Estimating the Population Prevalence of Diagnosed and Undiagnosed Diabetes

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OBJECTIVE—Health administrative data are frequently used for diabetes surveillance, but validation studies are limited, and undiagnosed diabetes has not been considered in previous studies. We compared the test properties of an administrative definition with self-reported diabetes and estimated prevalence of undiagnosed diabetes by measuring glucose levels in mailed-in capillary blood samples.

RESEARCH DESIGN AND METHODS—A stratified random sample of 6,247 individuals (Quebec province) was surveyed by telephone and asked to mail in fasting blood samples on filter paper to a central laboratory. An administrative definition was applied (two physician claims or one hospitalization for diabetes within a 2-year period) and compared with self-reported diabetes alone and with self-reported diabetes or elevated blood glucose level ($\geq$7 mmol/L). Population-level prevalence was estimated with the use of the administrative definition corrected for its sensitivity and specificity.

RESULTS—Compared with self-reported diabetes, sensitivity and specificity were 84.3% (95% CI 79.3–88.5%) and 97.9% (97.4–98.4%), respectively. Compared with diabetes by self-report and/or glucose testing, sensitivity was lower at 58.2% (52.2–64.6%), whereas specificity was similar at 98.7% (98.0–99.3%). Adjusted for sampling weights, population-level prevalence of physician-diagnosed diabetes was 7.2% (6.3–8.0%). Prevalence of total diabetes (physician-diagnosed and undiagnosed) was 13.4% (11.7–15.0%), indicating that ~40% of diabetes cases are undiagnosed.

CONCLUSIONS—A substantial proportion of diabetes cases are missed by surveillance methods that use health administrative databases. This finding is concerning because individuals with undiagnosed diabetes are likely to have a delay in treatment and, thus, a higher risk for diabetes-related complications.

Diabetes Care 36:3002–3008, 2013

The rapid rise in diabetes incidence and prevalence is placing substantial strains on health care systems in terms of management of both the disease itself and its complications (1). Accurate disease surveillance, therefore, is critical to making proper projections of health care needs and costs. In Canada, the National Diabetes Surveillance System (NDSS) tracks diabetes prevalence through physician billing and hospital admissions databases (2–4). Similar algorithms have been used in the U.S. and other countries (3,5–12). Although these administrative health database definitions have been validated through medical record (4,13), survey (4,6,8,14,15), and medication use data (4,10,16), no validation study of claims-based administrative algorithms has accounted for previously undiagnosed diabetes.

In the current study, we validated an administrative database diabetes definition and estimated the prevalence of physician-diagnosed diabetes through a population-based health survey. We used a novel approach to estimate the prevalence of undiagnosed diabetes that involved mailed-in capillary blood samples in which fasting glucose levels were measured at a central laboratory. Finally, by using survey data and glucose levels to correct the administrative database diabetes definition, we estimated the actual diabetes prevalence and compared this with what would have been estimated by the uncorrected definition.

RESEARCH DESIGN AND METHODS—The source population included residents of the Canadian province of Quebec. The Régie de l'assurance maladie du Québec (RAMQ), the government body that administers the public insurance plan for physician services and hospitalization costs, generated a stratified random sample (*n* = 6,247) for this study, oversampling less populated regions (17). These individuals were surveyed by telephone or mail and asked to mail in a self-collected capillary blood sample for glucose testing, as described later. Study procedures were approved by the Commission d'accès à l'information du Québec and the Institutional Review Board of the McGill University Health Centre.

The survey questionnaire was administered by trained Quebec Statistical Institute (QSI) staff from 31 March to 14 July 2009, including weekdays and weekends and daytime and evening hours by telephone. Before the telephone survey, a letter describing the study was sent, giving an option to respond to the survey by mail. Participants were queried about diabetes with the following survey question: "Have you ever been told by a doctor or another health professional that you had diabetes?" Other data collected were sociodemographic factors, family history of diabetes, engagement in regular exercise, smoking, height and weight, and use of health care services. QSI survey questions were based on those of the Canadian Community Health Survey (18).

