

Moving Toward a Better Health Data System for Ontario



ICES Investigative Report

April 2006

Moving Toward a Better Health Data System for Ontario

ICES Investigative Report

Author

Karey Iron, MHSc

April 2006

Publication Information

Published by the Institute for Clinical Evaluative Sciences (ICES) © 2006

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system or transmitted in any form or by any means, electronic, mechanical, photocopying, recording or otherwise, without the proper written permission of the publisher.

How to cite this publication

Iron K. Moving toward a better health data system for Ontario. ICES Investigative Report. Toronto: Institute for Clinical Evaluative Sciences; 2006.

Institute for Clinical Evaluative Sciences (ICES)
G1 06, 2075 Bayview Avenue
Toronto, ON M4N 3M5
Telephone: 416-480-4055
www.ices.on.ca

Author's Affiliations

Karey Iron, MHSc

Health Information Officer, Institute for Clinical Evaluative Sciences

Acknowledgments

ICES wishes to thank the following individuals for their key advisory role in the production of this report.

Internal Critical Review

Andreas Laupacis

President and CEO, Institute for Clinical Evaluative Sciences

Paula McColgan

Vice President, Policy and External Relations, Institute for Clinical Evaluative Sciences

Geoff Anderson

Senior Adjunct Scientist, Institute for Clinical Evaluative Sciences

Don DeBoer

Director, Data Management, Institute for Clinical Evaluative Sciences

Douglas Manuel

Scientist, Institute for Clinical Evaluative Sciences

Michael Schull

Scientist, Institute for Clinical Evaluative Sciences

Kathy Sykora

Director, Programming and Biostatistics, Institute for Clinical Evaluative Sciences

Jack Tu

Senior Scientist, Institute for Clinical Evaluative Sciences

Knowledge Transfer

Camille Marajh

Manager, Institute for Clinical Evaluative Sciences

Evelyne Michaels

Editor, Institute for Clinical Evaluative Sciences

Cleo Surace

Knowledge Transfer Coordinator, Institute for Clinical Evaluative Sciences

Laura Benben

Senior Web and Graphic Designer, Institute for Clinical Evaluative Sciences

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

Publication Information	i
Author's Affiliations	ii
Acknowledgments	iii
About ICES	iv
List of Exhibits	vi
Executive Summary	1
How could health information be improved for health system performance evaluation in Ontario?	1
Moving towards a newer, better health data system.....	2
Background and Framework	3
Does Ontario have the information to measure health system performance?	3
Do existing data support health system performance measurement?	4
The framework for measuring health system performance	4
Population characteristics and need for care	6
Quality, timeliness and appropriateness of care	8
Health care outcomes	10
Utilization of services	13
Health care system characteristics	15
Summary	17
The existing "data gaps" in health information	17
Discussion	18
Filling the "data gaps": What should our priorities be?	18
Next Steps	19
How should we address these priorities?	19
What are the potential benefits of a new centralized health information agency?	21
Conclusion	22
Appendix	24
Appendix 1. Types and examples of data used in Ontario for health planning and performance	23
Appendix 2. Implications of currently available data for measuring health care performance by proposed framework components, Ontario 2006	24
Appendix 3. Factors important for good quality health data for use in performance and decision-making...	27
References	28

List of Exhibits

Exhibit 1	Framework for measuring health system performance in Ontario.....	5
Exhibit 2	Measuring risks for chronic disease and use of preventive practices in the population.....	8
Exhibit 3	Measuring quality, timeliness and appropriateness of care.....	10
Exhibit 4	Measuring health care outcomes.....	12
Exhibit 5	Measuring utilization of services	15
Exhibit 6	Measuring health care system characteristics.....	17
Exhibit 7	Proposed data quality framework for better health information in Ontario	21

Executive Summary

Health system performance “scorecards” provide health care policy makers, planners—and often the public—with an overall view of how well the health care system is serving the needs of the population. The ultimate goal is to improve both the quality of health care and system accountability.

Concentrated efforts have been made toward improving the health data that are used to develop performance scorecards. This has led to a better understanding of health care spending, delivery, prioritization of health services—and also to improved patient outcomes—within organizations such as the U.S. Department of Veterans Affairs and the National Health Service in the United Kingdom.

Measuring various aspects of a health care system is a highly complex task. Many different system characteristics must be evaluated, and many sources of data are needed in combination to fully measure these characteristics. In Ontario, as in many other jurisdictions, there are limitations in how the routinely collected health data can be used for health system evaluation. This makes it difficult to measure health system performance accurately and comprehensively.

Issue

On December 1, 2005, the Ontario Ministry of Health and Long-Term Care (MOHLTC) announced a new Information Management Strategy. This initiative aims to support “accountability, quality improvement and evidence-based decision-making” by tracking and monitoring how well the health care system serves the people of Ontario. The MOHLTC is actively working to increase health data quality to support this new strategy. But despite these efforts, there is growing concern that the scope, detail, quality and coordination of health data in Ontario are insufficient for continuous health system evaluation, particularly at the local level.

This report will demonstrate how the current organization, availability and quality of health data in Ontario affect our ability to evaluate different aspects of our health care system. Several generic “real world” scenarios are provided to demonstrate how the current system for producing and sharing health care data in Ontario is—and isn’t—working.

How could health information be improved for health system performance evaluation in Ontario?

Concerted efforts are required to bolster the availability and quality of health information in Ontario. Immediate attention to five major areas of concern would greatly enhance our ability to evaluate health system performance:

- **Update and validate demographic information**—People with older (red and white) health cards should be expected to provide updated demographic information (name and address) as is required of citizens with the newer (green) health cards. This should be introduced immediately. Validation of this information against other sources should be required.
- **Provide timely access to up-to-date Vital Statistics**—Accurate and timely information about births and deaths in Ontario is currently not available for health system evaluation. Vital statistics data should be supplied directly by the Office of the Registrar General for health system planning. The feasibility of collecting health card numbers on death certificates should be explored, and the correct address information on the death registration should be ensured.
- **Create a complete and comprehensive primary care database**—Ideally, this would include information from all primary care providers including: reasons for the patient’s visit; what treatment or advice was provided; and the outcome of the visit (e.g., referral for testing; referral to a specialist or to some other provider; or a drug prescription). At a minimum, however, it would be useful to design a mechanism to collect comprehensive encounter information compatible with the Ontario Health Insurance Plan (OHIP) data for all primary care providers.

- **Create a complete and comprehensive database of laboratory data**—This would capture data from **all** Ontario labs, including patients' health card numbers, the reasons for each test and the test results. (In fact, the Ontario Laboratory Information System [OLIS] is currently underway; data collection is set to begin in 2006 with partial data available in 2007).
- **Create a complete and comprehensive prescription drug database**—This would include data for **all** patients to be obtained at the time each drug is dispensed. The database would cover prescription drugs administered in-hospital and in other institutions such as long-term care facilities.

