*Enhancing the effectiveness of health care for Ontarians through research*

ICES Institute for Clinical Evaluative Sciences

# Improving Health Care Data in Ontario

## ICES Investigative Report

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# About ICES

## Ontario's resource for informed health care decision-making

ICES (Institute for Clinical Evaluative Sciences) is an independent, non-profit organization that conducts research on a broad range of topical issues to enhance the effectiveness of health care for Ontarians. Internationally recognized for its innovative use of population-based health information, ICES knowledge provides evidence to support health policy development and changes to the organization and delivery of health care services.

Unbiased ICES evidence provides fact-based measures of health system performance; a clearer understanding of the shifting health care needs of Ontarians; and a stimulus for discussion of practical solutions to optimize scarce resources.

Key to ICES research is our ability to link anonymous population-based health information on an individual patient basis, using unique encrypted identifiers that ensure privacy and confidentiality. This allows scientists to obtain a more comprehensive view of specific health care issues than would otherwise be possible. Linked databases reflecting 12 million of 30 million Canadians allow researchers to follow patient populations through diagnosis and treatment, and to evaluate outcomes.

ICES brings together the best and the brightest talent under one roof. Many of our faculty are not only internationally recognized leaders in their fields, but are also practising clinicians who understand the grassroots of health care delivery, making ICES knowledge clinically-focused and useful in changing practice. Other team members have statistical training, epidemiological backgrounds, project management or communications expertise. The variety of skill sets and educational backgrounds ensures a multi-disciplinary approach to issues management and creates a real-world mosaic of perspectives that is vital to shaping Ontario's future health care.

ICES collaborates with experts from a diverse network of institutions, government agencies, professional organizations and patient groups to ensure research and policy relevance.

# Contents

# Executive Summary

## Issue

Ontario is falling behind the public's expectations, and the ability of other jurisdictions, to plan and improve the quality, efficiency and effectiveness of health care services – all of which require comprehensive and reliable health care data. For example, the U.S. Department of Veterans' Affairs (VA) has transformed the performance and efficiency of the health care it delivers through a substantial investment in health care data. In Ontario, large data deficiencies appear to be worsening, even to the point of having several hundred thousand more people registered with Ontario Health Insurance Plan (OHIP) cards than are alive in Ontario. The VA recently reported on 17 quality measures (explained in Exhibit 2)—Ontario has sufficient data to fully report on only one of these, and has a very limited amount of data on eight others.

Researchers who regularly use Ontario's administrative health care data, such as scientists at the Institute for Clinical Evaluative Sciences (ICES), are aware of the data deficiencies and, to date, have been able to produce accurate and useful information based on existing data. There is concern, however, that this will not be possible in the future, particularly given the growing expectations of policy makers as Ontario moves into the era of evidence-based planning, decision-making and policy development.

## Study

This independent assessment was undertaken at the request of the Health Results Team of the Ministry of Health and Long-Term Care (MOHLTC) to provide a key component of the MOHLTC's broader review of the health information resources needed to improve accountability, system management and quality of care in Ontario. The report describes the usefulness and limitations of Ontario's existing health care data and outlines necessary improvements to data and data quality in order to meet the health care system's growing information and performance management needs.

## Findings

To effectively plan and evaluate health care services in Ontario, health care data should be:

- **Comprehensive** – Include all services;
- **Complete** – Include all settings, providers and populations;
- **Accurate** – Reflect actual utilization and patient-provider characteristics;
- **Timely** – For use in real-time management and planning;
- **Linkable** – Connect different services that people receive to provide analyses that reflect the complexity of the health care system;
- **Anonymous** – Data use must adhere to strict privacy regulations (*Health Information Protection Act, 2004*);
- **Usable** – Analysts must have access to data that is organized in a readily usable form; and,
- **Consistent over time.**

## Implications

The following enhancements would help ensure that health care data in Ontario becomes more robust:

- Identify where services are provided;
- Collect consistent physician identifiers in all health administrative data;
- Implement quality assurance for the Canadian Institute for Health Information Discharge Abstract Database (DAD) and OHIP "shadow billing";

- Increase physician service information to ensure complete coverage;
- Provide results of selected diagnostic and lab tests;
- Ensure that OHIP cards are valid, and relevant demographic and eligibility information is up-to-date;
- Complete population coverage of drug dispensing information;
- Complete coverage of diagnostic and lab tests;
- Expand and improve content of physician service information;
- Expand population characteristics to include risk factors; and;
- Improve accuracy of information about deaths.

# Introduction

This report provides recommendations for how existing health care data must be improved (immediately and in the medium-term) to plan, evaluate and improve the delivery of health care in Ontario. The focus is on provincial data for services provided within the publicly funded health care system.

In particular, the report describes current uses of available data and data characteristics required to monitor the health system. Also provided are specific examples of how to close information gaps, address data deficiencies and ensure that required data is available to support planning and evaluation needs of the Ontario Ministry of Health and Long-Term Care (MOHLTC) and others.

The modest investment needed to improve data will result in a sizable return in investment in the form of improved health care planning and delivery. Not only will this mean improved efficiency, but a more effective health care system for improving the health of Ontarians. Without increased investment in basic data, it will become increasingly difficult to describe and evaluate health care services in Ontario.

## Background

Historically, health care service data was collected as part of the billing and payment process. Though not intentionally collected for other purposes, these data are successfully used to describe the quantity and quality of health care services. Today, there is widespread awareness that health care organizations and delivery can be improved through better planning, evaluation and system monitoring. However, this is highly dependent upon access to quality data to support informed decision-making.

In some respects, Ontario has advanced beyond many provinces by mandating implementation of systems for the collection of routine data, such as the National Rehabilitation Reporting System (NRS), the National Ambulatory Care Reporting System (NACRS), and the Continuing Care Reporting System. In other cases however, Ontario is behind its provincial counterparts, as is the case with pharmaceutical prescribing information, available for the entire population in British Columbia, but only available primarily for residents aged 65 and older in Ontario.

