
Quebec Integrated Chronic Disease Surveillance System (QICDSS), an innovative approach

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Abstract

Introduction: With the growing burden of chronic diseases, surveillance will play an essential role in improving their prevention and control. The Institut national de santé publique du Québec has developed an innovative chronic disease surveillance system, the Quebec Integrated Chronic Disease Surveillance System (QICDSS). We discuss the primary features, strengths and limitations of this system in this report.

Methodology: The QICDSS was created by linking five health administrative databases. Updated annually, it currently covers the period from January 1, 1996, to March 31, 2012. The operational model comprises three steps: (1) extraction and linkage of health administrative data according to specific selection criteria; (2) analysis (validation of case definitions essentially) and production of surveillance measures; and (3) data interpretation, submission and dissemination of information. The QICDSS allows the surveillance of the following chronic diseases: diabetes, cardiovascular diseases, respiratory diseases, osteoporosis, osteoarticular diseases, mental disorders, Alzheimer's disease and related disorders. The system also lends itself to the analysis of multimorbidity and polypharmacy.

Results: For 2011–2012, the QICDSS contained information on 7 995 963 Quebecers with an average age of 40.8 years. Of these, 95.3% met at least one selection criterion allowing the application of case definitions for chronic disease surveillance. The actual proportion varied with age, from 90.1% for those aged 19 years or less to 99.3% for those aged 65 years or over.

Conclusion: The QICDSS provides a way of producing population-based data on the chronic disease burden, health services and prescription drug uses. The system facilitates the integrated study of several diseases in combination, an approach rarely implemented until now in the context of population surveillance. The QICDSS possesses all the essential features of a surveillance system and supports the dissemination of information to public health decision-makers for future actions.

Keywords: *surveillance, chronic diseases, health administrative databases, surveillance model, public health*

Introduction

According to the World Health Organization¹ and the United Nations,² the chronic disease burden is increasing and will continue to grow. Strategies for preventing and controlling chronic diseases are necessary to address this burden, and the development of surveillance plays a fundamental role.³ Surveillance data contribute to identifying population sub-groups affected by chronic diseases (or at high risk of developing such diseases) and help to determine their needs. Surveillance data can also guide the implementation of prevention programs and facilitate the planning of health care services and orient public health priorities.

Chronic diseases warrant enhanced surveillance⁴ in Quebec because the aging population in this province entails a heavy burden on the health care system. This is especially true for the most prevalent, disabling, or early death associated chronic conditions such as diabetes, cardiovascular diseases, respiratory diseases, osteoarticular diseases, osteoporosis, mental disorders, Alzheimer's disease and related disorders. To tackle this issue, the Ministère de la Santé et des Services sociaux (MSSS) du Québec has mandated the Institut national de santé publique du Québec (INSPQ) with the task of overseeing chronic disease surveillance in the province using health administrative data.