Moving towards a newer, better health data system

The first and most important priority is to develop an electronic system to track **all** uses of Ontario's health care system. This includes information about why people visit health care providers, about prescription drug dispensing, and about laboratory tests and test results. This kind of system will provide real-time health service and clinical information for all Ontarians.

Such electronic systems are already pervasive in our society (for example, credit and debit cards, use of bar codes on retail products). The technology exists. But transferring such modalities to a large and tremendously complex health care system will require considerable leadership, political will and cooperation among health care stakeholders.

We propose a dedicated and centralized agency with *the legislative authority* to move the health information agenda forward in a holistic, strategic and timely manner. To start, the health information agency would assemble, link and maintain all routinely collected health data and would systematically evaluate and report on data quality to improve its usefulness for system performance measurement. New information, such as registries or other clinical data sets, would be linked to the system as they become available.

The ability to measure how the health system works is necessary to fully understand and bolster patient outcomes and system efficiency. A new, centralized and dedicated health information agency to manage existing health data is a necessary first step toward a fully electronic health data system. Such a system will allow us to capture and provide real-time health service and clinical information for all Ontarians.

Background and framework

In recent years, concentrated efforts have been made towards improving the quality of health data. This has led to a better understanding of health care spending, delivery and prioritization of health services in organizations such as the U.S. Department of Veterans Affairs and the National Health System (NHS) in the United Kingdom. In fact, these organizations have found that investment in a high quality health information system has improved both patient care and patient outcomes.¹⁻³

On December 1, 2005, the Government of Ontario released the Information Management Strategy.⁴ The goal of this new strategy is to “track and monitor how the health care system serves the public” with a particular focus on “producing better data, supporting accountability and quality improvement through performance measurement, and supporting evidence-based decision-making.”

The Ministry of Health and Long-Term Care (MOHLTC) is actively working to increase institutional-level data quality to support this new strategy. Despite these efforts, there is growing concern that the scope, detail, quality and coordination of health data in Ontario are insufficient to attain and sustain health system evaluation, particularly at the local level.

This report will demonstrate how the current organization, availability and quality of health data in Ontario affect our ability to evaluate different aspects of our health care system. It proposes a system for organizing and maintaining high quality health information which is so vital to the future of health care in Ontario.

Does Ontario have the information to measure health system performance?

Many current sources of health data exist that are accessible and useful to evaluate the quality and performance of Ontario’s health care system. For example:

- Administrative data capture information about health services and are typically collected by the province for payment or funding purposes (e.g., office visits to physicians who are paid under OHIP, surgical procedures done in hospitals, and drug claims for persons over age 65 who are covered by the Ontario Drug Benefit [ODB] program.)
- One available source of demographic information about Ontarians (e.g., age and address) is the Registered Persons Database (RPDB). This registry is managed by the MOHLTC and contains information about Ontarians who hold valid health insurance cards. It is also a source for the identification of deaths in Ontario. The RPDB is routinely used for health system performance measurement because it can be linked anonymously to routinely collected health services data. Other sources of demographic information exist—for example, the Canadian Census—but these information sources cannot be linked to other databases.
- Some information about the medical specialty of physicians who are licensed to practice in Ontario and their location of practice is available and is being used for health system planning.
- Population-based surveys, such as the Canadian Community Health Survey collected by Statistics Canada, are used to measure the health of the population. Survey information can augment administrative data by providing information about health service use, health status, smoking rates or dietary practices in the population. The information in these surveys is most useful when it can be linked to administrative data.

- Dedicated registries capture very detailed diagnostic, treatment and follow-up information about patients with certain clinical conditions such as stroke or cancer. The data from these registries can also be linked to administrative data and then used for health system evaluation and clinical service planning. Such registries include the Canadian Stroke Network (CSN), the Cardiac Care Network (CCN) and the Ontario Cancer Registry (OCR).

The collective use of these data is crucial to understanding both the health of the population and how the health care system works. But certain limitations exist which may make it difficult to use these data for accurate and comprehensive performance measurement (Appendix 1).

Do existing data support health system performance measurement?

Health system performance “scorecards” aim to improve both the accountability and the quality of health care. They give health care policy makers, planners, providers—and often the public—an overall view of how well the health care system is serving the needs of the population. However, a particular indicator or set of indicators, such as chronic disease prevalence rates or average wait times for Magnetic Resonance Imaging (MRI) or Computerized Tomography (CT) scans, is only as relevant and valid for health care planning as the quality and robustness of the data from which the indicator(s) has been derived.

Ontario has been a leader in comprehensive performance reporting in many clinical areas, including surgical procedures,⁵⁻⁷ cardiac care,⁸⁻¹² and the use and effects of particular drugs in the elderly.¹³⁻¹⁷ The data used to report on these areas are readily available for performance evaluation and are of relatively good quality. But other key areas of the system, such as management of chronic disease and illness prevention practices by primary care physicians, cannot be fully evaluated because the relevant data are either unavailable or of poor quality.

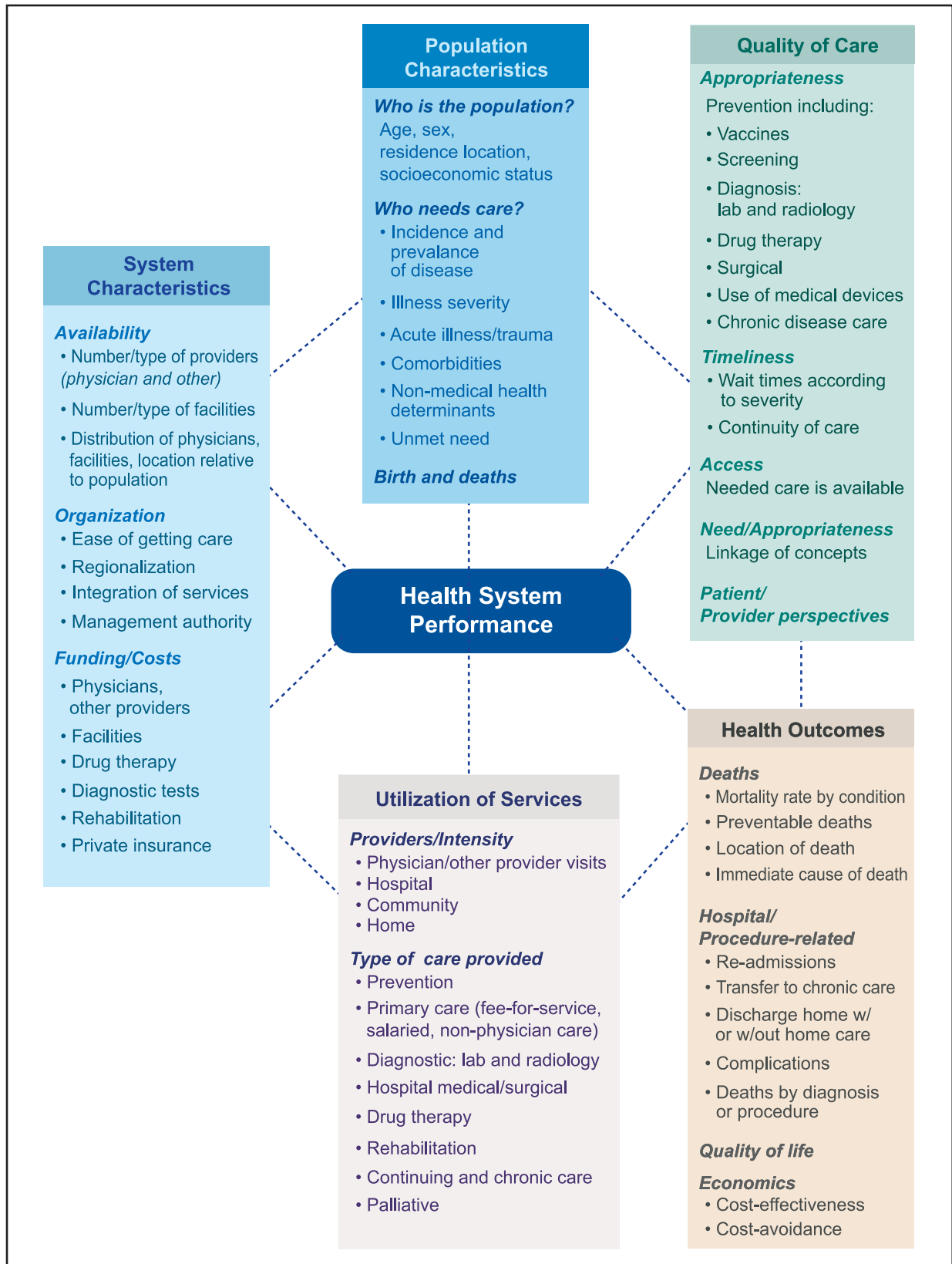
The framework for measuring health system performance