Overall, Ontario and Canada lag behind other jurisdictions in terms of having basic, high quality data for planning, evaluation and system monitoring, and the breadth of information needed to manage emerging health system priorities is not available. For example, the quality of existing databases has been steadily eroded through changes to delivery and remuneration of some health care services, such as emergency department physicians, which has resulted in fragmented and less complete physician service data at the level of individual physicians (Exhibit 1). This data deficiency creates significant challenges in evaluating whether new programs, such as Telehealth and the Universal Influenza Vaccination Program, have reduced emergency department visits.

In terms of requirements for more detailed data, reducing waiting lists for magnetic resonance imaging (MRI) and computerized tomography (CT) scans are a priority for government and Ontarians. However, there is no data available regarding the length of time that patients are waiting. Determining whether patients are waiting too long requires additional information, such as the reason for the test, the date of referral and the result of the test, which is currently not available.

Researchers who regularly use Ontario’s administrative health care data, such as scientists at the Institute for Clinical Evaluative Sciences (ICES), are aware of the data deficiencies and, to date, have been able to produce accurate and useful information based on existing data. There is concern, however, that this will not be possible in the future, particularly given the growing expectations of policy makers as Ontario moves into the era of evidence-based planning, decision-making and policy development.

## Limitations

This independent assessment was undertaken at the request of the Health Results Team of the Ministry of Health and Long-Term Care (MOHLTC) to provide a key component of the MOHLTC's broader review of the health information resources needed to improve accountability, system management and quality of care in Ontario.

This assessment is limited to Ontario health care data that is used at ICES. It describes the utility and limitations of Ontario's existing health care data used at ICES and outlines necessary improvements to data and data quality in order to meet the health care system's growing information and performance management needs.

It is recognized that there are datasets that are not available at ICES, as well as data that is held in-house and not typically required for the types of studies undertaken at ICES (i.e. Ontario Healthcare Financial and Statistical System). Individuals with significant expertise in the area of financial reporting would be better equipped to comment on the breadth, quality, and utility of routinely collected financial data in Ontario, and as such, this area is not addressed in this report.

## How health care data is used for system monitoring

Health care data is used for a wide range of purposes. For example, it is used to describe how services are provided and to illustrate service changes from year to year. Physician service information is used in human resource planning to estimate the number of physicians needed in the future. Population-based health care data is vital in evaluating the performance of the health care system.

In many situations, performance measures require that information be adjusted to ensure comparability. For example, comparing heart attack survival between hospitals requires adjusting for differences in the severity of heart attacks seen in each hospital. Further, many of the most helpful performance measures require a combination of different databases. For instance, to examine whether patients with heart attacks are discharged with appropriate medications requires the linkage of at least two databases—one that identifies all patients with heart attacks, and another that provides information about drug use.

The U.S. Department of Veterans' Affairs (VA) is an organization that has transformed the performance and efficiency of health care delivery over the last decade through a significant investment in health care data for planning and evaluation. They have demonstrated a rapid improvement in disease prevention and chronic disease management through enhanced information systems and quality feedback. Of the 17 measures recently published by VA (Exhibit 2), ICES is able to report fully on one, and to a limited extent on eight others. ICES' reporting capability on two additional measures will be available by spring 2005.

In a recent exercise, ICES developed current and potential indicators for system-wide and population-based health system reporting in Ontario. The framework included the following four domains:

1. Access to publicly funded health care;
2. Health human resources in publicly funded health services;
3. Consumer and population health status; and,
4. Health system outcomes.

However, with existing data ICES can measure only seven of 16 proposed indicators (Exhibit 3).

## Why the quality of important health care data is deteriorating

Changes to the way health care is delivered and funded are compromising the quality of routinely collected data. For example, the way emergency department physicians are paid has changed from fee-for-service (payment for each service provided) to sessional (payment based on hours or days worked) with "shadow billing" (submission of an OHIP claim indicating that a service was provided, without directly receiving payment for the service). Reduced incentives to accurately shadow bill have resulted in an apparent, though inaccurate, reduction in physician visits for many emergency departments in OHIP data. Incomplete OHIP data is an issue with all physicians on alternate payment plans (not fee-for-service) in which appropriate incentives to shadow bill have not been established.

Similarly, a change in how hospitals are paid for inpatient care has resulted in variations in coding practices, making it appear that hospitals are treating people of increasing degrees of illness. These variations across hospitals make it difficult to track performance measures that adjust for the severity of patient illness from year to year (Exhibit 4).

# Characteristics of Quality Health Care Data

For health care data to be high quality, easy-to-use and relevant in planning and evaluation, it must be:

- **Complete** – Include all settings, providers and populations;
- **Comprehensive** – Include all services;
- **Accurate** – Reflect actual utilization and patient-provider characteristics;
- **Timely** – For use in real-time management and planning;
- **Linkable** – Connect different services that people receive to provide analyses that reflect the complexity of the health care system;
- **Anonymous** – Data use must adhere to strict privacy regulations (*Health Information Protection Act, 2004*);
- **Usable** – Analysts must have access to data that is organized in a readily usable form; and,
- **Consistent over time.**

**Completeness** – Health care data should include most of the population, settings and providers in Ontario. A good example of a health care service for which there is complete basic data is acute care hospital inpatient admissions, which are captured in the Canadian Institute for Health Information Discharge Abstract Database (DAD).

Conversely, increasing fragmentation and erosion of completeness is occurring in physician service claims data. OHIP is the main source of physician service data, while services delivered at Community Health Centres, Health Service Organizations and a number of academic institutions are excluded. The increasing number of alternative payment plans (APPs) with reduced financial incentives for submission of service delivery information also contributes to erosion of data quality. Ultimately, with varied sources and structures of physician service data, it is impossible to create a complete picture of physician care in Ontario. It is also difficult to examine how reforms to primary care affect quality of care and service delivery. Furthermore, as service claims increasingly omit payment-for-service, it becomes problematic to estimate the cost of care for individual services.