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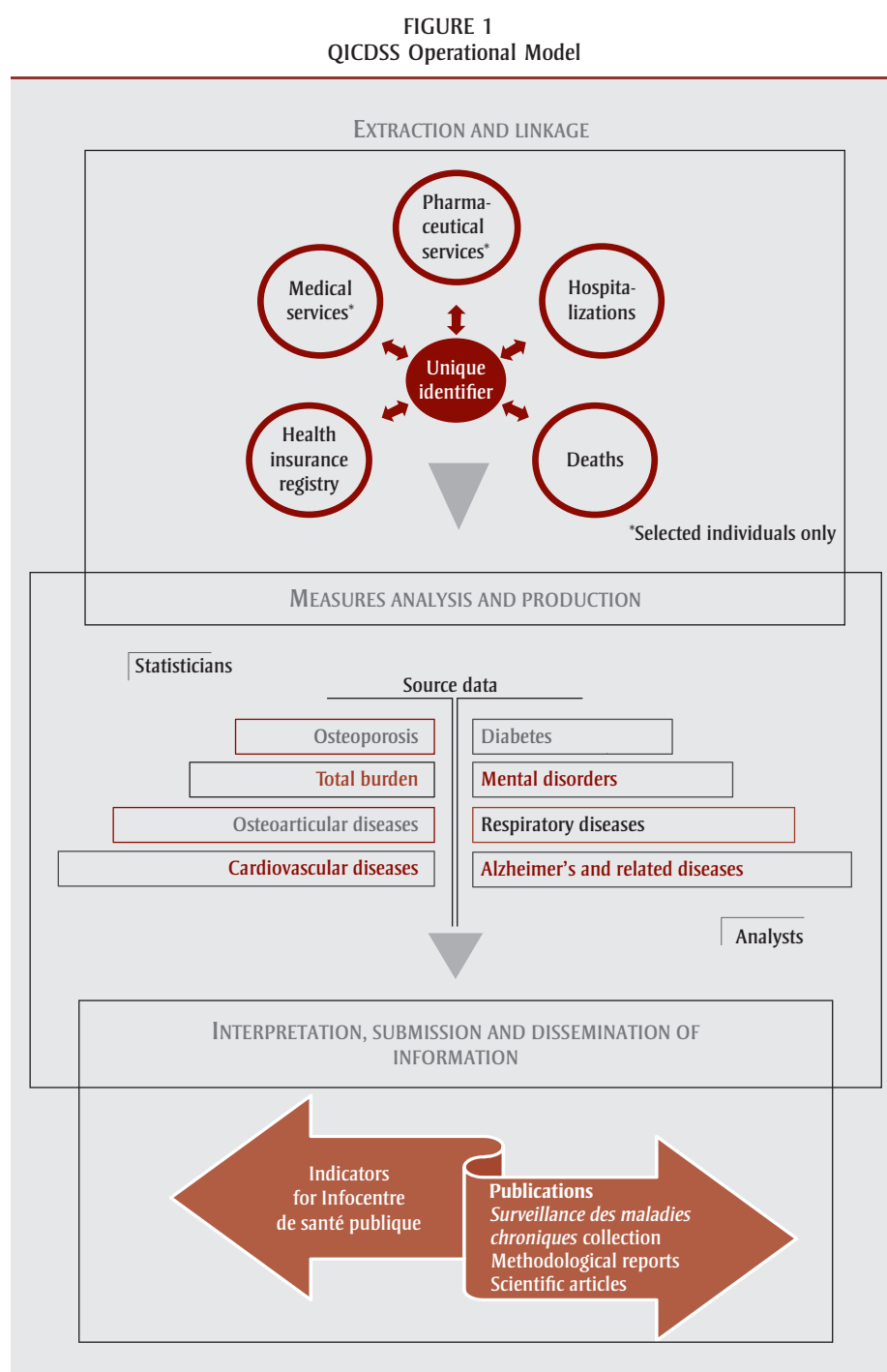
In a universal health care system like the one in Quebec, health data collected for administrative purposes constitute a valuable source of information for chronic disease surveillance.⁵ Such data allow the calculation of accurate and reliable measures,^{6,7} continuously and systematically. Furthermore, linking several databases makes it possible to study various health-related outcomes, including the use of health care resources. Data mining is practical, relatively simple, accessible and cost effective. As the databases are population-based, biases associated with sample-based studies (particularly selection, recall and non-response biases) are minimized.^{8,9} However, since these types of databases are designed for administrative purposes, their use in epidemiological surveillance requires the application of rigorous quality standards.

This is why the INSPQ created the Quebec Integrated Chronic Disease Surveillance System (QICDSS). In this paper, we look at the system's content, strengths, limitations and potential uses. An integrated approach was deemed necessary to address both traditional surveillance objectives for individual diseases but also newer approaches such as the combination of several diseases. Like the other provinces and territories in Canada, Quebec participated in the National Diabetes Surveillance System (NDSS), a system created to address information gaps about prevalence and consequences of diabetes in Canada.¹⁰⁻¹² Quebec has been able to apply NDSS methodology for the surveillance of other chronic diseases, particularly within the Canadian Chronic Disease Surveillance System (CCDSS).

Methods

Data sources

The QICDSS data are extracted from five linked health administrative databases that are updated annually. As illustrated in the upper part of Figure 1, these data sources are the health insurance registry (Fichier d'inscription des personnes assurées [FIPA]), the hospitalization database (MED-ÉCHO - Maintenance et exploitation des données pour l'étude de la clientèle hospitalière), the vital statistics



death database, the physician claims database, and the pharmaceutical services database (for persons aged 65 and older). Of the many variables in these databases, only those relevant to chronic disease surveillance have been integrated into the QICDSS. The health insurance number (HIN) constitutes the key for linking data. The data available in fall 2013 covered the period of January 1,

1996, to March 31, 2012, with the exception of the death database (up to December 31, 2009).

- The health insurance registry, which is administered by the Régie de l'assurance maladie du Québec (RAMQ),¹³ contains demographic and geographic records on people who have a valid and active HIN, as well as data about

their eligibility and admissibility to the province's public health and drug insurance plans.