The framework in Exhibit 1 (see page 5) details many overlapping characteristics of Ontario's health care system which must be measured *and linked together* in order to fully evaluate health system performance. The framework has been designed as a web to highlight the interactive nature of the system. The components of this model, which are based on international and provincial system performance literature,^{1, 18-22} include:

- **population characteristics**
- **utilization of health services**
- **the quality of health care**
- **health outcomes including death and quality of life**
- **system characteristics such as organization, funding and costs, and efficiency**

What follows is a deeper discussion of various characteristics in the proposed framework for health system performance measurement. For each characteristic we present a hypothetical but typical “real world” health care scenario that illustrates how currently available data can and cannot be used to evaluate the health care system (Exhibits 2–6). (*See Appendix 2 for a more detailed compendium of the data, data gaps and implications for the health care system.*)

Exhibit 1: Framework for measuring health system performance



Data Source: Institute for Clinical Evaluative Sciences, 2006

Population characteristics and need for care

- Each person in Ontario who is eligible for universal health care has a unique health card number (HCN). Among other things, the HCN is used by physicians, hospitals and labs when they bill the province for the services provided to individual patients.
- In Ontario, the MOHLTC manages a central registry called the Registered Persons Database (RPDB) that contains information about persons who hold a health card. The data include HCN, date of birth, sex, address and date of death (if relevant). New HCNs are added as new persons become eligible for health care; old HCNs become invalid as people die, for example.
- The RPDB can be used in health system performance evaluation to identify groups of people who are similar in age and sex and who live in similar geographical areas. This information can be linked with other more clinical administrative data to track and examine trends in health care and outcomes for groups of persons with similar diseases, conditions and health care experiences. This can help governments, hospitals and others plan for the future delivery of health care services.
- Although the RPDB may be useful for the government to track who is eligible for health care in Ontario, it could be greatly improved for the purposes of health system performance measurement:
 - About half of all health card users (those with older red and white cards) are not currently required to report changes in their demographic information, such as a change of address. This makes it difficult to accurately estimate health care use in geographic areas where many people still have these older cards. People with newer (green) cards are required to update their information regularly.
 - The RPDB is updated by Vital Statistics (births and deaths) data from the Registrar General of Ontario. There is evidence that address information was missing for up to one in five people who died in Ontario over the past three years.²³ Further, when the RPDB data were compared to census information, the number of persons in this registry exceeded the number of persons in Ontario by between six and 10 per cent (up to 30 per cent in some urban centres).²⁴ Such findings raise grave concerns about the use of this registry for health system performance measurement.
- Before we can determine the health care needs of Ontarians, we need to know how many people are experiencing health problems, the nature and severity of their illnesses, who may be at risk for developing disease, and what Ontarians are doing to keep healthy (regular exercise, quitting smoking). Tracking such information over time can help to better plan for future needs.
- Many health problems (e.g., hypertension, arthritis) and risk factors for illness (e.g., obesity, low family income) are difficult to capture using current administrative data. Although broad estimates of some conditions and risk factors can be obtained through self-reported, population-based surveys, it is useful to understand how persons with chronic conditions or risk factors access and actually use health services. To do this, survey respondents are sometimes asked to provide their HCN, which is then used to anonymously link survey responses to routine administrative data.
- The most recent Ontario information that can link survey data to actual health services use in Ontario was collected by telephone as part of the 2001 Canadian Community Health Survey (CCHS). The most recent clinically-based survey—that is, data which included actual measurements of respondents' blood pressure—is more than 15 years old (the 1990 Canadian Heart Health Survey).
- Despite major campaigns to immunize Ontarians against influenza, data on who is receiving flu shots and any related health outcomes (e.g., vaccine reactions, flu diagnosis, visits to emergency departments) are not complete. While it may be easy to capture information about flu shots delivered by OHIP-paid physicians, there is no way to capture immunization data from other settings (e.g., community health centres, schools, workplaces, shopping malls), or immunization delivered by public health nurses and other non-physician providers.

Exhibit 2: Measuring population characteristics and need for care

<p><i>An obese 45-year old woman who recently moved from Sarnia to Toronto goes to her new family doctor (FP/GP) to check her high blood pressure. The doctor assesses the woman to be at risk for diabetes and refers her to a nutritionist. At the same time the physician asks if she would like to be vaccinated against influenza. She replies that she has already received the vaccine at her place of work.</i></p>		
Component we need to measure	Can we measure it accurately?	If “yes” why? If “no” why not?
Place of residence for 45-year old woman	Maybe	A central registry (RPDB) tracks demographic information for Ontario health card holders; BUT update of information is not reinforced for persons with older health cards (red and white cards).
Visit to family doctor	Yes, if the doctor is paid under OHIP; less certainty if the doctor is paid by salary	Little information exists about patients who consult FP/GPs paid outside OHIP (e.g., via community health centres, health services organizations, family health teams).
Follow-up for hypertension	Maybe, if the doctor is paid by OHIP, but information may be missing	Physicians paid through OHIP are not required to state diagnosis or reasons for visit in their billing claims; if they choose to do so, the current form allows them to provide just one reason using an imprecise coding scheme.
Risk for diabetes, referral to nutritionist/exercise program	No; may be able to estimate from population-based surveys	Survey data that can be linked to health outcomes or health services use are not collected routinely.
Person receives influenza vaccine at work	No	Data not collected; only vaccines administered by physician paid by OHIP are captured.
<p style="text-align: center;">Implications for health care system evaluation</p> <ul style="list-style-type: none"> • The demographic information for all persons who are eligible for health care in Ontario (RPDB) needs to be updated on a regular basis for performance measurement and tracking purposes. • The population affected by chronic conditions such as hypertension, arthritis and asthma cannot currently be identified and monitored comprehensively for health services use and health outcomes. This is important for planning future health services. • The populations who are at risk for disease or who adopt preventive practices recommended by health care providers cannot currently be identified and monitored for health service use and health outcomes. This is important for planning future health services. • The activities of providers who are not paid through OHIP cannot be captured in the current system of data collection. 		