Participants received capillary blood sampling instructions (Supplementary Fig. 1), lancing materials, and specially

printed Whatman No. 3 filter paper that included two drops of quality control solution. After an overnight fast, they were asked to clean their fingertip with an alcohol swab, puncture it with a lancet, and squeeze a drop of blood onto two circles printed on the filter paper. They were then asked to return the filter paper in the stamped, self-addressed envelope provided.

The blood samples were analyzed for glucose measurements at the central laboratory at Saint-Luc Hospital in Montreal. The centers of the blood spots were cut out by a hand-held 6-mm punch, and these were placed in tubes filled with 400 μL of 2.5% trichloroacetic acid solution. The tubes were shaken manually at 10-min intervals for 1 h at room temperature and then centrifuged at 3,000 rpm for 10 min. Supernatants were transferred into sampling cups and immediately analyzed by observing the reaction with hexokinase. The eluate:reagent ratio was set at 1:11, and the reaction was monitored bichromatically (340 and 380 nm) at 37°C for 6 min. The results were recorded from the calibration curve established according to standards prepared on the date the filter papers were issued to participants. Because glucose values may have a maximum decay of 20% over time, the results were adjusted according to the value of the internal standard and the time elapsed between the dates of blood sampling and the date of measurement (19). This filter paper technique has been shown to have a coefficient of variance of 3.6% within assays and of 4.2% between assays. Correlation with ordinary whole-blood glucose dehydrogenase method is good ($r = 0.98$) (20).

Survey and glucose results were linked to health administrative data for the period 1 January 1997 to 31 December 2009. The research team received no nominal information. We examined baseline characteristics of the entire sample, survey respondents, and the subgroup providing glucose samples. Variables were a socioeconomic status (SES) measure, with subindices of social and material deprivation, that was developed by the Institut national de santé publique du Québec on the basis of census enumeration area data on education level, employment/population ratio, and average income (21,22). This SES measure is associated with a higher risk of stroke mortality, myocardial infarction mortality, and disability in diabetes (23).

Within the survey sample, we compared the NDSS diabetes case definition

of two or more physical billings for diabetes and/or one or more hospitalizations for diabetes within a 2-year period from administrative databases, with self-reported diabetes from the survey as the reference standard. Within the subgroup with glucose values, we compared the NDSS definition with a diabetes definition that included self-report and/or elevated fasting glucose level. We selected a threshold of 7 mmol/L to define diabetes; this threshold is aligned with current clinical practice guidelines for diabetes diagnosis by fasting plasma glucose level (24–26). Although glucose measurements on capillary whole blood can be up to 15% lower than plasma because of the influence of hematocrit, the difference varies considerably (27). Thus, we opted for this conservative cutoff value to avoid overestimating prevalence.

For these comparisons, we calculated the κ statistic (Fleiss equation), sensitivity, specificity, positive predictive value (PPV), and negative predictive value. We then applied the NDSS definition to the entire random sample and used the sensitivity and specificity estimates to adjust prevalence estimates. The correction equation used was the following: [proportion of positive NDSS cases – (1 – specificity)] / (sensitivity + specificity – 1) (28). Finally, we extrapolated diabetes prevalence estimates from the sample to the Quebec population, using appropriate sampling weights as provided by the QSI.

As an alternative approach, we used logistic regression models derived from RAMQ baseline characteristics to impute self-reported diabetes and glucose values for those in the stratified random sample who had not completed the survey. A Bayesian approach available in the statistical software was selected for this multiple imputation. Again, we extrapolated to the Quebec population by sampling weights.

The RAMQ data linkage with the QSI survey data was executed and retrieved with SAS version 9.2 statistical software. Subsequent statistical analyses were performed with STATA version 11 software.

