety disorders, prevalence, self-report data, surveillance.

Introduction

Mental disorders are estimated to affect one in three Canadians in their lifetime (Pearson *et al.* 2013) with mood and anxiety disorders being the most common accounting for approximately 70% of all mental disorders (Public Health Agency of Canada, 2015). In addition to being common, mood and anxiety disorders

have a major impact on the daily lives of those living with the condition as they can cause significant functional impairment. According to the 2010 Global Burden of Disease Project, of the 25 most important causes of disease burden in Canada, major depressive disorder (one of the most common types of mood disorders) ranked fourth and anxiety disorders ranked 18th as assessed by disability-adjusted life years (disability-adjusted life years quantify both premature mortality and disability within a population) (Institute for Health Metrics and Evaluation, 2013).

Estimating the burden of mood and anxiety disorders can be challenging compared with other chronic

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conditions for a multitude of reasons. Firstly, it has been shown that a high proportion of people with symptoms do not seek treatment from health professionals and therefore remain undiagnosed. For instance, estimates from a population-based survey found that 1.6 million (or 6%) Canadians 20 years and older reported symptoms meeting the criteria for mental health problem but were undiagnosed (Lim *et al.* 2008). Several explanations for the low rates of treatment-seeking among those with these disorders have been proposed including: fear of stigma from health professionals and society (Stuart, 2008; Stuart *et al.* 2014), thinking the problem will go away on its own (Andrews *et al.* 2001) and low mental health literacy (Wang *et al.* 2007; Wang & Lai, 2008). In addition, unlike other chronic conditions with a clear physiological basis, there are currently no objective tests with which to assign a diagnosis. As a result, a diagnosis is based on the signs and symptoms reported by the patient, as well as those observed by the physician or relatives (Pies, 2007); therefore, it is possible that individuals can experience symptoms without meeting standard diagnostic criteria and yet receive a diagnosis. Furthermore, the varying duration of mental disorder episodes from one person to another poses another unique surveillance challenge in terms of being able to compute estimates of true incidence; however, it is possible to estimate various period prevalences.

Multiple data sources have been used to identify persons with mood and/or anxiety disorders, including population health surveys, administrative databases, medical chart abstraction and electronic medical records; however, no particular method has emerged as the best option for surveillance purposes. In Canada, the Canadian Community Health Survey (CCHS), administered by Statistics Canada has been the primary means of estimating the prevalence of mental disorders. This cross-sectional, population-based survey has regularly monitored the number of people with a 'professionally diagnosed' mood disorder and/or anxiety disorder along with other long-term conditions which are expected to last or have already lasted 6 months or more.

On account of Canada's public-insurance model of health care delivery, physician billing claims and hospital discharge abstract records have also been used for surveillance of mental disorders in Canada (Public Health Agency of Canada, 2013). In 2010, the Public Health Agency of Canada expanded the Canadian Chronic Disease Surveillance System (CCDSS) to include surveillance of mental disorders including mood and/or anxiety disorders. The CCDSS is a network of provincial and territorial surveillance systems that identifies disease events based on algorithms

applied to administrative health data such as physician billing claims and hospital discharge abstract records.

While both of these surveillance data sources can provide national estimates for mood and/or anxiety disorders they are not without limitations. For instance, cases captured by the CCHS rely on self-disclosure and are limited to the Canadian household population, while cases identified by the CCDSS depend on a relevant diagnostic code being captured in provincial and territorial administrative health databases. As a result there are advantages to triangulating findings, an approach used to synthesise multiple data sources at the level of interpretation, to help offset the biases or short-comings found in any single data source (Rutherford *et al.* 2010). This approach is often used to validate results, increase credibility and gain a more detailed understanding of the findings (Cohen & Manion, 1986; Donoghue & Punch, 2003); however, it should not be confused with cross-validation which requires data linkage at the individual level. Furthermore, given that mood and anxiety disorders are typically underreported, assessing the true prevalence is especially challenging making the advantages of triangulation particularly valuable. It is also important to keep in mind that the performance of an indicator within any single data source may change over time. Changes in care delivery, health behaviour and care-seeking behaviour can impact both the true and estimated incidence and prevalence of a specific disease over time.