FP/GP Family practitioner/General practitioner; RPDB Registered Persons Database; OHIP Ontario Health Insurance Plan

Quality, timeliness and appropriateness of care

- When it comes to health care, the concept of quality is difficult to define, let alone to measure. Most recently, quality care has been measured by comparing evidence-based practice guidelines (involving screening, diagnostic and treatment regimens) to how patients are managed in the “real world.”
- Timeliness of health care is even more difficult to define because the concept relies not only on need and access to services, but also on patient preferences and perspectives. Nevertheless, wait times benchmarks for diagnostic services (such as CT and MRI scans), for cancer and cardiac treatment, and for cataract and some types of orthopaedic surgery have been developed both nationally and provincially. In Ontario, the MOHLTC is developing a Wait Times Strategy Information System that will track wait times at 50 hospitals, which represent 80 per cent of the total procedure volumes (in the clinical areas listed above).²⁵
- Physicians who are paid under the OHIP fee-for-service system submit billing claims to the government in order to be paid for their services. These data can be used to understand what physician services are being provided to Ontarians. But while the information may be detailed enough to examine the rates of services, it may be less helpful if we wish to understand why the services were rendered. As more and more physicians elect to be paid through alternate payment plans (e.g., they receive a salary), it may be even more difficult to accurately measure Ontarians’ access to physicians and to understand what services they are receiving and why. This is a particular problem for the evaluation of primary care.
- In order to examine appropriateness of care, we need to understand how health care need, timeliness and access are related. This requires information that is consistent and linkable over time. Moreover, having data which include patient and provider perspectives is important if we are to fully understand how health care is delivered and received in Ontario.
- The use of evidence-based screening and disease prevention practices are difficult to completely measure. For example, mammography rates for women in Ontario can be calculated, in part, by using physician billing claims data. But whether the mammogram is being done to screen for potential disease or to follow up after previous disease, cannot be determined. About 15 per cent of women aged 50–69 years obtain their screening mammograms through The Ontario Breast Screening Program (OBSP). These data are collected and available through Cancer Care Ontario (CCO).

Exhibit 3: Measuring quality, timeliness and appropriateness of care

<p>A 54 year-old woman is referred by her FP/GP for a routine screening mammogram which is done two months after referral. The FP/GP receives the result of the mammogram within two days: a mass in the breast is suspected; a biopsy is recommended. The woman is referred to a surgeon and waits two weeks for an appointment. The biopsy is done and sent for analysis. The result is deemed to be unclear. The woman waits another two weeks to see the surgeon who explains the biopsy results and recommends breast surgery. The surgery takes place three weeks later; the lump is completely removed and found to be benign.</p>		
Component we need to measure	Can we measure it accurately?	If “yes” why? If “no” why not?
Referral for mammogram and date of referral by family doctor	No	Referral dates are not collected. There is no information if the FP/GP is not paid under OHIP.
Screening mammogram	No	The OHIP coding system does not distinguish screening mammograms from diagnostic mammograms. Data about women who receive their screening mammogram through the OBSP (women ages 50 to 69 years) are collected separately.
Referral to surgeon and date of referral	No	Referral information is not available.
Pathology/laboratory result	No, unless the patient was diagnosed with cancer	Pathology reports for cancer patients are electronically organized by Cancer Care Ontario. Reports for other patients are not available.
Time from surgeon visit to surgery	Yes	These data are available through hospital discharge data.
<p style="text-align: center;">Implications for health care system evaluation</p> <ul style="list-style-type: none"> • We cannot fully evaluate who receives screening mammography according to practice guidelines. • Mammography data are fragmented. • We cannot determine wait times from FP/GP referral to procedure or to specialist visit. • No pathology/lab test or results are electronically available (with the exception of persons who are positive for cancer). 		

FP/GP Family practitioner/General practitioner; OHIP Ontario Health Insurance Plan; OBSP Ontario Breast Screening Program

Health care outcomes

- The Office of the Registrar General of Ontario (RGO) collects information about all deaths in Ontario. These data are sent to Statistics Canada which updates the Ontario death file to include Ontarians who have died while outside the province. The file is then sent back to Ontario for use. This whole process can take as long as three years. The MOHLTC is now using death data from 2002 because timely and high quality Vital Statistics information is not accessible directly from the RGO for health planning. The RPDB is currently the only source for identifying deaths in Ontario for health system evaluation and this does not always correspond with Statistics Canada death information—the cause of death is not available. (Concerns about the quality of RPDB data have already been discussed.)
- Deaths that occur in Ontario hospitals are adequately captured through the hospital discharge abstract data (DAD) collected by the Canadian Institute for Health Information (CIHI). However, the cause of death is not recorded.
- Data on the outcomes of hospital care, such as complications from a surgical procedure or re-admissions, are often well-captured through the DAD. It is possible to use the DAD to track patients once they leave the hospital (e.g., whether the patient goes home or to another health care facility). However these data are not coded with great accuracy.
- Evaluation of health outcomes is linked to how patients are treated, either surgically, or medically with prescription drugs. The Ontario Drug Benefit (ODB) program collects comprehensive information about prescription drug treatment provided to persons age 65 and over. However, no such information is electronically available—for the purpose of health system measurement—for those under age 65, for elderly persons who rely on private drug insurance, or for people who receive medication as hospital in-patients.
- The evaluation of physical and emotional functioning can provide information about a patient's quality of life (QOL). Typically, this information is captured through patient-based surveys or through disease-based registries. But such information is not routinely collected; if it exists, it may not be in a format that is useful for health planning. Long-term care facilities do collect some QOL information. This may help them to determine the overall functioning of their residents so that health care resources can be appropriately allocated according to need.