- The hospitalization database (MED-ÉCHO) contains information on inpatient discharges from Quebec hospitals that provide general or specialized care. The data cover acute care and day surgeries and relate 1) to the hospital stay itself (location, duration, patient origin and destination); 2) diagnoses (at admission, primary diagnosis, secondary diagnoses, and cause-of-death diagnosis); 3) services (described according to location [room], medical specialty or diagnosis); 4) intensive care; and 5) interventions (therapeutic, diagnostic, surgical and obstetric). Diagnostic codes are based on the *International Classification of Diseases, 9th Revision* (ICD-9) up to March 31, 2006, and the Canadian enhancement of the tenth revision (ICD-10-CA) thereafter. ICD-10-CA lists as much as 25 secondary diagnoses, versus 15 in ICD-9. Intervention codes are based on the Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures (CCP), in conjunction with ICD-9, and the Canadian Classification of Health Interventions (CCI), in conjunction with ICD-10-CA. The number of interventions in the CCP is 10, while the CCI has 20. Medical registrars are responsible for encoding the data provided by physicians.
- The vital statistics death database records all deaths of Quebecers, including those that occur outside the province. The records are submitted by physicians who report deaths or by coroners, and include the date, primary cause of death and, since January 1, 2000, up to 10 contributing causes. Before that date, only one additional cause could be entered for deaths attributable to an external cause. Cause-of-death codes are based on the ICD, with January 1, 2000, being the transition date from ICD-9 to ICD-10 codes.
- The physician claims database collects data related to fee-for-service billings, that is, the payment claims that health professionals submit to the RAMQ. Each record includes the code associated with the service rendered and optionally, in 91% of claims submitted between 1996–1997 and 2011–2012,

the most relevant ICD-9 diagnostic code. Also included are data on health professionals themselves (treating or referring professionals) and the location where the service was provided.

- The pharmaceutical services database centralizes prescription drug claims submitted under the public drug insurance plan. Data related to private insurance plans (which cover a significant portion of the Quebec population) are not included. This database covers over 90% of people aged 65 years or older as Quebec senior citizens are automatically covered (data on seniors covered by a private plan or living in long-term care facilities are not included). The records include prescription drugs information (drug code, dose, number of renewals, duration of treatment, etc.) and health professionals information (prescriber's class and specialty).

Since these databases contain little socioeconomic information, the QICDSS incorporates the material and social deprivation index, an ecological substitute of the socioeconomic status developed by the INSPQ.¹⁴ Combining six indicators from the Canadian census at the dissemination area (DA) level (the smallest geographical unit for which census data are produced), this index is attributed to each individual through a correspondence file linking DAs and six-character postal codes in the FIPA. The six indicators are 1) the proportion of people who do not have a high-school diploma; 2) the employment-to-population ratio; 3) the average personal income; 4) the proportion of widowed, separated or divorced people; 5) the proportion of people living alone; and 6) the proportion of single-parent families. The first three of these indicators relate to the material dimension of the deprivation index, while the rest relate to the social dimension.¹⁴

Operational model

The QICDSS operational model (Figure 1) is structured around three steps linked to one of the three components of surveillance systems: data extraction and linkage, measures analysis and production, and interpretation and dissemination of information. Since a description of this

model has been published elsewhere,¹⁵ we will only include a brief description here.

Extraction and linkage of health administrative data

The INSPQ receives, for the selected variables, anonymous unique identifiers and complete individual information for the entire Quebec population for three of the databases (FIPA, hospitalizations and deaths). Due to access-to-information restrictions, individual information from the other two databases is limited to people who are at risk for at least one of the chronic diseases studied. These people are identified using selection criteria that relate to diagnostics, medical acts, hospital procedures and pharmaceutical codes. In order to obtain historical data, selection criteria about those at risk are also applied when extracting data from the mortality and hospitalization databases. The diagnostic or cause-of-death codes list used for the patient selection is presented in Table 1. The pharmaceutical, medical act and hospital intervention codes are available upon request.

At INSPQ, some criteria are applied to the FIPA to create the QICDSS insurance registry: data of an individual inscribed in the FIPA for the year under consideration are preserved if the eligibility and admissibility criteria of this individual are met for at least one day during the year in question (that is to say that his HIN is in effect). Periods of ineligibility are associated with death, emigration, the transition period prior to immigration, or an absence of more than six months from the province. Also excluded are periods of inadmissibility during which a person does not have an active health insurance card. However, in order to obtain population counts that approximate official demographic data, the admissibility criterion is not applied to women aged 18 to 25 years and to men aged 18 to 29 years, as many people in these age groups do not renew their health insurance card. We should emphasize that most of the Quebec population is included in the FIPA registry. Therefore, this registry can be used as a population-counting tool, as its data are similar to the official demographic data published by the Institut de la statistique du Québec.¹⁶

TABLE 1
List of diagnostic or cause-of-death codes used to select individuals potentially affected by a chronic disease in QICDSS