RESULTS

Stratified random sample
Among the 6,247 individuals from the sample at the time of the study, 12 had moved out of the province of Quebec, 10 were deceased, and 1 was <20 years of age. Of the original random sample, 33.9% either had an incorrect telephone number or did not have a listed telephone

number, 9.6% did not respond to telephone calls, and 56.1% (n = 3,504) were contacted by telephone. Among individuals contacted by phone, 83.9% (n = 2,940 [47.1% of the original sample]) completed the telephone-administered questionnaire. We received an additional 566 (9.1% of the original random sample) questionnaires by mail. Thus, the final response rate was 56.1%, comprising 3,506 participants among whom 95.8% (n = 3,322 [53.2% of original sample]) agreed to record a linkage between survey and health administrative data. A total of 1,829 participants (29.3% of original sample [52.2% of survey respondents]) provided mailed-in blood samples of which 89.1% (n = 1,629 [26.1% of original random sample]) were analyzable. Nonanalyzable samples were mainly a result of inadequate quantities of blood (Fig. 1).

Individuals in the stratified random sample had a mean age of 49.7 (SD 16.4) years and were equally distributed between men and women (Table 1). The proportion of NDSS cases was highest among survey respondents who provided analyzable blood samples (10.3% [95% CI 8.8–11.8%]) followed by survey respondents as a whole (8.5% [7.6–9.4%]) and the original random sample (7.5% [6.8–8.2%]). Survey respondents and participants who provided analyzable blood samples were comparable with the original random sample for other baseline characteristics. Likewise, survey data on body mass index, ethnicity, family history of diabetes, and frequency of physician visits did not differ importantly.

Validation of the NDSS case definition
Among survey respondents, the NDSS and self-reported diabetes definitions were concordant (κ statistic 0.79 [95% CI 0.76–0.83]) (Table 2). Table 3 shows the sensitivity, specificity, and PPV of the NDSS case definition, using self-reported diabetes as the reference standard. Sex-specific analyses suggested similar sensitivity (women 81.4% [95% CI 73.0–88.1%], men 86.5% [79.9–91.5%]), PPV (women 75.4% [66.8–82.8%], men 79.5% [72.4–85.5%]), and specificity (women 98.2% [97.4–98.8%], men 97.7% [96.7–98.4%]). When the self-report and/or elevated glucose level definitions were used as the gold standard, concordance with the NDSS definition was lower (κ statistic 0.67 [0.62–0.71]) (Table 2). The prevalence of diabetes among men was higher
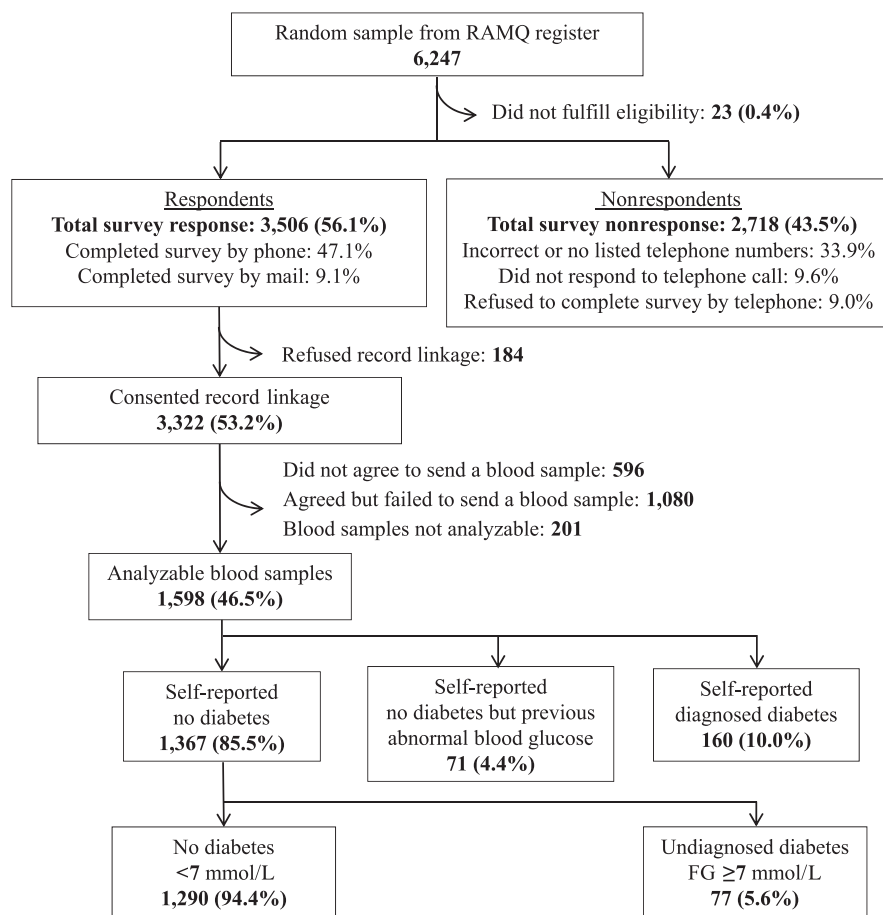
Figure 1—*Flow diagram of participants in QSI survey and home fasting blood glucose sampling. FG, fasting glucose.*