Exhibit 4: Measuring health care outcomes

<p>A retired, self-sufficient 64 year-old man is brought by ambulance to a hospital emergency department where he is diagnosed with a severe stroke. After receiving the appropriate medical treatment, he is admitted as an in-patient. After several weeks of in-hospital rehabilitation therapy, he has partially recovered but can no longer live at home. He is assessed by the hospital's community services program and is transferred to a long-term care facility. After six months in the long-term care facility, he dies.</p>		
Component we need to measure	Can we measure it accurately?	If "yes" why? If "no" why not?
Persons living alone and/or retired	No	Such data that can be linked to health outcomes or health service use in Ontario are not routinely collected; but, this information <i>may be</i> available through the Statistics Canada Census and some population surveys.
Arrival at hospital by ambulance	Partly	The dedicated ambulance reporting system does not include health card number (HCN). But the in-patient and emergency department data do contain information about the means by which patients arrive at the hospital.
Stroke diagnosis	Partly	These data may be captured in the emergency department data (NACRS) or in the hospital discharge abstract database (DAD), but may not be complete.
Pre-hospital medications	No	Such data are not accessible.
In-hospital medications	No	Information about drugs used to treat patients in-hospital may be collected by hospitals, but the information is not available province-wide for evaluation. Some information may exist within the Canadian Stroke Registry, but it is not comprehensive or routinely available.
Severity of symptoms/functional status	No	Functional status and QOL information for hospital patients is not routinely collected. Some data may exist within the Canadian Stroke Registry.
Hospital rehabilitation	Maybe	Details are not captured routinely; some data may exist within the Canadian Stroke Registry.
Transfer to long-term care and quality of life evaluation	Yes	The hospital data include transfer information, but the accuracy of these data is questionable. Physical functioning in long-term care facilities has recently been captured, but not for all residents.
Death in long-term care facility	Maybe	Such information is not routinely captured through the provincial long-term care database. A death would be reported through Vital Statistics (VS), but these data are not available from the RGO in a timely manner for health system evaluation. RPDB data may be used but without certainty; cause of death information is not included in RPDB.

Implications for health care system evaluation

- There are currently no electronic data to determine patients' living situation prior to hospitalization.
- Information about what happens to patients in the hospital (DAD) is not detailed enough to capture patients who have undergone non-surgical procedures or who have received certain treatments. Hospital data includes information about some—but not all—diagnostic imaging tests; information about drug treatments provided to hospital patients is not available in a standard format across hospitals.
- Drug treatments can be captured for people age 65 and over who obtain medications through the ODB plan.
- Functional QOL information is only partially captured for residents in long-term care facilities.
- Timely and accurate death data are not accessible from RGO for the purpose of province-wide health planning.

DAD Hospital Discharge Abstract Database; **NACRS** National Ambulatory Care Registry System; **VS** Vital Statistics from the Registrar General of Ontario; **ODB** Ontario Drug Benefits; **QOL** Quality of Life; **RGO** Office of the Registrar General

Utilization of services

- Measurement of health services use deals primarily with numbers and rates of discrete (separate) events. Planners use this information to understand how Ontarians use health services over time and across different parts of the province. Much of the information can be linked anonymously from one database to another to describe continuity of care throughout the system. However, despite the abundance of available information that captures service use, many gaps still exist.
- Information about how specific population groups—such as low-income or immigrant Ontarians—use health services is available through health surveys, but some of this information is not robust enough to analyze by geographic area and therefore would not be useful for local health system planning.
- Information about health services provided by non-physician practitioners such as midwives, nurse practitioners and nutritionists is not comprehensive or linkable to other administrative data; therefore it is impossible to routinely examine delivery of these services in relation to downstream health care services and outcomes. Information about services provided by doctors who are paid through salary is not complete or linkable to other administrative data. This makes the comprehensive evaluation of primary care impossible.
- Similarly, little information exists about barriers that individuals may face in accessing health care or about persons who do not access health care at all. Population-based surveys may collect some relevant information but not on a regular basis.

Exhibit 5: Measuring utilization of services

<p>The Chief Executive Officer of a Local Health Integration Network (LHIN) is planning for orthopaedic surgical and rehabilitation services in his area. He needs information about the age and gender of people in his geographical area who have undergone orthopaedic surgery in the previous five years. He needs to know what types of procedures they had and how many procedures were performed in each of the LHIN area hospitals during that five-year time period. He would like to track the health services needs of patients and see which services they receive after being discharged from hospital. Finally, he would like to know how his LHIN compares with others in providing orthopaedic and rehabilitation services.</p>		
Component we need to measure	Can we measure it accurately?	If “yes” why? If “no” why not?
Who has had orthopaedic surgery in the area covered by a LHIN over the past five years?	Yes (partly)	The rate of orthopaedic surgical procedures, along with demographic patient information including age, gender and place of residence, are all captured fairly well through the DAD. Other demographic information (e.g., socioeconomic status, ethnicity) about people who have orthopaedic surgery is difficult to obtain.
Services that patients need	No	This information is not routinely collected. The Ontario Joint Registry has some information about functional status, but the data are not complete. This provincial initiative has recently been folded into a national joint registry, which has dropped the collection of information about patients’ physical functioning.
Referral to rehabilitation	Yes (partly)	Data exist about referral to institutional community care. Home care rehabilitation data are not well captured. Private rehabilitation data are not captured.
Type and intensity of rehabilitation	No	Data on service intensity not captured.
<p style="text-align: center;">Implications for health care system evaluation</p> <ul style="list-style-type: none"> • Hospital discharge abstract data are available, and the quality is good enough to allow for tracking of some surgical procedures. • Important information about patients’ need for services before and after orthopaedic surgery health services is lacking. • Detailed information about rehabilitation is lacking. 		

DAD Hospital Discharge Abstract Database

Health care system characteristics

- Information about health care human resources in Ontario—especially the number of providers, their ages, their specialties and where they practice—is necessary to ensure that Ontarians will have ongoing, timely and appropriate access to care. Many initiatives are now underway to help track the health care workforce in Ontario. One example of such an initiative is the Ontario Physician Workforce Database (OPWD), a collaborative effort among Ontario researchers and government policy makers. This project is aimed at creating better data and analytic methods which can be used to develop a more accurate picture of Ontario’s physician workforce. Similar initiatives focused on other health care providers, such as nurses, are underway, but the data they provide are not detailed enough to be useful in comprehensive system performance measurement.
- Primary care reform has been flagged as a priority in Ontario. Many multidisciplinary practice models have been encouraged and implemented to improve access to primary care. Unfortunately, the information systems necessary to evaluate the resource implications for primary care are not currently available.
- It is difficult to measure the intensity of resources needed to service special populations, such as the homeless.
- As the Local Health Integration Networks (LHINs) become fully up and running in Ontario, it will be necessary to ensure that all health data can be analyzed by geographic area. However, many data sources are not collected or organized in a way that will facilitate local area analyses.