Disease	ICD-9	ICD-10-CA/ICD-10
Diabetes	250; 648.0; 648.8; 790.2	E10–E14; O24; O99.8; R73
Cardiovascular diseases and associated risk factors	272, 278, 305.0, 305.1, 357.5, 362, 362.11, 362.3, 390–459, 514, 518.4, 584.5, 584.9, 585, 586.9, 745–747, 785–786, 788.5, 797–799, 989.84, V158.2, V451	E66, E78, F10, F17, G45, G62.1, H34, I00–I99, J81, M30.3, N17, N18–N19, Q20–Q28, R00–R09, R34, R54, R57, R96–R98, T65.2, Z50.2, Z71.4, Z72.0, Z99.2
Respiratory diseases	490–493, 496, 460–462, 464–466, 480–486	J20, J45–J46, J40–J44, J00–02, J04–06, J12–18, J21–22
Osteoporosis	733, 805–814, 818–825, 827–829, 905, 731	M80–M81, S12, S22, S32, S42, S52, S62, S72, S82, S92, T02, T08, T10, T12, T14, T911–T912, T921–T922, T931–T932, T940, M88
Osteoarticular diseases	710–729, 274, 446, 696	M00–M99
Mental disorders, Alzheimer's disease and related disorders	046, 290–319, 331, 332, 797	F00–F99, A81, B24, G10, G20, G30, G31, G35

Abbreviations: ICD-9, International Classification of Diseases, 9th Revision; ICD-10, International Statistical Classification of Diseases, 10th Revision; ICD-10-CA, Canadian Enhancement of the International Statistical Classification of Diseases, 10th Revision; QICDSS, Quebec Integrated Chronic Disease Surveillance System.

Note: The total burden includes all these diseases.

The process of creating the QICDSS and data access both meet stringent standards of security and privacy. Government bodies in legal possession of the databases (RAMQ and MSSS), the public health ethics committee and the Commission d'accès à l'information du Québec evaluated and approved the creation process. The data are stored on a secure server at the INSPQ. Access to data is logged and is limited to authorized personnel of the Chronic Disease and Injury Surveillance Unit according to different levels of access.

Measures analysis and production

People with chronic diseases are identified using case definitions specific to each disease. Validation studies are essential in order to select case definitions that will minimize classification errors. Table 2 shows a few examples of case definitions applied to the QICDSS databases and their respective validation studies.^{17–21}

Thanks to its extensive coverage of the Quebec population, the QICDSS data can be used to describe the scope of chronic diseases at the provincial and regional levels according to various determinants (age, sex, deprivation), as well as to analyze trends and make projections. An integrated approach facilitates the development of new indicators for disease outcomes (excess mortality, rate of complications); it also enables comparisons of hospital services use between people who suffer from a chronic disease and those who do not, and helps the analysis of

disease continuums and care trajectories. In addition to conventional surveillance measures, the QICDSS can also produce innovative ones, such as multimorbidity and polypharmacy measures.

Interpretation, submission and dissemination of information

Data interpretation and knowledge transfer are essential components of surveillance.^{5,22} QICDSS dissemination modes include the transmission of aggregate data to various public health stakeholders (particularly the regional public health authorities) through the secure Internet site of the Infocentre de santé publique du Québec, the transmission of summary aggregated data to the Public Health Agency of Canada through CCDSS, and the publication of various documents (for example, thematic series, such as the *Surveillance des maladies chroniques* collection, methodological reports and scientific articles).

Results

The first QICDSS data transmission to the INSPQ, conducted in 2010, covered the period from January 1, 1996, to March 31, 2009. Since then, the system has been updated annually, every summer. Thus, in the fall of 2013, the QICDSS' coverage extended until March 31, 2012.

Table 3 shows various characteristics of the population of the QICDSS insurance registry. In fiscal year 2011–2012, 99.1% (n = 7 995 963) of the Quebec popula-

tion¹⁶ was eligible and admissible to the RAMQ health insurance (average age 40.8 years). The proportion of the population aged 65 years and older was 16.0%. This proportion increased between 2001–2002 and 2011–2012. More than half of the people in this age group were women (56.2%) and 89.9% were enrolled in the drug insurance plan. Close to half of all Quebecers lived in the Montréal Census Metropolitan Area (48.2%). The rural population is the only population segment that has tended to decrease slightly over time. Between 2.5% (2001–2002) and 1.3% (2011–2012) of the population was not associated with any geographical area due to a missing or erroneous postal code. While the proportion of people enrolled in the drug insurance plan decreased slightly between 2001–2002 and 2011–2012, their actual number increased.