Studies of drug utilization, used for many purposes including quality of care measures and disease registries, also suffer from lack of complete data. Through the Ontario Drug Benefits Program (ODB), the MOHLTC has information on drugs dispensed to people aged 65 years and older and other selected groups. While complete drug prescribing data is available in some other provinces, incomplete data in Ontario prevent inclusion of those under age 65 years in important descriptive analyses related to this costly component of the health care system.

**Comprehensiveness** – Health care data should be available for most types of publicly funded health care services, such as prevention, childhood care, obstetrics, chronic disease management, mental health, hospital care, long-term care, home care, drugs, diagnostics and palliative care, though this is currently not the case. In particular, data should be routinely collected for priority MOHLTC initiatives for which there is no data, or, at best, very limited data. For example, numerous provincial and national recommendations to develop a comprehensive vaccine registry, available in other provinces, have been made over the past ten years. However, the expanded immunization program, including universal influenza vaccination, still has limited data collection systems in place to monitor who receives immunization. Consequently, evaluation of the program’s success in reducing inappropriate use of health care services and overcrowding in emergency departments during influenza outbreaks is limited.

Existing laboratory and diagnostic data are also quite limited. While glucose tests performed by a community-based laboratory can be identified through OHIP payment, those performed in a hospital laboratory are not identified because hospital laboratory services are funded through hospital global budgets and no claims are submitted to OHIP.

A modern health care system requires a modern approach to health planning and evaluation, which requires a greater scope of data content. For example, to plan for MRI and CT scanners, several factors must be determined: how many people need the investigations; the length of the waiting period; and whether the wait period is inappropriate (i.e. causing harm or unnecessary anxiety). While data exists on the number of people receiving outpatient MRI and in- and outpatient CT scans, and the dates the tests were performed, there is no other related information readily available. To assess the MOHLTC's priority of appropriate access to diagnostic tests, data collection would have to be expanded to include information on referring physicians (consultation/referral dates), the results of diagnostic investigations, and reasons why people are investigated (i.e. prevention or diagnosis).

**Accuracy** – When basic information is missing or of poor quality, the usefulness of health services data for even the simplest planning efforts becomes limited. For example, it is important to determine the location of services to support planning for Local Health Integration Networks (LHINs). However, OHIP claims have little information on where the physician service was provided, or the home address of the person who received the service. The central Registered Persons Database (RPDB) contains address information for people receiving OHIP services, but it is not regularly updated. In urban areas, some age groups have 30% more people identified in the RPDB than Statistics Canada population estimates.

As another example, the MOHLTC is encouraging the organization of physicians into health centres and family practice groups. However, because there is no central repository of information, such as the type of practice setting of physicians, it is not possible to describe and evaluate the performance of these new groups.

In some situations, basic information is collected, but there are few incentives or quality control initiatives to ensure that the information can be used. For example, physicians record the reason or diagnosis for the patient visit in OHIP claims, but there are no mechanisms to ensure that the information is accurate. The most common diagnoses for non-laboratory physician services in OHIP are "diagnosis not required/not stated" (30% of services) and "other ill-defined conditions" (> 2% of services). A culture of quality assurance needs to be fostered for many existing datasets in Ontario.

**Timeliness** – The time between the date that information is collected and when it is available to planners and researchers varies from one month (for ODB data) to two to four years for Vital Stats data (births and deaths). Many important data such as acute care hospital discharges (DAD) and emergency department use (NACRS) take up to 18 months to become available to Ontario planners and researchers. These timeframes need to be much shorter to be useful in real-time performance measurement and planning.

**Linkability** – Many quality measures and other uses of health care data require that health care is examined across different sectors. For example, describing whether people with severe heart failure are discharged from hospital with appropriate medications requires a combination of hospital, diagnostic and drug data.

**Anonymity** – ICES and other health services researchers must adhere to high standards of data use as outlined in privacy legislation and data agreements with data custodians.

**Usability** – Health care data are stored in different datasets, constantly change over time and are of variable quality. This means that data can only be used by a relatively small number of highly experienced and trained researchers and analysts.

**Consistency over time** – Because health care data has uses other than province-wide planning and evaluation, they often vary from place to place. For example, APPs each collect physician service data differently, such that there is no single report of physician service use in Ontario that is comprehensive for most physician services. Furthermore, data change over time to reflect new billing codes.

# Available Data at ICES

ICES houses more than 18 datasets and 15 are individually linked to the central patient registry (RPDB). The MOHLTC is the custodian for nine of these datasets. Other data custodians include Statistics Canada (population health surveys), Cancer Care Ontario (Ontario Cancer Registry) and the Cardiac Care Network. In addition, linked to RPDB are individual study data that contain a greater degree of clinical data. Disease-specific and other datasets are created using validated algorithms and supplemental information. These types of data include the Ontario Diabetes Database, Ontario Myocardial Infarction Database and the ICES Physician Workforce Database (IPWD). The data custodian and ICES sign an agreement that outlines the specific use for each dataset housed at ICES. ICES recently signed a data agreement with the MOHLTC to transfer four new datasets to ICES, including data on long-term care residents and ambulance response.

Exhibit 5 shows the characteristics of the major datasets and Exhibit 6 describes these characteristics in greater detail. It is helpful to think beyond individual datasets to how the data is organized around components or sectors of the health care system. For example, OHIP data contain information from several different health care sectors including physician office consultations, emergency department visits and hospital care, as well as lab and diagnostic procedures. OHIP data is almost always used to describe province-wide provider services. However, there are no currently available data on nurse practitioners, midwives and many other non-physician primary care providers.

# Improving Data Quality

Several key issues must be addressed to improve health care data quality in Ontario. The first is to identify existing data and how these are used for system-wide, population-based health system monitoring. The second priority, to identify data gaps or needs to allow monitoring of key areas of the health care system, should be undertaken by both the research community and the MOHLTC. Finally, a formal process is needed to address data gaps and needs, and to support continuous quality improvement through systematic development of data. This will require strong leadership by the MOHLTC and consultation with researchers, data custodians and stakeholders who create, collect and ensure the quality of health care data.