than among women (by NDSS criteria, 13.3% [10.9–15.7%] vs. 7.7% [5.9–9.5%], respectively; by self-report and/or elevated glucose level, 18.5% [15.7–21.3%] vs. 11.6% [9.4–13.8%], respectively).

Diabetes prevalence within the random sample

The proportion of NDSS positive cases in the random sample was 7.5% (95% CI 6.9–8.2%) (women 6.9% [6.0–7.8%], men 8.2% [7.2–9.2%]) (Table 4). Adjusted for test properties when diabetes by self-report was the reference standard, diabetes prevalence was 6.6% (6.0–7.2%) (women 6.4% [5.5–7.3%], men 6.9% [6.0–7.8%]); multiple imputation methods yielded an estimate of 6.6% (5.9–7.2%). Adjusted for test properties when diabetes by self-report and/or elevated fasting glucose level was the reference standard, the prevalence estimate was 10.8% (10.1–11.5%); multiple imputations methods yielded an estimate of 11.2% (10.4–12.0%).

Estimating the population prevalence of diabetes

After adjusting the weighted prevalence estimate by using the test properties of the NDSS criteria derived from self-reported diabetes (7.7% [95% CI 6.8–8.6%]), the resulting population prevalence estimate for diagnosed diabetes and total diabetes was 6.8% (5.7–7.9%) and 11.2% (9.6–12.8%), respectively. When the prevalence estimate for undiagnosed diabetes in Quebec was added to the weighted prevalence of diabetes by self-report, the total diabetes prevalence in Quebec was 13.4% (11.7–15.0%).

CONCLUSIONS

Principal findings

This study demonstrates that a widely used administrative database definition for physician-diagnosed diabetes has a high concordance with self-reported diabetes identified through survey (κ statistic 0.79, sensitivity 84.3%, specificity 97.9%). However, concordance is lower

with diabetes identified by self-report and/or glucose testing by mailed-in blood samples (κ statistic 0.66, sensitivity 58.2%, specificity 98.7%). A substantial proportion of diabetes cases are not captured by either administrative data or self-report because both rely on physician diagnosis. Accounting for the sampling weights of survey respondents, the 2009 Quebec population prevalence of physician-diagnosed diabetes identified by means of the administrative algorithm or self-report was ~7%. The prevalence rose to >11% with the inclusion of previously undiagnosed diabetes. Thus, ~40% of diabetes cases in the province of Quebec appear to be undiagnosed.

The 84.3% sensitivity estimate of the NDSS case definition for physician-diagnosed diabetes detected in the current study is similar to the 85% sensitivity reported by Hux et al. (4) in Ontario, who compared the NDSS case definition with self-reported diabetes from the National Population Health Survey. The sensitivities of the NDSS case definition of these studies were somewhat higher than that reported in Manitoba (6) (76%; reference standard was self-reported diabetes from Manitoba Heart Health Survey [MHHS]) and Minnesota (8,15) (76% and 74%; reference standard was self-reported diabetes from a health maintenance organization survey and a Medicare health beneficiaries survey, respectively). Specificities of these studies were uniformly high (>97%).