People potentially affected by at least one of the studied chronic diseases were selected from the various health administrative databases according to several criteria. Table 4 shows the number and proportion of individuals who met at least one selection criterion, by age and year. A large proportion of the population can be found in the QICDSS, particularly in older age groups, given the higher prevalence of many chronic diseases in these age groups and the selection criteria that were applied. In 2001–2002, 97.9% of people listed in the registry met at least one criterion, a proportion that rose to 99.7%

TABLE 2
Examples of case definitions used in the QICDSS

Disease	Age, years	Case definition	Diagnostic codes		Intervention codes	Validation studies
			ICD-9	ICD-10-CA		
Ischemic heart diseases	≥ 20	Two diagnoses of ischemic heart diseases in the physician claims database within a one-year period (365 days) OR one diagnosis (primary or secondary) OR one intervention code for ischemic heart diseases in the MED-ÉCHO database	410–414	I20–I25	CCP ^a 48.02, 48.03, 48.11–48.19 CCI ^b 1.IJ.50, 1.IJ.57.GQ, 1.IJ.54, 1.IJ.76	Tu et al., 2010 ¹⁹
Diabetes, hypertension	≥ 1 (diabetes), ≥ 20 (hypertension)	Two diagnoses of diabetes (or hypertension) in the physician claims database within a two-year period (730 days) OR one diagnosis (primary or secondary) of diabetes (or hypertension) in the MED-ÉCHO database <i>Exclusion of gestational diabetes (or hypertension) cases</i> ⁴³	250 (diabetes) 401–405 (hypertension)	E10–E14 (diabetes) I10–I15 (hypertension)		Ouhoumane et al., 2010 ⁴⁴ Hux et al., 2002 ¹⁷ Quan et al., 2009 ²⁰ Tu et al., 2007 ²¹
Osteoporotic fractures	≥ 50	One medical act in the physician claims database corresponding to an open reduction, a closed reduction, or immobilization of a fracture OR one medical act corresponding to a primary visit or an orthopedic consultation with a diagnosis of fracture plus at least one other medical consultation with a diagnosis of fracture at the same site within a 4-month period		See reference ¹⁸		Jean et al., 2012 ¹⁸

Abbreviations: CCI, Canadian Classification of Health Interventions; CCP, Canadian Classification of Diagnostic, Therapeutic and Surgical Procedures; ICD-9, International Classification of Diseases, 9th Revision; ICD-10-CA, Canadian Enhancement of the International Statistical Classification of Diseases, 10th Revision; QICDSS, Quebec Integrated Chronic Disease Surveillance System.

^a CCP is associated with ICD-9 in the hospitalization database prior to April 1, 2006.

^b CCI is associated with ICD-10-CA in the hospitalization database.

among those aged 65 years or older. In 2011–2012, 95.3% of the people in the registry met at least one criterion. This slight decrease relative to 2001–2002 may be attributable to a shorter follow-up period, which reduces the likelihood of meeting at least one selection criterion, particularly among younger people (90.1% among those aged 19 years or less). It is important to note that people who meet selection criteria are potentially at risk but not all of them necessarily have a chronic disease. For example, for the surveillance of cardiovascular disease, selection criteria identified 6 164 006 people (77.1%) in 2011–2012. In fact, for that year, 1 483 168 people aged 20 years and older (23.8% crude prevalence) met the case definition of hypertension presented in Table 2, which allows the evaluation of the burden of this problematic in terms of incidence and prevalence.

Discussion

Surveillance is a fundamental step in measuring the evolution of the health status of the population. In Quebec, data collection of health events has evolved and currently consists of three steps: data collection itself, analysis and interpretation, and the timely dissemination of information to decision-makers who oversee disease prevention and control. Quebec's most relevant data sources for the purposes of chronic disease surveillance are health administrative databases. They are updated systematically; they can also be linked and they require little effort or additional cost.

The QICDSS constitutes an inestimable source of information on Quebec's chronic disease burden as it covers all health care services used by the population, from

medical consultations to deaths, via hospitalizations and drug use. The system enables up-to-date chronic disease surveillance and takes into account their co-occurrence and the organization of health care services, extremely important aspects in an aging population. In short, the QICDSS data addresses a growing need for information on populations that are vulnerable to chronic diseases.^{23–24} With data available from 1996 and yearly updates, the system facilitates the analysis of health care services use,²⁵ trend studies and projections for different population cohorts.^{26,27} The information derived from the QICDSS contributes to a better understanding of the continuum of disease prevention, progression, treatment and outcomes (impact of public health programs, use of health care services, treatment compliance, etc.), leading to a more efficient planning of public health resources and interventions.