The purpose of this study is to compare trends in the estimated prevalence of mood and/or anxiety disorders using data from the CCDSS and CCHS. Reviewing, synthesising and interpreting data from these two sources will help identify potential factors that underlie the observed estimates and inform public health decision making and actions. Furthermore, different countries may have alternative strategies for monitoring the mental health of their population and an expanded literature of describing the patterns of prevalence seen with different methods/data sources may ultimately facilitate the emergence of a consensus about best practices.

Methods

Data sources

The CCDSS identifies disease events from administrative data – including physician billing claims, hospital discharge abstract records (which do not include emergency department data) – linked to provincial/territorial health insurance registry data (Public Health Agency of Canada, 2013). All residents who are eligible to receive provincial or territorial health insurance are included, representing 97% of the Canadian

population. Exclusions include Canadians covered under federal health programmes, such as First Nations on reserve [under the *Indian Act*, an 'Indian Reserve' is land held by the Crown 'for the use and benefit of the respective bands for which they were set apart' under treaties or other agreements. The reserve system as governed by the Indian Act relates to First Nations bands and people, referred to in a legal context as Indians. Available from: www.thecanadianencyclopedia.ca/en/article/aboriginal-reserves/ (accessed 19 October 2014)], refugee protection claimants, full-time members of the Canadian Forces, eligible veterans, individuals in the Royal Canadian Mounted Police and federal penitentiary inmates (Public Health Agency of Canada, 2010).

The CCHS is a cross-sectional population-based survey that uses computer-assisted telephone interviews to assess various health states, health determinants and risk factors among Canadians. The CCHS covers the population 12 years of age and older living in private dwellings in the ten provinces and three territories. Exclusions from the survey's coverage include: individuals living in institutions, homeless persons, First Nations population living on reserve, full-time members of the Canadian Forces and residents of certain remote regions. These exclusions represent less than 3% of the target population (Statistics Canada, 2013).

Study population

A case was identified within the CCDSS if that person had a mood disorder, an anxiety disorder or both by way of the following case definition: at least one physician billing claim or hospital discharge abstract with any of the following ICD-9 or ICD-9-CM codes: 296, 300 or 311, or their ICD-10-CA equivalents (i.e. F30-F39, F40-F48 and F68). Under this case definition, individuals had to qualify as a case in a given fiscal year to be counted in that fiscal year; thus, the prevalence estimates reflect an annual prevalence. Due to the high rates of comorbidity (Regier *et al.* 1998; Kaufman & Charney, 2000; Wittchen *et al.* 2003; King-Kallimanis *et al.* 2009) and varying coding practices across jurisdictions, mood disorders cannot be differentiated from anxiety disorders at the national level in a meaningful way (Kisely *et al.* 2009a).

Questions on professionally diagnosed mood and anxiety disorders first appeared in the CCHS in 2003, i.e. 'Do you have a mood disorder such as depression, bipolar disorder, mania or dysthymia?' and 'Do you have an anxiety disorder such as a phobia, obsessive compulsive disorder or a panic disorder?' (Statistics Canada, 2004, 2006, 2008, 2009, 2010). These questions were included in the chronic conditions module which focused on conditions diagnosed by a health

professional that had lasted, or were expected to last, 6 months or longer (Statistics Canada, 2004, 2006, 2008, 2009, 2010); however, the time frame that respondents received their mood and/or anxiety disorder diagnosis was not specified. Until 2007, the CCHS 'core survey' was conducted biennially, with special focus surveys conducted in the intervening years. Since 2007, the CCHS has been conducted on an annual basis and the core surveys have been renamed the 'Annual Component'. In this study, both mood and anxiety disorder cases diagnosed by a health professional were included from the CCHS, for comparability purposes with the CCDSS data.