Three of the most important datasets (RPDB, OHIP and DAD) are deteriorating in content, completeness and/or quality. Left untended, the issues with these datasets will eventually make even simple descriptions of the health care system difficult, such as when people visit physicians or whether the quality of hospital care is improving or declining. Several potential solutions are to:

- Maintain and improve the current system that is based on collecting information for individual services.
- Abandon the current principle of collecting individual service information and replace it with an approach that collects a representative sample.
- Rely on self-reported information from surveys.
- Perform detailed chart reviews.
- Develop electronic medical records (EMRs), which can be used for a variety of purposes, including planning and evaluation.

Each of these solutions is useful in various instances. However, the only feasible method of maintaining data of sufficient quality and breadth for regional health care planning and evaluation in Ontario is to collect data on the majority of individual health services for the entire population. In some situations, such as for simple descriptive purposes, it may be reasonable to reduce the breadth of service coverage if the sub-sample is representative of all services. Notably, most performance measures and other detailed evaluations require data with complete coverage.

Surveys and detailed chart reviews are essential data sources, but alone cannot meet most planning, evaluation and system monitoring information needs. For example, patient surveys can capture some emergency services information, but would not capture measures of emergency department performance, such as “door-to-needle” time for heart attack treatment. The latter information should be captured in NACRS, but it is not being consistently coded and does not include sufficient detail. Reliable information on “door-to-needle” time can only be captured through chart abstraction studies, which would need to be performed on an on-going basis, in a myriad of settings, making this option impractical. Furthermore, chart reviews and surveys do not assess care across the health care system and are of limited use in reflecting complexity of care. However, these reviews are valuable for ensuring data integrity and quality assurance of routinely collected health administrative data, and are currently under-used in this regard.

Current data is insufficient to support the planning and evaluation of MOHLTC priority areas such as primary care reform, access to key services, chronic disease management and prevention. With improvements to the breadth of coverage and quality, administrative data could become a valuable resource for health system quality monitoring and planning. A tremendous amount of health care information is maintained in electronic format in different sectors, particularly hospitals, pharmacies, laboratories and radiology departments. While EMRs offer tremendous potential for integrating this information, these sophisticated systems will not be available for some time. However, for provincial planning and evaluation there is no need to wait for province-wide EMRs, though new ways of sharing and using existing electronic data for all Ontarians need to be developed.

The following examples illustrate how data can be improved for maximum utility. Many of these examples require little or no additional resources.

**Identify where services are provided**
The location of physician office consultations and laboratory and diagnostic tests is either missing or of questionable quality. For example, a physician may work at one office but bill for services from another location.

**Collect consistent physician identifiers in all health administrative data**
There is a unique physician identifier in datasets such as the IPWD, but not in other data such as DAD and NACRS. In the latter data, individual hospitals use physician identifiers that are unique to their organization, which are not the same as other hospitals or the IPWD.

**Increase provider information**
According to MOHLTC estimates, up to 40% of physicians receive at least some payment outside the OHIP fee-for-service envelope. Currently, no single data source identifies physicians who receive funding from many of the APPs. This information is valuable for human resource planning and performance evaluation of primary care initiatives and should be included with physician characteristics data.

**Quality assurance for DAD and OHIP "shadow billing"**
Changes to funding affect the way that data is coded. In the case of DAD, there are notable variations in coding between hospitals. For OHIP, "shadow billing" can result in a reduced number of claims. Re-abstraction studies and/or other quality assurance initiatives are needed to validate and/or create adjustments for changes in data coding/quality. While some studies have more recently been initiated to examine data quality in DAD, such studies should be on-going and similar initiatives should be undertaken with OHIP.

**Increase physician service information to ensure complete coverage**
The most recent estimate is that OHIP covers 94% of the physician services provided to the population. However, the true number is likely lower and continues to decrease. There is no readily available data that can be used to examine all physician services including community health centres, health services organizations, the Southeastern Ontario Academic Medical Organization and other academic health service arrangements. Attempts to include this information in province-wide planning and evaluation studies have been unsuccessful. These data must be combined into a uniform system for physician services data.

**Provide results of selected lab and diagnostic tests**
Test results are a key data source for quality measures and for monitoring wait times. For example, for diabetes care, hemoglobin $A_1C$ control is associated with favourable health outcomes, and is therefore a well-established quality measure. Understanding the proportion of CT scan results that found an abnormality may help establish appropriate levels of CT examinations. Test results could be submitted to the MOHLTC along with billing information, or to another organization that is involved in assessing health system performance, such as ICES.

**Ensure that OHIP cards are valid, and that relevant demographic and eligibility information is up to date**
This is crucial to accurately assess the geographic variability in access to care and health outcomes, as well as in assessing the impact of socioeconomic status on health and health care use. The significant discrepancy between the number of registered OHIP cards and the Statistics Canada census data for the Ontario population is a serious concern, as is the fact that OHIP recipients are not mandated to update their card when they move to another address.

**Complete population data coverage for drug dispensing information**
The MOHLTC collects drug-dispensing information for people aged 65 years and older, in addition to other specific populations covered by the ODB. However, this only allows for a limited assessment of drug use by Ontarians. Point of dispensing information should be available for all prescribed drugs, as is the case in British Columbia.

**Complete data coverage of diagnostic and lab tests**
Currently, it is not possible to identify many diagnostic and laboratory tests that are performed in hospitals. It should be possible to determine when the tests were done, regardless of location, as these services are important components of many quality measures.

**Expansion and improvement of physician service information**
There are hundreds of physician service diagnostic codes, but few of these are for health priorities such as mental health and preventive services (e.g. immunization). There should be incentives and other systems in place to improve the quality of physician service information.

**Expansion of population characteristics to include risk factors**
Following age and sex, the most important risk factors for future health include blood pressure, smoking and weight (body mass index). Management of these risk factors is a cornerstone of health prevention and chronic disease management. Quality measures for these programs should include information on preventable risks. It may not be necessary to collect this information on the whole population, as carefully selected samples would be adequate.