Of note, we determined the point estimate of the NDSS sensitivity for physician-diagnosed diabetes to be slightly better for men than for women. Variations in the diagnostic accuracy of the NDSS criteria across subgroups were also identified in an earlier Canadian study by Koleba et al. (16). It has been proposed that women are more likely to present with multiple medical complaints (29); therefore, diabetes is not as frequently coded as the primary diagnosis even if these women have diagnosed diabetes. Heterogeneity in NDSS criteria accuracy among subgroups that are based on demographic characteristics has also been reported in other studies (30).

Correction factors

Under the assumption that self-reported diabetes is a gold standard for physician-diagnosed diabetes, the following correction factor could be applied to prevalence estimates derived from the NDSS case definition: (proportion of diabetes cases − 0.021)/0.822. Importantly, however, the

Table 1—*Selected baseline characteristics from RAMQ administrative databases and QSI survey item responses*

Baseline characteristic	Entire stratified random sample	Survey respondents[a]	Participants who provided analyzable blood glucose samples
Patients (n)	6,247	3,322	1,598
Age (years)	49.7 (16.4)	51.2 (15.1)	52.4 (14.4)
Diabetes by NDSS criteria	469 (7.5)	283 (8.5)	165 (10.3)
Self-reported diabetes	—	261 (7.9)	160 (10.0)
Women	3,206 (51.3)	1,767 (53.2)	845 (52.9)
Rural residence[b]	1,018 (16.3)	560 (18.9)	290 (18.1)
Hospitalization in the past year	617 (9.9)	354 (10.7)	184 (11.5)
Hypertension in the past year	608 (9.7)	334 (10.1)	175 (11.0)
Ischemic heart disease in the past year	226 (3.6)	129 (3.9)	66 (4.1)
Heart failure in the past year	140 (2.2)	69 (2.1)	32 (2.0)
Cancer in the past year	247 (4.0)	134 (4.0)	72 (4.5)
Material deprivation index[c]	2.9 (1.5)	2.9 (1.5)	2.9 (1.5)
Social deprivation index[c]	3.0 (1.5)	2.9 (1.5)	2.8 (1.5)
Survey respondents	3,322 (53.2)	—	—
BMI (kg/m^2)	—	26.3 (5.1)	26.5 (5.4)
Family history of diabetes	—	1,417 (42.7)	722 (45.2)
Non-Caucasian ethnicity	—	1,204 (36.2)	523 (32.7)
Self-reported regular physician visits (annually)	—	2,593 (78.1)	1,269 (79.4)

Data are mean (SD) or n (%). BMI, body mass index. [a]This group represents the 3,322 survey respondents who agreed to have their responses and biochemical data linked to RAMQ information. [b]Residence status of 13.7% individuals in the random sample was missing. [c]Material and social deprivation indices are scored from 1 to 5 on the basis of quintiles, and mean (SD) of the quintiles are reported.

NDSS case definition was found to have a higher false-positive rate compared with self-report diabetes alone than with diabetes identified by self-report and/or glucose testing (22.3% vs. 10.3%). Some participants may have failed to report physician-diagnosed diabetes, but would have been captured by the NDSS criteria or through mailed-in samples if fasting glucose values remained elevated. Failure to report diabetes on surveys could result from lack of comprehension (e.g., perceiving that treatment cures disease) or the stigma of having a chronic disease commonly associated with poor lifestyle habits. Despite this shortcoming, self-report from surveys is a suitable case ascertainment technique for diabetes surveillance of the whole population because it potentially covers individuals who do not come into regular contact with health services (6,31,32).

Alternative reference standards used to validate claims-based administrative algorithms, such as medication dispensation administrative data or primary care chart reviews, may not be representative of the general population (4). Quebec prescription databases are populated only with data on individuals who are covered by the public drug insurance plan, including persons ≥65 years of age, recipients of last-resort financial assistance, marginalized social groups, the self-employed, and individuals in the workforce who do not have private drug insurance (4,33). In addition, medication dispensation data do not capture patients who are not receiving pharmacologic therapy. With respect to primary care chart reviews, some diabetes cases may be missed because not all patients undergo glucose testing. Even if medical chart reviews are conducted in randomly selected family physician offices, results may not always be generalizable to the entire population, underscoring the potential utility of mailed-in blood samples in systematic glucose testing for population prevalence estimation.