TABLE 3
Characteristics of the population eligible and admissible to the RAMQ (QICDSS insurance registry), by year and sex

Characteristics	2001–2002			2006–2007			2011–2012		
	Total, n (%)	Men, n (%)	Women, n (%)	Total, n (%)	Men, n (%)	Women, n (%)	Total, n (%)	Men, n (%)	Women, n (%)
Totals, N	7 462 734	3 671 680	3 791 054	7 693 005	3 788 475	3 904 530	7 995 963	3 944 033	4 051 930
Age, years									
0–19	1 809 881 (24.2)	924 135 (25.2)	885 746 (23.4)	1 769 931 (23.0)	903 109 (23.8)	866 822 (22.2)	1 774 008 (22.2)	904 998 (22.9)	869 010 (21.4)
20–34	1 489 603 (20.0)	757 321 (20.6)	732 282 (19.3)	1 513 723 (19.7)	768 269 (20.3)	745 454 (19.1)	1 570 545 (19.6)	794 491 (20.1)	776 054 (19.2)
35–49	1 867 632 (25.0)	935 077 (25.5)	932 555 (24.6)	1 781 591 (23.2)	893 773 (23.6)	887 818 (22.7)	1 644 967 (20.6)	827 610 (21.0)	817 357 (20.2)
50–64	1 314 602 (17.6)	648 868 (17.7)	665 734 (17.6)	1 539 363 (20.0)	761 368 (20.1)	777 995 (19.9)	1 730 025 (21.6)	857 495 (21.7)	872 530 (21.5)
65–74	550 633 (7.4)	252 505 (6.9)	298 128 (7.9)	583 269 (7.6)	273 945 (7.2)	309 324 (7.9)	702 847 (8.8)	336 325 (8.5)	366 522 (9.0)
≥ 75	430 383 (5.8)	153 774 (4.2)	276 609 (7.3)	505 128 (6.6)	188 011 (5.0)	317 117 (8.1)	573 571 (7.2)	223 114 (5.7)	350 457 (8.6)
≥ 20	5 652 853 (75.7)	2 747 545 (74.8)	2 905 308 (76.6)	5 923 074 (77.0)	2 885 366 (76.2)	3 037 708 (77.8)	6 221 955 (77.8)	3 039 035 (77.1)	3 182 920 (78.6)
≥ 65	981 016 (13.1)	406 279 (11.1)	574 737 (15.2)	1 088 397 (14.1)	461 956 (12.2)	626 441 (16.0)	1 276 418 (16.0)	559 439 (14.2)	716 979 (17.7)
Area of residence									
Metropolitan Montréal area	3 494 352 (46.8)	1 703 296 (46.4)	1 791 056 (47.2)	3 697 988 (48.1)	1 805 106 (47.6)	1 892 882 (48.5)	3 854 436 (48.2)	1 882 226 (47.7)	1 972 210 (48.7)
Other metropolitan area	1 355 600 (18.2)	657 155 (17.9)	698 445 (18.4)	1 487 679 (19.3)	723 752 (19.1)	763 927 (19.6)	1 553 851 (19.4)	758 107 (19.2)	795 744 (19.6)
Medium-size city	849 668 (11.4)	415 180 (11.3)	434 488 (11.5)	919 989 (12.0)	451 586 (11.9)	468 403 (12.0)	943 244 (11.8)	462 976 (11.7)	480 268 (11.9)
Rural area	1 579 561 (21.2)	799 839 (21.8)	779 722 (20.6)	1 512 145 (19.6)	767 632 (20.3)	744 513 (19.1)	1 539 409 (19.3)	782 331 (19.8)	757 078 (18.7)
Not determined	183 553 (2.5)	96 210 (2.6)	87 343 (2.3)	75 204 (1.0)	40 399 (1.1)	34 805 (0.9)	105 023 (1.3)	58 393 (1.5)	46 630 (1.1)
Population enrolled in drug plan (≥ 65 years)^a	896 015 (91.3)	371 076 (91.3)	524 939 (91.3)	981 267 (90.2)	414 220 (89.7)	567 047 (90.5)	1 147 415 (89.9)	499 499 (89.3)	647 916 (90.4)

Abbreviations: RAMQ, Régie de l'assurance maladie du Québec; QICDSS, Quebec Integrated Chronic Disease Surveillance System.

^a People enrolled for at least one day in the year in question.

Essential features and strengths of the QICDSS

The QICDSS meets all five basic requirements of a public health surveillance system:^{5,22,28} 1) simplicity and flexibility, 2) acceptability, 3) sensitivity and positive predictive value, 4) representativeness, and 5) timeliness.