Statistical analysis

Estimates from the CCHS were weighted to reflect the Canadian population using weights provided by Statistics Canada (2004, 2006, 2008, 2009, 2010). The 95% confidence intervals (95% CI) were calculated using exact standard errors generated through bootstrap re-sampling (Rust & Rao, 1996). The prevalence rates for mood and/or anxiety disorders were compared across the CCDSS and CCHS surveys by age and sex for all available years of data from 2003 to 2009 (except for 2004 and 2006 as the CCHS did not capture mood or anxiety disorders in those years). Prior to 2005, CCDSS data from Nunavut, one of the three Canadian territories, were unavailable therefore, CCHS data from Nunavut were not included in the analyses (note, the population of Nunavut is approximately 0.1% of the overall Canadian population) [Statistics Canada. Population by year, by province and territory. Available from: www.statcan.gc.ca/tables-tableaux/sum-som/101/cst01/demo02a-eng.htm (accessed 19 September 2014)]. Summary rates were age-standardised to the Canadian population as of 1 October 1991 (a census year). All analyses were restricted to individuals aged 15 years and older in order to match the age groupings of the CCDSS and CCHS and data. All analyses were performed with SAS Enterprise Guide version 5.1 (SAS Institute, Cary, NC).

Results

According to results from the CCDSS, there were over 29 million Canadians aged 15 years and older with valid provincial or territorial health care insurance in 2009/2010. Similarly, weighted results from the 2009 CCHS estimated a population of over 27 million age 15 years and older.

In 2009, the prevalence of diagnosed mood and/or anxiety disorders was 11.3% based on administrative

Table 1. Age-standardised prevalence rates and rate ratios of mood and/or anxiety disorders by sex: CCDSS and CCHS aged 15 and older, Canada 2003–2009^a

Sex	Year	CCDSS age-standardised prevalence rate (95% CI)	CCHS age-standardised prevalence rate (95% CI)	CCDSS:CCHS prevalence rate ratios
Both	2003	12.4 (12.4–12.4)	7.6 (7.4–7.9)	1.6
	2005	12.2 (12.2–12.2)	8.3 (8.1–8.5)	1.5
	2007	11.6 (11.6–11.7)	9.6 (9.2–9.9)	1.2
	2008	11.4 (11.4–11.4)	10.0 (9.6–10.4)	1.1
	2009	11.3 (11.3–11.3)	9.4 (9.0–9.8)	1.2
Female	2003	15.9 (15.9–15.9)	9.9 (9.5–10.2)	1.6
	2005	15.6 (15.6–15.6)	10.6 (10.3–11.0)	1.5
	2007	14.8 (14.8–14.9)	12.4 (11.8–13.0)	1.2
	2008	14.5 (14.5–14.5)	12.7 (12.1–13.3)	1.1
	2009	14.3 (14.3–14.3)	11.9 (11.3–12.6)	1.2
Male	2003	8.9 (8.9–8.9)	5.4 (5.1–5.6)	1.7
	2005	8.8 (8.8–8.8)	5.9 (5.6–6.2)	1.5
	2007	8.4 (8.4–8.4)	6.7 (6.3–7.2)	1.3
	2008	8.3 (8.3–8.3)	7.2 (6.7–7.7)	1.2
	2009	8.3 (8.2–8.3)	6.9 (6.4–7.4)	1.2

Source: Public Health Agency of Canada using 2003–2009 data from the Canadian Chronic Disease Surveillance System (CCDSS), 2003–2009 data from the Canadian Community Health Survey (CCHS), Statistics Canada and 1991 Census population for age-standardisation.