**Availability of more accurate information about deaths**
ICES does not have access to Statistics Canada census data, resulting in an underestimation of the number of outpatient deaths. Coordination between the Office of the Registrar General and the MOHLTC to ensure that important vital statistics such as “cause of mortality” are added or linked to the RPDB is crucial to ensuring accuracy.

# Conclusions

Though critically important, health care data in Ontario is, in many ways, getting worse due to lack of attention to data integrity and fundamental changes to the way clinical services are funded and delivered. Current data cannot support modern health care planning, evaluation and system monitoring. Other jurisdictions have demonstrated that improved data can lead to large gains in efficiency and improvements in the performance of the health care system. In this regard, Ontario is lagging behind.

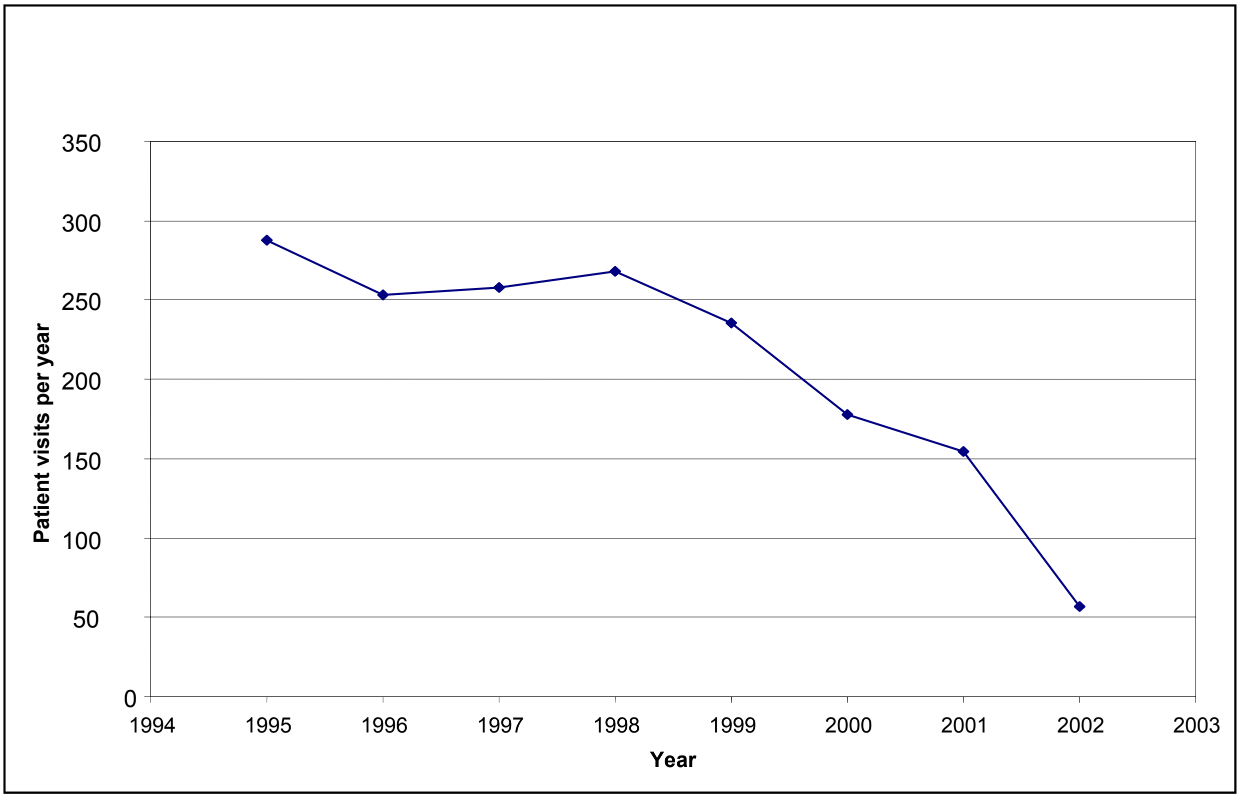
There is need for a consultative process between the MOHLTC and other stakeholders regarding the systematic development of data that can be used to monitor Ontario's health care system and to support continuous quality improvement. The consultative process should foster better communication between researchers with health care data experience who understand the value and limitations of existing data, and the MOHLTC as data custodian with responsibility for the development of a comprehensive strategy for health system measurement and information management.

# Recommendations

1. The MOHLTC should strive to develop health care data of sufficient quality to allow for modern, well developed planning, evaluation and system monitoring.
2. The MOHLTC should create a senior-level data integrity committee to oversee and coordinate the development and improvement of health care data. The committee should have representation from major data creators, such as physicians, hospitals, and pharmacists and their representative bodies (i.e. Ontario Hospital Association, Ontario Medical Association, Ontario Pharmacists Association) and data users, such as government, planners and researchers. This committee would advise the MOHLTC on a data strategy, including short- and medium-term goals to address data gaps and improve existing data needed for health system management.
3. For each health care sector with unique health care data, there should be a data integrity working committee comprised of the MOHLTC, data custodians, data creators and data users. These committees would be responsible for ensuring the development and quality of data for their respective sectors.

# Exhibits

**Exhibit 1. Emergency department service claims in 17 hospitals with a marked decrease in Ontario since 1999***



*Changes to the way in which physicians are paid have spuriously reduced the number of recorded visits.