- Since human and material resources are limited, the secondary use of health administrative data is relatively simple and economical. The annual addition of new selection codes and potential cases ensures that QICDSS remains flexible. However, this flexibility is limited by certain legal constraints. Furthermore, the system is not able to quickly respond to health care organizational changes or to the addition of diseases or data sources (e.g. database on family medicine groups).
- The acceptability of the QICDSS is excellent. Organizations responsible for these health administrative databases agree that they are used for surveillance purposes. Decision-makers are already using the information from the system and recognize its relevance. Moreover, regional surveillance stakeholders who make extensive use of the QICDSS information wish to play an active role in system activities.
- Validity measures, such as sensitivity and positive predictive value, vary from one disease to the next and are dependent on case definitions. When surveillance covers an entire population, the goal is to achieve a balance between these two validity measures for every disease and every case definition.
- The QICDSS also stands out in terms of representativeness, as it links several data sources within a universal health care system. This extensive coverage allows extrapolating the information to the entire population, describing socio-demographic, economic and geographical characteristics and minimizing many selection biases. The QICDSS's ability to link different data sources also increases the quality and usefulness of the information it generates.
- Timeliness is not as critical a factor in chronic disease surveillance as in other

TABLE 4
Number and proportion of people who meet at least one QICDSS selection criterion,^a by year and age

Characteristics	2001–2002		2006–2007		2011–2012	
	Total (insurance registry), n	≥ 1 selection criterion, n (%)	Total (insurance registry), n	≥ 1 selection criterion, n (%)	Total (insurance registry), n	≥ 1 selection criterion, n (%)
Totals	7 462 734	7 307 855 (97.9)	7 693 005	7 511 892 (97.6)	7 995 963	7 617 930 (95.3)
Age, years						
0–19	1 809 881	1 764 479 (97.5)	1 769 931	1 710 415 (96.6)	1 774 008	1 599 191 (90.1)
20–34	1 489 603	1 435 025 (96.3)	1 513 723	1 453 093 (96.0)	1 570 545	1 464 750 (93.3)
35–49	1 867 632	1 830 421 (98.0)	1 781 591	1 744 230 (97.9)	1 644 967	1 586 085 (96.4)
50–64	1 314 602	1 299 876 (98.9)	1 539 363	1 519 958 (98.7)	1 730 025	1 700 141 (98.3)
≥ 65	981 016	978 054 (99.7)	1 088 397	1 084 196 (99.6)	1 276 418	1 267 763 (99.3)

Abbreviation: QICDSS, Quebec Integrated Chronic Disease Surveillance System.

^a People who meet diagnostic, pharmaceutical, therapeutic (acts or treatments) or cause-of-death criteria associated with the chronic diseases studied in the QICDSS (see Table 1).

surveillance systems (e.g. infectious disease surveillance). Nevertheless, because it is updated annually, the QICDSS is able to produce timely incidence measures and thereby facilitates intervention within a reasonable timeframe.

In short, the QICDSS possesses all of the attributes required for a surveillance system and, as it is based on health services use within the context of a universal health care system, it meets the fundamental principle of surveillance, namely the presence of a functional health care system.⁵

Among other QICDSS's strengths, let us emphasize that access to source data (gross data) enables quality control at the different stages of data processing and analysis. Although the RAMQ is itself responsible for applying some of the selection, extraction and linkage criteria, and also for encrypting HINs, the INSPQ still receives data in the form of individual records. Furthermore, the addition of a deprivation index makes the QICDSS an important source of information on the impacts of social inequalities in health.^{23,24} The system also allows the INSPQ to produce aggregate chronic disease surveillance measures for Quebec that can be harmonized with those of other Canadian provinces and territories participating in the CCDSS, an initiative coordinated by the Public Health Agency of Canada. Finally, the fact that data are collected for administrative purposes can be advantageous from a quality stand-

point, particularly in the case of pharmaceutical services data. According to Tamblyn et al.,²⁹ this type of data is accurate and remarkably complete, since claimants know they may not receive payment if they provide incorrect or incomplete information when submitting their claims.

Comparison of QICDSS with other surveillance systems

The QICDSS compares favourably with other surveillance systems deployed worldwide. In the United States, the Institute of Medicine developed a nationwide framework for surveillance of cardiovascular and chronic lung diseases that severely criticized the lack of a national surveillance system capable of disseminating timely information to decision-makers.³⁰ Indeed, although American data sources include, among others, population surveys (such as the National Health and Nutrition Examination Survey [NHANES]), registries for specific diseases, population cohort data (such as the Framingham and Rochester cohorts³¹) and insurance claims data, none of these data sources could be linked in order to establish a national profile or produce incidence information until recently. The National Center for Health Statistics now links several population surveys with death certificates, Medicare and Medicaid services data, historical social security data and other data sources.³² Australia bases much of its surveillance activities on survey data, most notably the Australian Bureau of Statistics National Health

Survey (NHS).³³ The United Kingdom's population surveillance strategy also rests on the integration and processing of new data sources, such as acute and chronic disease registries and behavioural follow-up data (smoking, diet, exercise, etc.).³⁴ Given its flexibility, the QICDSS could easily incorporate this type of information. In fact, other Canadian provinces, such as Ontario³⁵ and Manitoba,³⁶ have access to linked health administrative databases but also incorporate survey data into their surveillance systems.