^a2003 estimates – data from nunavut not included.

data v. 9.4% using self-reported data (Table 1 and Fig. 1). Overall, the prevalence estimates from administrative data were consistently higher than those from self-report; however, these differences decreased over time (rate ratios for both sexes: 1.6–1.2). This phenomenon was mainly due to an increase in the prevalence of self-reported cases. While there was also a slight simultaneous decline in the CCDSS prevalence during the study period, the trend over a longer time frame (i.e. 1996/1997 to 2008/2009) was actually relatively stable (data not shown). Furthermore, the prevalence estimates from administrative data were consistently higher compared with estimates from self-reported data for both males and females (with females having higher rates overall compared with males); however, these differences also decreased over time.

In 2003, the differences between the prevalence rates from the two data sources were substantial across all age groups (Fig. 2). Over time, these differences decreased with the prevalence from CCHS approaching that of the CCDSS in all age groups under 70. Starting in 2007, among those under 25 years of age, the differences were no longer statistically significant. Similarly, in the final year, there were fewer differences between the two data sources among middle aged individuals (i.e. age groups 40–44 and 45–49 years). While substantial differences between the two data

sources persisted among those 70 years and older, they also decreased over time.

Discussion

In summary, the prevalence estimates for mood and/or anxiety disorders based on administrative data were consistently higher compared with those derived from self-reported data for both men and women (11.3 and 9.4% in 2009, respectively). However, due to an increase in the prevalence of self-reported cases, these differences decreased over time (rate ratios for both sexes: 1.6–1.2). Prevalence estimates were consistently higher among females compared with males irrespective of data source. The prevalence rates reported within this study are broadly consistent with other sources of epidemiological survey and administrative health information (McDougall *et al.* 2007; Kessler & Üstün, 2008; Kessler *et al.* 2009; Kisely *et al.* 2009a). The consistently higher estimates derived from administrative v. self-report data are supported by findings from a study by Palin *et al.* (2012) which suggested that administrative data may capture less severe or subclinical cases compared with survey data. Having said that, there is some question whether administrative data can ever be used for the accurate detection of depression prevalence due to the

Fig. 1. Age-standardised prevalence of mood and/or anxiety disorders by sex: Canadian Chronic Disease Surveillance System (CCDSS) and Canadian Community Health Survey (CCHS) age 15 years and older, Canada 2003–2009^a.

Source: Public Health Agency of Canada using 2003–2009 data from the CCDSS, 2003–2009 data from the CCHS, Statistics Canada and 1991 Census population for age-standardisation;

^a2003 estimates – data from nunavut not included.

Fig. 2. Age-specific prevalence of mood and/or anxiety disorders: Canadian Chronic Disease Surveillance System (CCDSS) and Canadian Community Health Survey (CCHS) age 15 years and older, Canada 2003–2009^a.

Source: Public Health Agency of Canada using 2003–2009 data from the CCDSS and 2003–2009 data from the CCHS. ^a2003 estimates (E) – data from NU not included. ^EInterpret with caution due to high sampling variability.

incomplete recognition of depression clinical practice (Townsend *et al.* 2012). While some psychiatric epidemiological surveys have reported higher prevalence rates than found in our study (Kessler & Üstün, 2008; Kessler *et al.* 2009), some of these may have been at risk of overestimating the prevalence (Mitchell, 2012). Whereas those surveys that reported lifetime prevalence rates may be flawed by recall bias (Streiner *et al.* 2010).

Although the differences in prevalence estimates between the two data sources were evident across all age groups, the narrowing of these differences was greater among adolescent, young and middle-aged adults compared with those older (i.e. 70 years and older). This could be due to an issue of overdiagnosis in the clinical setting, a failure to self-report or a combination of both. Although, some studies using survey data have shown that the lower prevalence observed among older adults with mood and anxiety disorders is not due to underreporting (Kessler *et al.* 2010; Hobbs *et al.* 2014). Furthermore, the pattern of declining age-specific self-reported prevalence is consistent with studies that use diagnostic instruments such as the Composite International Diagnostic Interview which do not require disclosure of a diagnosis, only reporting of symptoms (Patten, 2009; Simpson *et al.* 2012). Assuming this is true, administrative data may overestimate the prevalence of these disorders in older adults as a result of the greater number of opportunities to recognise/diagnose less severe or subclinical cases in this segment of the population given they are the most frequent users of the health care system (Canadian Institute for Health Information, 2011).