In contrast to other validation studies of administrative algorithms, we measured fasting glucose levels on mailed-in blood samples to generate a new reference standard that took into account undiagnosed diabetes cases. We are thus able to propose the following correction factor to estimate the population prevalence of total diabetes from the NDSS case definition: (proportion of diabetes cases − 0.011) / 0.574. Hux et al. (4) reported a 1998 diabetes prevalence in Ontario of ~6.8%, which was very similar to the physician-diagnosed diabetes population prevalence found in the current study. By applying our proposed correction equation, the 1998 Ontario population prevalence of both physician-diagnosed and undiagnosed diabetes would have, in fact, been closer to 9.6%.

Table 2—*Two-by-two tables for diabetes by NDSS criteria against 1) self-reported diabetes and 2) self-reported diabetes and/or undiagnosed diabetes (total diabetes)*

		Self-reported diabetes[a]		
		Yes	No	Total
Diabetes by NDSS criteria	Yes	220	63	283 (8.5%)[b]
	No	41	2,998	3,039
	Total	261 (7.9%)[c]	3,061	3,322
κ statistic		0.79 (95% CI 0.76–0.83)		

		Self-reported diabetes and/or undiagnosed diabetes (total diabetes)[d]		
		Yes	No	Total
Diabetes by NDSS criteria	Yes	148	17	165 (10.3%)[e]
	No	105	1,328	1,433
	Total	253 (15.8%)[f]	1,345	1,598
κ statistic		0.67 (95% CI 0.62–0.71)		

[a]Two-by-two table derived from the 3,322 survey respondents. [b]Prevalence by NDSS criteria was 283/3,322 = 8.5%. [c]Prevalence by self-report was 261/3,322 = 7.7%. [d]Two-by-two table derived from the 1,598 participants who provided an analyzable blood sample. [e]Prevalence by NDSS criteria was 165/1,598 = 10.3%. [f]Prevalence by self-report and/or elevated fasting glucose was 253/1,598 = 15.8%.

Prevalence of undiagnosed diabetes
Despite differences in sampling frame and statistical techniques to correct for nonparticipation, our estimates for the prevalence

Population prevalence of diabetes

Table 3—Test properties of NDSS criteria for self-reported diabetes and total diabetes

Test property	Self-reported diabetes from survey[a]	Total diabetes[b]
Patients (n)	3,322	1,598
Sensitivity	84.3 (79.3–88.5)	58.5 (52.2–64.6)[c]
Specificity	97.9 (97.4–98.4)	98.7 (98.0–99.3)[c]
PPV	77.7 (72.4–82.4)	89.7 (84.0–93.9)
NPV	98.7 (98.2–99.0)	92.7 (91.2–94.0)
ROC area	91.1 (88.9–93.3)	78.6 (75.6–81.7)
κ statistic	79.2 (75.8–82.6)	66.6 (61.9–71.4)
Prevalence (NDSS)	8.5 (7.6–9.4)	10.3 (9.5–11.1)
Prevalence (self-report/self-report + fasting glucose)	7.9 (7.0–8.8)	15.8 (14.0–17.6)

Data are % (95% CI) unless otherwise indicated. NPV, negative predictive value; ROC, receiver operating characteristic. [a]Self-reported diabetes from the QSI survey was used as the reference standard to validate the NDSS case definition. [b]Total diabetes represents the sum of physician-diagnosed diabetes and undiagnosed diabetes. [c]These test measures do not reflect the actual sensitivity and specificity of the NDSS case definition for physician-diagnosed diabetes. They represent the correction factors of the NDSS case definition for both diagnosed and undiagnosed diabetes, bearing in mind that undiagnosed diabetes cases do not appear in health administrative databases.

of undiagnosed diabetes were comparable with the MHHS in 1998 and the U.S. National Health and Nutrition Examination Survey (NHANES) in 1999–2002 (34,35). The MHHS (n = 2,792) was conducted in a stratified random sample of the Manitoba population wherein >60% of the participants had their fasting glucose level measured from venous blood samples. NHANES 1999–2002 (n = 10,291) had fasting glucose samples drawn in a subsample without self-reported diabetes. In both these studies, undiagnosed diabetes comprised about one-third of diabetes cases (34,35).