Limitations of QICDSS

The primary limitation of the QICDSS has to do with the nature of the data sources it uses. Since health administrative databases are designed to meet administrative needs, databases³⁷ and case definitions^{17–19} need to be validated before using them for epidemiological purposes. Furthermore, even if validation studies demonstrate the quality of the selected case definitions, only health care services users and people who receive a diagnosis are included in the analysis, which leads to an underestimation of the actual magnitude of diseases. For example, a person might not know that he or she had a myocardial infarction and never consulted a physician, so this will not be counted in the QICDSS.³⁸

Moreover, certain data are absent from the QICDSS. For example, medical services of Canadian Armed Forces members are paid by the federal government.³⁹ Similarly, services that Quebec citizens receive in other provinces from physicians not

enrolled in the RAMQ are not included in the QICDSS at this time. However, work is currently underway to integrate that missing information, which would minimize the underestimations of the services received, particularly in the border regions (the Outaouais region, for example). Information on long-term care is also not included in the QICDSS and data on pharmaceutical services is limited to people aged 65 years or older.

Finally, some physicians in Quebec are not remunerated on a fee-for-service basis, which leads to an underestimation of services rendered and makes QICDSS a less sensitive tool.³⁹ Other forms of physician remuneration include salary-based compensation, fixed amount compensation (e.g. per-patient management fees for general practitioners), sessional compensation (or per diem) and, since September 1, 1999, blended compensation (a combination of fee-for-service and sessional compensation). In 2010–2011, these other forms of compensation accounted for 24% of physicians' remuneration, versus 16% in 1999–2000. The growing popularity of blended compensation since its introduction for specialists in 1999 accounts for much of this change: the sessional part of the blended compensation now accounts for 11.6% of all clinical payments to physicians, while salary-based compensation accounts for only 1.9%.⁴⁰ Although proportions of forms of remuneration (other than fee-for-service) have been increasing, the number of medical services provided on a fee-for-service basis increased by 8.8% between 2001 and 2007, following an 18-year low in 2001. The consequences of alternative forms of remuneration are felt most keenly in remote areas. Improving surveillance for these population groups requires alternative data sources or surveys. In the Aboriginal communities of Terres-Cries-de-la-Baie-James, for example, where all general practitioners are compensated under alternative arrangements, a data linkage pilot project with the Cree Diabetes Information System (CDIS) revealed that QICDSS identifies only 60% of the diabetes cases in the region, with an average lag time of 2.3 years after the incidence date of the disease. As this data linkage initiative provided a means of compensating for the

lack of information on other modes of remuneration, ongoing linkage of these two systems is under consideration. As for the presence of the private sector in Quebec's health care system, it remains marginal and primarily affects the fee-for-service database and the pharmaceutical services database (in the case of people aged under 65 years).

Finally, each chronic disease definition in the QICDSS has its limitations, thus complicating the study of multimorbidity. Moreover, health administrative databases generally do not disclose disease severity, nor do they provide a way of confirming diagnoses through clinical information. Health administrative databases also contain little information on chronic disease risk factors and no information on laboratory results or chronic disease lifestyle risk factors (diet, physical activity, smoking, alcohol consumption). However, the hospitalization database is an excellent source of information for certain risk factors and comorbidities since secondary diagnoses and diagnoses that contribute to hospital admission and length of stay are included (25 possibilities since April 1, 2006).

Conclusion

The chronic disease burden will continue to grow and will become more complex as the population ages and life expectancy rises. Chronic disease surveillance needs to be improved in order to identify both at-risk and affected populations, and to track the evolution of chronic diseases and the issues associated with them. The QICDSS is clearly the most appropriate way to realize chronic disease surveillance in Quebec. It maximizes the use of existing information systems, is economical, and provides reliable population data. It contains, with respect to the 2011–2012 period, individual, hospital, medical, socioeconomic, and cause-of-death data on close to 8 million Quebecers of all ages and from all regions. Thus, it allows a thorough study of the chronic disease burden. In addition, the QICDSS is consistent with the integrated model of chronic disease care prevention and control,⁴¹ whereas surveillance not only looks at each disease separately, but also considers the co-occurrence of diseases and its complications.

We therefore conclude that the QICDSS fully meets the objectives of an efficient, integrated surveillance system. It is flexible and can be enhanced and enriched as needs arise⁴². Indeed, incorporating data on chronic disease risk factors and lifestyle factors into the system will be considered. Also planned are linkages with other health administrative databases (including births and stillbirths), with health surveys and with information systems such as the Cree Diabetes Information System. This capacity to evolve makes QICDSS a truly innovative and responsive system. Note finally that QICDSS should be evaluated regularly in order to maintain its scientific rigour and ensure that the surveillance conducted with this system is efficient and useful for public health decision-making and action.

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