As previously mentioned, both data sources are not without their limitations. For instance, the CCHS relies on self-disclosure which may be problematic: particularly, for mental disorders due to issues of self-stigma. In addition, the CCHS coverage is limited to the Canadian household population, while the CCDSS covers all residents who are eligible for provincial or territorial health insurance and is therefore, is near universal. The two million (or 7%) difference between the two target populations as described in the result section may in part be due to the differences in the coverage between these two populations. Furthermore, since the case finding question within the annual CCHS asks respondents whether they have a mood or anxiety disorder that has been diagnosed by a health professional without specifying a particular time frame, we cannot assume that the estimates derived from the CCHS produce an annual prevalence rate and therefore, our ability to directly compare CCHS estimates to CCDSS estimates is limited.

Conversely, while the CCDSS does not rely on self-disclosure, it may have missed people that received a

mood and/or anxiety disorder diagnosis but were not captured in physician billing claims or hospital discharge abstract records. For instance, the CCDSS does not capture eligible cases who: presented to an emergency department only; received care in a hospital that does not submit discharge abstract data to the Discharge Abstract Database (or in the case of Quebec, the MED-ÉCHO); were seen and diagnosed by salaried physicians (including psychiatrists) that do not shadow bill [claims submitted to the provincial government by physicians on alternate payment plans for services they provide. Unlike physician claims submitted by fee-for-service physicians for payment, these claims are for administrative purposes only (i.e. as a record of services provided)]; sought care from community-based clinic or private setting (e.g. services from psychotherapists, psychologists, social workers or counsellors); or sought care but did not receive a relevant mood and/or anxiety diagnostic code due to psychological considerations such as concerns about protecting a patient's confidentiality leading some physicians to substitute non-mental diagnoses on claims (Rost *et al.* 1994; Townsend *et al.* 2012). In light of all of these potentially missed cases, it is worth mentioning that the primary care general medical system is the most widely used service for mental health reasons in Canada (Bland *et al.* 1990; Lin *et al.* 1996; Lefebvre *et al.* 1998; Vasiliadis *et al.* 2005). In addition, results from a feasibility study using administrative data for the surveillance of mental disorders examined the effect of including data from some community-based databases in two provinces (British Columbia and Nova Scotia) found that the prevalence of treated mental disorders increased by only 1% (Kisely *et al.* 2009b). Lastly, the impossibility to disentangle mood disorders from anxiety disorders in a meaningful way for the national surveillance of these disorders represents another limitation of the CCDSS (Kisely *et al.* 2009a). Societally, there have been efforts to increase awareness, understanding and acceptance of mental disorders towards people affected by these conditions. In Canada, for example, the creation of the Mental Health Commission of Canada in 2007 and the release of the first national Mental Health Strategy in 2012 (Mental Health Commission of Canada, 2012) were major steps forward in the recognition of this important public health problem. As well, the majority of the provinces and territories currently have mental health strategies and/or action plans in place. In addition, employers are paying more attention to workplace wellbeing in order to respond to the rising cost of absenteeism due to mental health problems (Morrison & MacKinnon, 2008). Furthermore, the media and public figures also have played a role in reporting and raising awareness

about mental disorders and suicides among young Canadians.

Without fear of judgement or discrimination, more people might be open to seeking care for their symptoms or speaking more openly about their emotions. In fact, it has been suggested that a changing conceptualisation of mental health has resulted in people being more likely to report that a mental health disturbance is due to a disorder rather than a reaction to stressful events (Simpson *et al.* 2012). Furthermore, efforts made in improving the mental health literacy of the general population (i.e. the knowledge and beliefs about mental disorders), may also aid in their recognition, management or prevention (Jorm, 2000). Another sign of the increasing acceptance and awareness of these disorders is the increasing use of antidepressant medications (Simpson *et al.* 2012; Reid, 2013). Marketing has played a role in the uptake of medications commonly prescribed for depression and anxiety (Spence, 2013).