NHANES 2003–2006 (n = 14,611) performed not only fasting glucose measurements but also glucose tolerance testing and glycated hemoglobin assessment in a subsample. Self-reported diabetes by survey was 7.8% of the general population, and undiagnosed diabetes estimated by fasting glucose was 2.5%. Compared with NHANES 1999–2002, it appeared that physician-diagnosed diabetes had increased from 6.5% and that undiagnosed diabetes, estimated solely on fasting glucose values, had fallen slightly from 2.8%. However, when all three diagnostic criteria were considered, the proportion of undiagnosed diabetes in NHANES 2003–2006 rose to 5.4%, specifically, 0.3% additional cases by glycated hemoglobin and 2.3% by oral glucose challenge (36).

Given that we only obtained fasting blood samples in the current study, we did not capture individuals with isolated elevations in postprandial glucose. Indeed,

the Decode Study on diabetes prevalence of 13 European cohorts and NHANES 2003–2006 reported that a substantial proportion of undiagnosed cases were only detected through an oral glucose challenge (36,37). Likewise, Zhang et al. (38) reported a modest sensitivity of 67% coupled with a high specificity of 98% for a fasting glucose level ≥6.7 mmol/L as an initial screening test compared with a reference standard that involved further evaluation with oral glucose tolerance testing. Their findings suggest that fasting glucose thresholds <7 mmol/L may capture some additional diabetes cases that would only have been detected after a 2-h glucose challenge.

Fasting glucose and glycated hemoglobin measurements are generally preferred to an oral glucose challenge as initial screening tests because of the ease of administration, greater acceptability to patients, and lower cost (39). Consequently, patients who present with isolated elevations in postprandial glucose levels often are missed in diabetes screening. These cases, however, likely represent individuals with early diabetes who are not uniformly treated pharmacologically in clinical practice.

Some clinical practice guidelines recommend verifying abnormal screening test results, in the absence of unequivocal hyperglycemia, with a second glucose test before making a clinical diagnosis (24–26). We acknowledge that in the current study, a single mailed-in fasting blood sample has potential sources of measurement error. Despite detailed written instructions, individuals may not follow these completely (e.g., fasting period), there may be differences in glucose levels from the first drop to the second drop of capillary blood because of more extravascular fluid in the former, the time elapsed from sampling to receipt of the mailed-in sample could affect measurement precision, and adjustments made to glucose values according to internal standards could have residual errors. However, Palardy et al. (19) demonstrated good correlation between blood glucose measurements derived from filter paper and venous whole-blood glucose. The filter paper collection method provides accurate and reproducible measurements of glycated hemoglobin (40,41). We had not measured glycated hemoglobin on the mailed-in blood samples because elevated glycated hemoglobin levels had not yet been internationally adopted as a clinical diagnostic criterion at the time of study formulation.

Table 4—Prevalence of physician-diagnosed diabetes and total diabetes

Diabetes prevalence	Physician-diagnosed diabetes[a]	Total diabetes[b]
Prevalence (NDSS) in entire random sample		
Unadjusted prevalence	7.5 (6.8–8.2)	7.5 (6.8–8.2)
Adjusted prevalence	6.6 (6.0–7.2)	10.8 (10.0–11.6)
Multiple imputation to random sample	6.6 (5.9–7.2)	11.2 (10.4–12.0)
Weighted prevalence (NDSS)	7.7 (6.8–8.6)	7.7 (6.8–8.6)
Adjusted weighted prevalence (NDSS)	6.8 (5.7–7.9)	11.2 (9.6–12.8)[c]
Weighted prevalence (self-report/self-report + fasting glucose)	7.2 (6.3–8.0)	13.4 (11.7–15.0)[d]

Data are % (95% CI). [a]Physician-diagnosed diabetes represents either NDSS positive case or self-reported diabetes from the QSI survey. [b]Total diabetes represents the sum of physician-diagnosed diabetes and undiagnosed diabetes. [c]The weighted prevalence by the NDSS case definition for the entire sample population of 6,247 individuals (7.7 [95% CI 6.8–8.6]) was adjusted by use of the capture rate of the NDSS for total diabetes. [d]Missing glucose values for non-participants were generated by multiple imputation for all survey respondents before correcting for sampling weights.