**Data source:** Ontario Health Insurance Plan

## Exhibit 2. Comparison of data for 17 quality measures between the U.S. Department of Veterans' Affairs health care system and the Ontario health care system

| Quality Measure | Status in Veterans' Affairs | Status in Ontario | Issues/Comments Related to Ontario |
|---|---|---|---|
| **PREVENTIVE CARE** | | | |
| **Mammography** | Yes | No | A population-based screening program exists in Ontario but it is not currently linked to administrative data, and it is not organized for quality measurement (planned linkage spring 2005). |
| **Influenza vaccinations** | Yes | No | Data is available for vaccines delivered in most physicians' offices and from special surveys (data not at ICES). No Ontario vaccine registry. Not possible to identify all recipients. Not routinely collected. |
| **Pneumoccocal vaccinations** | Yes | No | *Same as influenza vaccinations.* |
| **Colorectal cancer screening** | Yes | Limited | Limited data from Cancer Care Ontario database and from chart abstraction. |
| **Cervical cancer screening** | Yes | No | *Same as mammography.* |
| **OUTPATIENT CARE** | | | |
| **Diabetes** | Yes | Limited | Some information could be obtained using combined OHIP and DAD data. |
| – Annual measure of hemoglobin $A_1C$ | Yes | No | No data. |
| – Eye examination | Yes | Yes | OHIP data can be used. Although eye exams were de-listed, diabetes-related eye examinations continue to be covered. |
| – Lipid screening | Yes | No | No data. |
| **Hypertension** | | | |
| Blood pressure | Yes | Very limited | Most recent population-based estimates from the 1990 Ontario Heart Health Survey. |
| **Depression** | Yes | Very limited | Some limited data from the Ontario Health Survey Mental Health Supplement, collected every 5-6 years. Also some information of limited value (due to incomplete coverage and quality concerns) could be obtained using OHIP and DAD data. |

**Exhibit 2. Comparison of data for 17 quality measures between the U.S. Department of Veterans' Affairs health care system and the Ontario health care system (cont'd)**

| Quality Measure | Status in Veterans' Affairs | Status in Ontario | Issues/Comments Related to Ontario |
|---|---|---|---|
| **INPATIENT CARE** | | | |
| **Acute myocardial infarction (AMI)** | Yes | Limited | Some characterization of patients could be obtained using administrative (OHIP and DAD) data. However, this data lacks detail (e.g. lab and other test results, such as echocardiography, and is limited to outpatient testing. No data on inpatients. Detailed data can only be obtained through chart abstraction on a very limited (small sample, time limited) cohort. |
| – Aspirin within 24 hr after AMI | Yes | No | No data. |
| – Aspirin at discharge after AMI | Yes | No | No data. |
| – Beta-blockers after AMI | Yes | Limited | Data for patients ≥ 65 years old through ODB. |
| – ACE inhibitors | Yes | Limited | Data for patients ≥ 65 years old through ODB. |
| – Smoking cessation | Yes | No | Some, very limited information could be obtained in future using new OHIP code for smoking consultation. |
| – Congestive heart failure | Yes | Limited | *Same as AMI (top of page).* |
| – Ejection fraction checked | Yes | Limited | *Same as AMI (top of page).* |
| – ACE inhibitors | Yes | Limited | Data for patients ≥ 65 years old through ODB. |

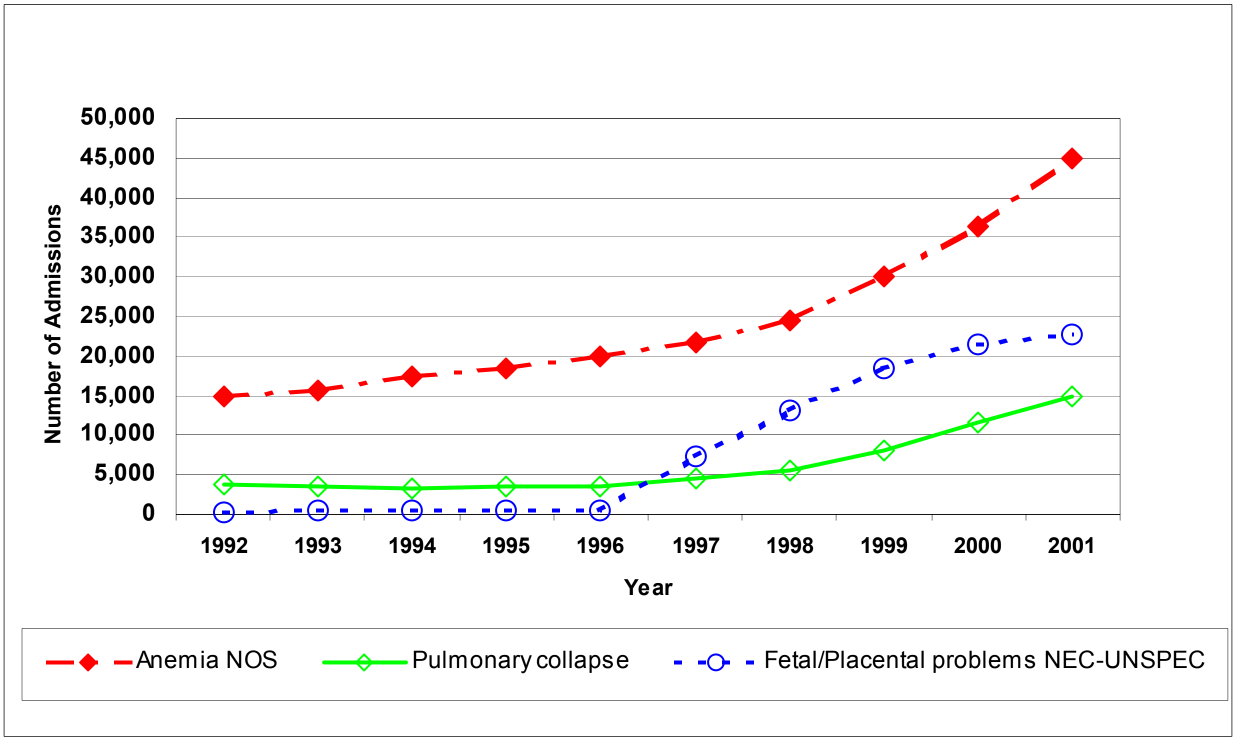
**Sources:** Jha AK, Perlin JB, Kizer KW,Dudley RA. Effect of the transformation of the Veterans' Affairs Health Care System on the quality of care. *N Engl J Med*. 2003; 348(22): 2218-27 and Institute for Clinical Evaluative Sciences.