While the differences we observed between self-reported and administrative data may reflect negative attitudes towards personal disclosure of mental disorders, the narrowing difference between the rates over time is noteworthy and may suggest that perspectives surrounding mental disorders are changing that is, stigma is diminishing and/or mentalisation is improving. In the context of stigma, being assigned a mental disorder diagnosis would be akin to having an 'attribute that is deeply discrediting' which reduces the bearer 'from a whole and usual person to a tainted, discounted one' (Goffman, 1963). With this in mind, a person that has been diagnosed with mood and/or anxiety disorder(s) may not be willing to disclose this to an interviewer as they are ashamed to do so. While the stigmatising physician (trying to protect their patients from what they may view as a harmful label of mental illness) may not have diagnosed their patient formally (e.g. told them that it was their 'nerves' or that there was 'nothing physically wrong') which may have resulted in the diagnosis not being reported later in a survey, even if it did appear as such in administrative data recorded by the physician. Diminishing stigma could therefore account for some of the observed changes over time. Another potential explanation may be related to mentalisation, i.e. a person who is not aware of their own struggle with mood and/or anxiety disorder(s) may not acknowledge or understand the idea of a diagnosis and therefore may have been less likely to report it on a survey even if the diagnosis was made and recorded in administrative data. This term is also referenced or referred to in the current literature as 'mental health literacy' (Jorm, 2000). Improved mentalisation or mental health literacy may also help to explain the convergence of estimates

based on self-reported v. administrative data over time.

While multiple data sources have been used to identify persons with mood and/or anxiety disorders – no particular method has emerged as the gold standard. As result, we must rely on imperfect surveillance data to guide public health decision making and action. Triangulation of multiple data sources can enhance confidence in the overall findings and further our understanding of trends. Findings from this study suggest that the prevalence of mood and anxiety disorders based on self-reported data is underreported although this appears to be improving over time. However, these two sources of data are distinct and cannot be used interchangeably (Palin *et al.* 2012). Future work including a data linkage exercise permitting a comparison of prevalence estimates and population characteristics from these data sources both separately and merged may enhance our understanding of their strengths and limitations of thereby furthering our understanding of the observed findings and trends.

Conclusions

While there has been a lot of debate about the best method to monitor prevalence of mood and/or anxiety disorders, there is still no perfect way to do so. There does seem to be a convergence of information from different sources which may in part be attributed to positive societal changes in perceptions of mental health. Additional studies using non-ecological data are required to confirm these possibilities.

Acknowledgements

Scott B. Patten is a Senior Health Scholar with Alberta Innovates, Health Solutions. The authors would like to acknowledge the members (current and past) of the CCDSS Mental Illness Working Group who help to inform the expansion of the CCDSS to include surveillance of mental illness: Cheryl Broeren, Leslie Anne Campbell, Wayne Jones, Steve Kisely, Alain Lesage, Adrian Levy, Elizabeth Lin, Peter Nestman, Kim Reimer, Mark Smith, Larry Svenson and Helen-Maria Vasiliadis. The research and analysis are based on self-report data (CCHS) from Statistics Canada and administrative data (CCDSS) from the respective provincial governments of Newfoundland and Labrador, Prince Edward, Nova Scotia, New Brunswick, Quebec, Ontario, Manitoba, Saskatchewan, Alberta, British Columbia, Yukon, Northwest Territories and Nunavut. The opinions, results and conclusions reported in this paper are those of the authors. No endorsement by

Statistics Canada or the provinces/territories is intended or should be inferred.

Financial Support

This research received no specific grant from any funding agency, commercial or not-for-profit sectors.

Statement of Interest

None.

Ethical Standards

This research does not contain clinical studies or patient data.

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