Exhibit 6: Measuring health care system characteristics

<p>A 35 year-old homeless woman comes to an out-patient walk-in clinic. She has no identification with her. She is frightened and confused and shows some signs of psychosis. The clinic is staffed with two FP/GPs, four nurse practitioners, five general clinical nurses and three nursing aides. The patient is calmed, assessed and referred to a community group home.</p>		
Component we need to measure	Can we measure it accurately?	If “yes” why? If “no” why not?
The number of people in Ontario who are eligible for health care but who don't have a health card	No	People without health cards cannot be systematically tracked to measure how services should be allocated.
Information about the homeless or persons receiving services for mental health	Perhaps, if the physician is paid through OHIP or if the patient is hospitalized	No data about patients treated in community health centres are available. Hospital information is available.
Need for mental health services by geographic area	Not with certainty; estimates exist based on past experiences	Crude estimates may be available from surveys, but these are not detailed enough to sufficiently plan for future services, particularly at the local level.
Community provider workload and intensity of workload by patient case mix	No	These data are not currently available for evaluation purposes.
Location, funding and staffing of community clinics	Yes, maybe	These data are not readily available for system evaluation.
<p style="text-align: center;">Implications for health care system evaluation</p> <ul style="list-style-type: none"> • Hospital-based mental health service information is available. However, we cannot currently measure with certainty the need for mental health and other community services. • The number of OHIP-paid doctors, their specialty, location and type of practice and workload (to a degree) can be measured through data from the Ontario Physicians Workforce Database (OPWD). The evaluation of primary care is still a problem because few data sources exist about the growing number of FP/GPs who elect to be paid by salary. • We cannot measure with certainty the number of allied health care providers (nurses, nutritionists, physiotherapists), their location of practice or their workload. 		

Summary

The existing “data gaps” in health information

We have used some generic scenarios to demonstrate how the current system for producing and sharing health care data in Ontario is—and isn’t—working. Broadly speaking, the gaps can be categorized as follows:

- No population-based data exist for health system evaluation.
- Some data exist but they are fragmented—that is, data are collected and housed in part by various organizations.
- Data exist but are not accessible for evaluation purposes.
- Data exist but are of such poor quality that they cannot be used to study system performance.
- Data exist but the quality is questionable and so cannot be used with certainty.

There are four priority areas which require immediate attention if planners, stakeholders and others wish to routinely monitor and accurately track Ontario’s health care system:

- **Update demographic data**—Understanding the most basic demographic information about Ontario residents—age, gender and where people live and die—is vital for health system performance measurement. Although this information is available through the federal census and survey data, it cannot be linked to other health services data to more broadly evaluate how the health system is working. Specifically, the information in the RPDB must be updated and validated regularly for the entire Ontario population, and timely Vital Statistics, including cause of death, must be made available from the Office of the Registrar General for health system planning.
- **Track patients with chronic diseases**—As the population ages, more people will be living with chronic conditions such as arthritis, hypertension and diabetes. People with such conditions will require intensive and long-term follow-up care by their doctors (most typically family physicians). Although chronic disease estimates are available from surveys and from some registries, they are typically not comprehensive enough to be linked with actual health services use and outcomes. A combination of universal laboratory test referral and test result data, data on medication use and physician and hospital data would greatly enhance our ability to evaluate the needs of Ontarians with chronic diseases.
- **Improve data on primary care and primary prevention**—The provincial government has pledged to increase access to primary care in Ontario by providing doctors with the infrastructure to expand their services. In some of these models, physician remuneration is based on salary; other models involve fee-for-service payments to doctors paid by OHIP. Currently, services provided by OHIP-paid physicians can be captured. However, services provided by salaried physicians or by other health care providers cannot be measured. Information about services related to primary prevention—for example, counselling about diet and exercise—is not available at all. Currently, we cannot determine whether the new practice models have helped to improve access to primary care.
- **Expand data on wait times for health services**—National and provincial strategies aimed at ensuring timely access to health care services are currently underway. For example, a Wait Times Strategy developed by the MOHLTC, provides public estimates of wait times for certain types of cancer and cardiovascular care, for hip and knee replacement surgery, for cataract surgery and for Magnetic Resonance Imaging (MRI) and Computerized Tomography (CT) scans.²⁵ However, wait times for primary care and wait times between a primary care referral and specialist care or diagnostic tests cannot currently be assessed. Attention to this information gap is of great importance because the primary care physician is seen as the “gatekeeper” to the entire health care system.

Discussion

Filling the “data gaps”: What should our priorities be?

Ideally, the first and most important priority is to develop an electronic system to track *all* uses of Ontario’s health care system. This would include information about why people visit health care providers, about prescription drug dispensing, and about laboratory tests and test results. Implementing such a system has been discussed at the national and provincial levels, and various initiatives have been proposed.

Such systems are already pervasive in our society—for example, credit and debit cards, and the use of bar codes on retail products. These systems are organized around unique numbers associated with payers or individuals and are updated and readily available in real-time. Most service suppliers have adopted the technology to make it easier for subscribers to consume goods, and individual privacy safeguards are built into these systems. But transferring such modalities for use in a large, tremendously complex health care system will require considerable political will, cooperation among health care stakeholders and public support.

To start organizing the health data system toward a real-time electronic system, the creation of a dedicated and centralized agency to lead this effort is proposed. This agency would need *the legislative authority* to move a health information agenda forward in a holistic, strategic and timely manner.

A primary function of the proposed agency would be to assemble all administrative health data used for performance measurement, linked where possible; the agency would provide the data to all users for system planning, performance measurement and evaluation purposes. The agency would also systematically evaluate and report on the quality of the data to improve its usefulness in system performance measurement.

Preparing for an electronic data system

The following initiatives would help organize Ontario’s health information to prepare for a comprehensive electronic data system:

- **Update demographic information** People with old (red and white) health cards should be expected to provide updated demographic information (name and address) as is required of citizens with the newer (green) health cards. This requirement should be introduced immediately.
- **Provide timely access to up-to-date Vital Statistics** This would include births and deaths data supplied directly by the Office of the Registrar General for health system planning. The feasibility of collecting health card numbers on death certificates should be explored, and the correct address information on all death registrations should be ensured.
- **Create a complete and comprehensive primary care database** Ideally, this would include information from all primary care providers including: reasons for the patient’s visit; what treatment or advice was provided; and the outcome of the visit (e.g., referral for testing; referral to a specialist or to some other provider; or a drug prescription). At a minimum, however, it would be useful to design a mechanism to collect comprehensive encounter information compatible with the OHIP data for all primary care providers.
- **Create a complete and comprehensive database of laboratory data** This would capture data from *all* Ontario labs, including patients’ HCNs, the reasons for each test and the test results. (In fact, the Ontario Laboratory Information System [OLIS] is currently underway; data collection is set to begin in 2006 with partial data available in 2007).
- **Create a complete and comprehensive prescription drug database** This would include data for *all* patients to be obtained at the time each drug is dispensed. The database would cover prescription drugs administered in-hospital and in other institutions such as long-term care facilities.

Next Steps

How should these priorities be addressed?

A new central health information agency should be formed to integrate currently fragmented health data.

A unified health system is required if we are to accurately measure the performance of Ontario's health care system. We propose the creation of a dedicated and centralized agency to lead this effort. *This agency would be given the legislative authority to move the health information agenda forward in a holistic, strategic and timely manner.*

Such an agency would depend on collaboration among current data collection agencies (data custodians and stewards), policy makers, data users, health care providers and institutional and professional associations in Ontario. The central agency would initially have access to the administrative health data in Ontario, linked where possible; the data would be shared among all users for system planning, performance measurement and evaluation purposes.

The new central health information agency will evaluate the quality of Ontario's health data and will provide feedback to custodians who collect the data.