## Exhibit 3. Proposed measurement framework for public reporting on the Ontario health care system and related ICES analyses

| Domain | Ability to assess through ICES Analyses | Issues/Comments |
|---|---|---|
| **ACCESS TO PUBLICLY FUNDED HEALTH CARE** | | |
| **Rates** | Yes | Crude and adjusted rates (sex, age, region, etc.) for many medical services (e.g. tests, surgeries) and changes over time in Ontario (e.g. change in MRI use in Ontario, 1992-2001, etc.) |
| **Waits** | Very limited | Wait time calculations are difficult using current administrative data at ICES, though some data (Cardiac Care Network) may allow for such calculations. There are smaller studies on very limited cohorts (e.g. 25% sample of breast cancer patients in Ontario) that use a combination of primary data collected through chart abstraction and administrative data. |
| **Appropriateness** | Very limited | Limited number of analyses; most involving project-specific data. |
| **Clinical need** | Very limited | Some analyses are performed. |
| **HEALTH HUMAN RESOURCES IN PUBLICLY FUNDED HEALTH SERVICES** | | |
| **Provider satisfaction and morale** | No | |
| **Access/unmet need** | No | |
| **Characteristics of the workforce** | Yes | Age, sex, regional patterns and changes over time; mainly for physician services. |
| **CONSUMER AND POPULATION HEALTH STATUS** | | |
| **Non-medical determinants of health** | Limited | Some analyses using behavioural determinants (e.g. smoking, physical activity) and socioeconomic status. |
| **Health status** | Limited | ICES atlases describe the health status of Ontarians and trends over time. However, these reports are seldom reproduced. |
| **Public health** | No | |
| **HEALTH SYSTEM OUTCOMES** | | |
| **Process of care and clinical outcomes** | Yes | |
| **Equity** | **Limited** | Analyses - socioeconomic status, gender and geography. |
| **Office and Community-based Care** | Yes | |
| **Institution-based Care** | No | |
| **Coordination of Care** | Yes | |

**Source:** Institute for Clinical Evaluative Sciences

**Exhibit 4. Number of hospital admissions* for selected diagnoses in Ontario, 1992 to 2001**



* A change in how hospitals are paid for inpatient care has resulted in variations in coding practices, making it appear that hospitals are treating people of increasing degrees of illness.

**Data source:** Canadian Institute for Health Information; Discharge Abstract Database

## Exhibit 5. Summary of data used at ICES

| Data Type | Data Source Available | Population Coverage | Comprehensive | Content | Timely | Quality | Easy to Use |
|---|---|---|---|---|---|---|---|
| | | Proportion of the population for whom data is available | Ability to identify all types of services in covered population | Information supports planning and evaluation | Frequency of updates to ICES | Precise and accurate | |
| Physician Services | OHIP | +++ | + | ++ | +++++ | + | + |
| Laboratory and Diagnostic Imaging | OHIP | ++ | + | ++ | +++++ | ++ | + |
| Central Patient Registry | RPDB | +++++ | N/A | ++ | +++++ | + | +++ |
| Hospitalization data | DAD | +++++ | +++ | +++ | ++ | +++ | ++ |
| Human Resources (provider manpower) | CPDB/OPHRDC | +++ (only MDs) | N/A | +++ | ++ | ++ | + |
| Drug | ODB | ++ | ++++ | +++++ | +++++ | ++++ | +++ |
| Emergency Department* | NACRS | +++++ | +++ | +++ | ++ | +++ | ++ |
| Complex Continuing Care | CCRS | +++++ | +++ | ++++ | ++ | ++++ | +++ |
| Inpatient Rehabilitation | NRRS | ++++ | + | ++++ | ++ | + | +++ |
| Long-Term Care | RCS-LTC | ++++ | N/A | ++++ | ++ | New Data (TBD) | ++ |
| Home Care | OHCAS | +++++ | + | +++ | ++ | ++ | ++ |
| Cardiac Care | CCN | +++++ | ++ | ++++ | ++ | ++++ | +++ |
| Cancer | CCO | ++++ | +++ | ++++ | ++ | ++++ | +++ |
| Health Behaviour and Sociodemographic | Population Health Surveys | ++++ | N/A | ++++ | ++ | ++++ | +++ |
| Public Health Services (e.g. healthy babies, healthy families) | No data available | | | | | | |

* As well as mandated outpatient clinics

**Source:** Institute for Clinical Evaluative Sciences

**LEGEND**

| | | | | |
|---|---|---|---|---|
| + | ++ | +++ | ++++ | +++++ |
| Extremely Poor | | | | Excellent |

## Exhibit 6. Description of health care data used at ICES

| Data | Type/ Source | Comprehensiveness | Content | Updates | Issues/Comments |
|---|---|---|---|---|---|
| **Ontario Health Insurance Plan (OHIP)** | Provides information on physician services in Ontario. Ministry of Health and Long-Term Care (MOHLTC) | Covers approximately 90-95% of physician services for majority of Ontario population. | Identifies fee-for-service. Contains physician identifiers, codes for service provided, dates and associated diagnoses, fees paid to physicians. | Monthly | Community Health Centres, Health Service Organizations and some academic alternative payment plans are not included. Also missing: some diagnostic procedures performed on an inpatient basis (e.g. radiology, ECGs), lab services provided at hospitals. |
| **Registered Persons Database (RPDB)** | Provides basic demographic information about anyone who has received an Ontario health card number. (MOHLTC) | Covers entire population of Ontario under OHIP. | Contains data on patients' demographic characteristics. | Monthly | Good information on sex and birth dates. Poor quality on death dates, 6% more OHIP numbers than actual residents in Ontario, postal code data often out of date. Information on eligibility start and end dates not usable in the current format. |
| **Discharge Abstract Database (DAD)** | Covers all inpatient hospital activity. (CIHI) | Includes all inpatient acute care discharges. | Covers all inpatient acute care diagnosis and procedures. | Annual | Standardized data collection. Diagnosis and procedure coding changes to ICD-10. Variations in coding between hospitals. Limited clinical detail. Long delay (over a year) for the most recent data. Very limited data available on in-hospital testing. |
| **Ontario Trauma Registry (OTR)** | Provides data on injury causes, hospitalizations, and deaths in Ontario (CIHI) | Data from all hospitals in Ontario. | New data to ICES. Variables require verification. | Annual | To be determined. |
| **Corporate Provider Database (CPDB) / Ontario Physician Human Resource Data Centre (OPHRDC)** | Source of information on physicians and postgraduate medical trainees. (MOHLTC/College of Physicians and Surgeons of Ontario/Ontario Medical Association/ Council of Ontario Faculties of Medicine). | All physicians in Ontario registered with the Royal College of Physicians and Surgeons of Canada. | Describes physician demographics (gender, sex, practice location), specialty (functional and certified), measures of physician activity (billings, workload, types or services provided), and full-time equivalents. | Semi-annual | Quality of data in the CPDB validated against the OPHRDC through periodic telephone interviews with physicians. Identifies physicians under APPs. Assigns only one 'functional specialty' per MD. Difficulty assigning FTEs as more physicians enroll in non-fee-for-service programs. |