The World Health Organization in 1999 (42) proposed a fasting whole-blood glucose threshold of 6.1 mmol/L for diabetes diagnosis. This lower threshold could arguably be chosen for initial diabetes screening by fasting whole-blood glucose to improve sensitivity, although recent clinical practice recommendations have not commented on the distinction between whole-blood and plasma glucose in diabetes screening (24). Of note, lowering the threshold to 6.1 mmol/L would effectively double the weighted prevalence of total diabetes from 13.4% (95% CI 9.6–12.8%) to 25.9% (23.5–28.3%). Thus, we still elected to perform our analysis with a cutoff value of 7 mmol/L to avoid overestimating the prevalence of total diabetes. Of importance, cases detected through such a screening strategy require confirmation through a more comprehensive diabetes evaluation with venous plasma blood glucose measurements. At the end of the current study, participants with a fasting glucose ≥6.1 mmol/L were informed by mail to consult a physician for a clinical assessment.

Utility of mailed-in blood samples for diabetes screening

Mailed-in blood samples for glycated hemoglobin and fasting glucose measurements arguably offer a more convenient, feasible, and cheaper approach for diabetes screening than in-person clinical evaluations. In addition to estimating the population-level prevalence of undiagnosed diabetes, this method could be used for diabetes surveillance of high-risk individuals at 1–3-year intervals (e.g., metabolic syndrome, history of gestational diabetes, family history of diabetes) (25,39) or used in combination with self-administered risk assessment tools (e.g., Finnish Diabetes Risk Score, Canadian Diabetes Risk Questionnaire) (25,43). Such a mailed-in blood collection strategy could be especially beneficial in medically underserviced areas and among patients unable or reluctant to participate in regular follow-up because of time constraints or competing responsibilities. Because we detected a higher proportion of undiagnosed diabetes among men who provided an analyzable blood sample, mail-in blood sampling may be particularly effective for diabetes screening in men.

Strengths and limitations

We observed a higher prevalence of physician-diagnosed diabetes cases among participants who provided mailed-in blood samples, suggesting that higher-risk individuals were generally more inclined to participate. Detection of undiagnosed diabetes was somewhat limited because some participants were unwilling or unable to provide a sample or provided an insufficient amount. Difficulties with comprehension and acting on the written instructions resulting from low levels of literacy and numeracy may have been a factor (44). Other potential contributing factors were poor dexterity or hand–eye coordination, visual impairment, physical or mental limitations, and fear of pain from sufficiently squeezing the pricked fingertip. Some individuals may doubt the utility of mailed-in capillary blood collection, be less concerned about developing diabetes, or be uncomfortable with unsupervised self-testing. We endeavored to correct for potential selection bias by adjusting for sampling weights and performing multiple imputations of the baseline information derived from administrative data that we had for all individuals, including non-respondents. Nonetheless, we acknowledge that there could be residual or unmeasured confounding.

Despite these potential limitations, the current findings indicate that in a predominantly single-payer environment, public administrative data provide a powerful resource for population-based evaluation of the burden of physician-diagnosed diabetes. However, the incorporation of home capillary blood glucose sampling provides evidence of glucose abnormalities in a substantial proportion of individuals, indicating that population-wide diabetes screening practices need to be improved. Mailed-in blood glucose measurements could be an important addition to surveillance strategies for individuals at high risk for diabetes and could help clinicians to prioritize patient evaluations. Increasing the detection of diabetes offers the potential for instituting early management strategies to stem the anticipated tide of diabetes-related complications from long-standing, untreated diabetes.

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