To date, the quality of Ontario's health care data has not been rigorously evaluated. A few condition-specific analyses have been reported,²⁶⁻²⁸ but no standard assessment criteria have been used. A proposed framework for data quality evaluation in Ontario (see Exhibit 7) draws upon the many data quality frameworks that have been proposed internationally,²⁹ in Canada,^{26,30,31} and in Ontario²⁴ (Exhibit 7; Appendix 3). Aside from data quality elements, this framework integrates the characteristics of health system performance measurement (as defined in Exhibit 1, page 5) along with health system priorities and information sources. The left side of the quadrant remains relatively stable over time while the right side changes according to data sources, planning and political priorities.

Data quality evaluations will be performed routinely and will use linked data where possible for validation purposes across data sets. Results from the evaluations will be provided to the data custodians who collect data and also to the users of the data to develop improved data quality strategies. Data quality initiatives that are already underway at the provincial level would feed into the evaluations developed through the new centralized health information agency.

Exhibit 7: Proposed data quality framework for better health information in Ontario

<p>Health system performance</p> <ul style="list-style-type: none"> • Population characteristics • Quality of care • Health care outcomes • Utilization of services • System characteristics 	<p>Dedicated priorities</p> <ul style="list-style-type: none"> • Population characteristics • Primary care • Chronic conditions • Wait time/appropriateness of services • Hospital/acute care
<p>Data quality factors</p> <ul style="list-style-type: none"> • Comprehensiveness • Completeness • Accuracy • Timeliness • Linkable • Anonymous • Temporal consistency • Accessible • Geographically compatible 	<p>Information sources</p> <ul style="list-style-type: none"> • Drug use data • Primary care data • Registered persons database • Population health surveys • Clinical registries • Community care data • Rehabilitation data • Diagnosis and procedure coding • Vital Statistics • Local health information networks

Data Source: Institute for Clinical Evaluative Sciences, 2006

About this Exhibit

- The top left quadrant describes what needs to be measured for health system performance (as in Exhibit 1, page 5)
- The bottom left quadrant determines data quality factors, based on previously published reports.^{24, 26, 29–31}
- The top right quadrant outlines priorities for health care determined by government, health care associations and organizations.
- The bottom right quadrant outlines sources of data that may be used for measurement.

Local-level data will be collected wherever possible to support the Local Health Integration Networks.

The proposed new centralized health information agency would work with data custodians and the Local Health Integration Networks (LHINs) to help fill information gaps which may impede local health planning. The agency would integrate some of the current initiatives that are underway provincially.

For example, the MOHLTC has initiated Local Data Management Partnerships (LDMPs) across LHINs, with the goal of improving the quality of acute care and community-based data at the local level. The centralized health information agency would distribute area-specific data to the LHINs and LDMPs so they would receive a similar data complement (wherever possible). This would help them to better manage their local health care priorities.

What are the potential benefits of a new centralized health information agency?

Unless immediate, consistent and legislated attention is paid to issues of health data integration and quality, it will be extremely difficult to give accurate, ongoing accounts of how well Ontario's health care system is serving the public. Here are some advantages to organizing Ontario's health data centrally:

- Data organized by the proposed new centralized agency can form the basis for a fully electronic health information system.
- The agency will have legislated authority and a clear mandate to improve the usefulness and quality of Ontario health data.
- Health information which is already available will become more useful to policy makers, planners and others because it will be organized and linked in one place and in one format.
- The new centralized agency will have input from all data custodians, users and relevant professional organizations. This will help ensure the relevance of the data for all users.
- All users will have equal and timely access to the improved and expanded data.
- Data quality will be assured through targeted assessment and benchmarking, as described above; all users would receive similar quality data.
- The coordination and equity of data distribution across LHINs and other organizations will be assured.
- Data linkage methodologies will be common and standardized across the province.
- The proposed new agency could provide analytic expertise, if required.

Conclusion

The ability to measure how the health system works is necessary to fully understand and bolster patient outcomes and system efficiency. A new, centralized and dedicated health information agency to manage existing health data is a necessary first step toward a fully electronic health data system. Such a system will allow us to capture and provide real-time health service and clinical information for all Ontarians.

Appendix 1

Types and examples of data used in Ontario for health planning and performance

Data type	Example	Purpose	Data elements	Advantages	Limitations
Administrative	Central Patient Registry; Registered Persons Database (RPDB)	<ul style="list-style-type: none"> Demographic data about Ontarians who are eligible to receive provincial health care 	<ul style="list-style-type: none"> Valid health card number Age, sex Current address Alive/dead 	<ul style="list-style-type: none"> Easy to use Collected and updated routinely 	<ul style="list-style-type: none"> Some data elements not required to be updated (patient address) Deaths not well documented
Administrative	Hospital discharge abstracts (DAD)	<ul style="list-style-type: none"> In-patient hospital stays used for funding purposes by MOHLTC & gleaned from patient charts Captures service use 	<ul style="list-style-type: none"> Patient demographics Diagnoses Procedures Costs per case for some hospitals Patient disposition 	<ul style="list-style-type: none"> Comprehensive Easy to use Data collection infrastructure in place Data collected by trained chart abstractors using national standards Electronically submitted Financial incentives 	<ul style="list-style-type: none"> Limited detail on treatments Some procedures not mandatory to capture (diagnostic testing for in-patients) Drug use in young and hospitalized population not captured Recent coding changes make trending difficult Dependent on the detail provided by physician completing the medical chart
Clinical registries and clinical chart abstraction	Registry of the Canadian Stroke Network	<ul style="list-style-type: none"> Augments administrative data Diagnosis and the management of stroke Education for stroke patients and families 	<ul style="list-style-type: none"> 10,000 stroke patients in 21 hospitals across Canada 	<ul style="list-style-type: none"> Largest stroke registry worldwide High level of clinical detail not found in administrative data 	<ul style="list-style-type: none"> Additional funding required Major coordination effort
Population-based surveys	Canadian Community Health Survey	<ul style="list-style-type: none"> Self-reported information on a range of health issues 	<ul style="list-style-type: none"> Demographic information Health status and chronic illness Healthy behaviours and lifestyles Determinants of health 	<ul style="list-style-type: none"> Generalized to population Level of detail not provided in administrative data Perspectives on health care 	<ul style="list-style-type: none"> Reliability of self-reported information One-time data collection Additional funding required May not be useful for small areas May not be linkable

Appendix 2

Implications of currently available data for measuring health care performance by proposed framework components, Ontario, 2006