| Data | Type/ Source | Comprehensiveness | Content | Updates | Issues/Comments |
|---|---|---|---|---|---|
| **National Ambulatory Care Reporting System (NACRS)** | Captures patient visits to hospital emergency departments, same day surgery and selected outpatient services. (CIHI) | Covers emergency department visits. Day surgery and mandated outpatient clinics (i.e. oncology, dialysis and cardiology). | Includes acuity, diagnoses, interventions, demographic and complaint information. | Annual | Lack of standardization in coding across facilities. Data not submitted by all emergency departments until 2002/03. Diagnosis and procedure coding changes to ICD-10. Limited clinical data. |
| **Ambulance Response Information System (ARIS)** | Collects information on ambulatory dispatch and calls. (MOHLTC) | Covers the Province of Ontario. | New to ICES. Includes name, birth date, date and time of call, dispatch, arrival, departure, some diagnoses and complaints. | Annual | Very poor data, many missing fields. Not linkable to other data, no OHIP numbers. |
| **Resident Classification System–Long-Term Care (RCS-LTC)** | Collects data on long-term care (nursing homes) patients. (MOHLTC) | All publicly funded long-term care institutions in Ontario. | New data to ICES. Variables require verification. | Annual | To be determined. |
| **National Rehabilitation Reporting System (NRS)** | Contains client data collected from participating Canadian adult inpatient rehabilitation facilities and programs. (CIHI) | Covers all hospitals in Ontario. | Collects sociodemographic and administrative data, health characteristics, activities and interventions. | Annual | New program so there may be data inaccuracies. Voluntary reporting to 2002. |
| **Ontario Home Care Admin. System (OHCAS)** | An administrative database that identifies clients of the Ontario Home Care Program. (MOHLTC) | Covers all publicly funded Home Care services in Ontario. | Records demographic, diagnostic and treatment information on clients of Ontario Home Care Program. | Annual | Activities performed and diagnoses often missing. Not validated (e.g. large numbers of visits attributed to a single patient. No idea of cost, time spent at individuals' homes). |
| **Continuing Care Reporting System (CCRS)** | Collects records of patient assessment in complex continuing care hospitals in Ontario. (CIHI) | All hospital services in Ontario. | Information on physical, cognitive, behavioural, psychosocial diseases, health conditions, treatments and procedures. | Annual | Very rich dataset. New data at ICES. Long delay (over a year) for most recent data. |
| **Cardiac Care Network of Ontario (CCN)** | Data from all 12 hospitals in Ontario that perform adult cardiac catheterization and surgery. (CCN) | Covers almost all cardiac patients in Ontario. | Contains basic demographics, clinical information and additional patient information specific to the encounter. | Annual | Some variables gathered by the hospitals are not stored in the central registry. |

| Data | Type/ Source | Comprehensiveness | Content | Updates | Issues/Comments |
|---|---|---|---|---|---|
| **Ontario Drug Benefit Program (ODB)** | Contains claims for prescription drugs received under the ODB program but mostly for patients aged ≥ 65 years. (MOHLTC) | Covers Ontarians aged ≥ 65 years. | Data on most filled prescriptions for this group of patients. | Monthly | No information for those <65 years of age, no indication for treatment. |
| **Ontario Cancer Registry (OCR)** | Computerized database of information on all Ontario residents newly diagnosed with cancer or who have died of cancer. Cancer Care Ontario (CCO) | Entire Ontario population. | Contains information on patient demographics, cancer diagnosis details, death information, referrals, consultations and treatments. | Projected annually | Does not include stage of disease or date of progression (when applicable). Treatment data not complete. Many dates related to waiting time queue management are missing. No true date of referral. No date of clinical diagnosis. |
| **SURVEYS**<br>*Statistics Canada Census data, National Population Health Survey (NPHS), Ontario Health Survey (OHS), Canadian Community Health Survey (CCHS), National Longitudinal Survey of Children (NLSC), Ontario Heart Health Survey (OHHS), Ontario Health Survey Mental Health Supplement (OHSMHS) | | | | | |
| ***Listed above** | Information on health behaviour, health status, health care use, and socio-demographic implications at various geographic levels. (MOHLTC; Statistics Canada) | Varies. Sample size from 4,000–43,000. | | Variable. Every 2–6 years | Self-reported measures. Limited sample size (estimates for Health Regions). Ecological fallacy. Some surveys can be linked to Administrative Health data. |
| **Primary Data** | Typically chart abstraction (e.g. data from patients' medical charts in hospitals, cancer centres, physician offices, etc.) | Based on small cohorts. | Contains detailed information on patients' sociodemographic and clinical characteristics, and administrative processes. | Collected only once | Good clinical detail not presented in administrative data. Data obtained at one point and for selected cohort only. Costly to abstract. Difficult to get good, consistent data quality. |

**Source:** Institute for Clinical Evaluative Sciences