Patient characteristics	Examples of current data used to inform	Examples where data are adequate	Examples where data are inadequate	Major implications of currently available data
<p>Description of Ontario population</p> <p>Who is ill?</p> <p>Disease incidence</p> <p>Disease prevalence</p> <p>Illness severity</p> <p>Comorbidities</p> <p>Non-medical risks</p> <p>Unmet need</p> <p>Acute care/trauma</p>	<ul style="list-style-type: none"> • RPDB/ Vital Statistics (VS) • CCHS • Others surveys • OCR • CCN • ODB • OHIP claims 	<ul style="list-style-type: none"> • Survey data can define chronic conditions, preventive practices and risk factors but is self-reported, not routinely repeated and often not linkable to other data sources • Registries (cancer, cardiac) • Acute care amenable conditions (trauma) 	<ul style="list-style-type: none"> • Number of eligible health card number holders in RPDB exceed Ontario population by 6–10% in certain populations • Address and demographic information in RPDB flawed, especially in areas of high mobility, like Toronto • RPDB incomplete in identifying deaths (cause of death not available) • Chronic conditions (e.g., arthritis, migraine, hypertension, back pain) difficult to capture with accuracy • Illness severity only in registries • Lab/diagnostic imaging to define diagnosis not available • Timely VS not available via Registrar General for health planning (last update 2002) • Determinants of health through survey only 	<ul style="list-style-type: none"> • Demographic information about population inaccurate and incomplete for many areas • Can't do geographic analysis, for example, by LHIN with confidence • Can't define population with chronic conditions and associated severity of illness with confidence in Ontario or by LHIN • Can't determine number of deaths, location of deaths or cause of death with confidence in certain populations • Can't determine number of births with confidence • Can't determine illness severity • Can't determine prevention practices (e.g., smoking cessation)

Implications of currently available data for measuring health care performance by proposed framework components, Ontario, 2006 (Cont'd)

Quality of care	Examples of current data used to inform	Examples where data are adequate	Examples where data are inadequate	Major implications of currently available data
Appropriateness Timeliness Access Need, appropriate care and access combination Patient/provider perspectives	<ul style="list-style-type: none"> • RPDB/VS • CCN • OCR • Other registries (OMID, stroke, etc.) • Ad hoc surveys • ODB • Clinical practice guidelines • OHIP claims • Hospital discharge abstracts (DAD) • NACRS 	<ul style="list-style-type: none"> • CCN and CCO registries define illness severity and treatment; urgency scales for priority treatment and wait times • Drug therapy for persons over 65 years • Trauma or acute care amenable conditions • Appropriateness for and access to surgical procedures may be determined 	<ul style="list-style-type: none"> • Incomplete influenza vaccination data • Reasons for diagnostic & lab tests and results not available • Cancer screening data fragmented, especially for mammography • Lab/diagnostic imaging to define diagnosis not available • No routine data on provider/patient perspectives • No accurate death data 	<ul style="list-style-type: none"> • Cannot evaluate with confidence whether flu vaccine program has made a difference to health care use • Cannot evaluate wait times for diagnostic imaging by illness severity • Cannot evaluate mammography rates with confidence • Cannot determine prescription drug use for persons under 65 years • Cannot determine time from diagnosis of chronic illnesses to appropriate treatment • Cannot determine wait times for physician office visits • Cannot determine whether some evidence-based guidelines are being followed

Health outcomes	Examples of current data used to inform	Examples where data are adequate	Examples where data are inadequate	Major implications of currently available data
Death Hospital/procedure Quality of life Health Status Economic	<ul style="list-style-type: none"> • RPDB/VS • DAD • NACRS • CCRS • NRS • OHCAS • MIS • CCHS 	<ul style="list-style-type: none"> • Hospital-related outcomes (LOS, readmissions, complications, in-hospital deaths, etc.) • Quality of life & health status information from surveys • Linkage from acute care to community care • Cardiac home care and cancer care outcomes • Economic data available in some cases • Drug-related outcomes in the elderly 	<ul style="list-style-type: none"> • Death information deficient • Survey data not timely or routinely collected • Home care data deficient (but overhaul is underway) • Long-term care outcomes not well defined • Reasons for community care not well captured • Economic data difficult to use and may not be detailed enough 	<ul style="list-style-type: none"> • Cannot determine dates or causes of death with certainty • Cannot determine whether many clinical programs are bettering patients clinically, functionally or emotionally especially once they have left the hospital • Outcomes such as quality adjusted life years cannot be calculated with certainty in many cases • Cannot evaluate patient outcomes of primary care models

Implications of currently available data for measuring health care performance by proposed framework components, Ontario, 2006 (Cont'd)

Utilization	Examples of current data used to inform	Examples where data are adequate	Examples where data are inadequate	Major implications of currently available data
Who provides care & with what intensity? What type of care provided?	<ul style="list-style-type: none"> • RPDB/VS • OHIP claims • DAD • NACRS • CCRS • NRS • MIS • CCHS 	<ul style="list-style-type: none"> • Rates of hospital and some office-based procedures • Physician visits for most specialties • Rates of emergency department use • Community care encounter data (but no clinical detail) • Use of prescription drugs for persons 65 years and over • Rates of evidence-based cardiac treatment protocols based on registry data 	<ul style="list-style-type: none"> • Primary care outside fee-for-service • Disease prevention activities • Nursing encounter data • Allied health provider data • Home care data deficient • Drug use for persons age 64 years and under • Lab and complete diagnostic testing use 	<ul style="list-style-type: none"> • Cannot calculate rates of primary care visits and for what purpose • Cannot calculate rates of having a regular family doctor • Cannot determine rates of many diagnostic and lab tests; these are purported to be major factors in increased health care spending over the past 10 years • Cannot determine rates of disease prevention activities • Cannot determine extent of public health services in general

System resources	Examples of current data used to inform	Examples where data are adequate	Examples where data are inadequate	Major implications of currently available data
Availability Organization Funding/costs	<ul style="list-style-type: none"> • OPWD • LHIN geography • Number of resources/facilities by LHIN • MIS for hospital global funding 	<ul style="list-style-type: none"> • Number, specialty of physicians by LHIN • Number of facility type by LHIN • Funding by LHIN • Fee-for-service payments 	<ul style="list-style-type: none"> • Non-fee-for-service primary care • Other health care providers • Ontario case costing project only includes 17 hospitals 	<ul style="list-style-type: none"> • Information by LHIN on salaried providers • Resources for rehabilitation fragmented • MIS data difficult to use and interpret for health system performance

CCHS Canadian Community Health Survey; **CCN** Cardiac Care Network; **CCO** Cancer Care Ontario; **CCRS** Chronic Care Reporting System; **DAD** Hospital Discharge Abstract Database; **LHIN** Local Health Integration Network; **LOS** Length of Stay; **MIS** Management Information System; **MOHLTC** Ministry of Health and Long-Term Care; **NACRS** National Ambulatory Care Reporting System; **NRS** National Rehabilitation System; **OCR** Ontario Cancer Registry; **ODB** Ontario Drug Benefits; **OHCAS** Ontario Home Care Administration System; **OHIP** Ontario Health Insurance Plan; **OMID** Ontario Myocardial Infarction Database; **OPWD** Ontario Physician Workforce Database; **RPDB** Registered Persons Database; **VS** Vital Statistics

Appendix 3

Factors important for good quality health data for use in performance and decision-making

Data quality factor	Definition	Example of good quality data	Example of poor quality data
Completeness	100 per cent coverage of population	Hospital discharge abstracts	Population receiving primary care
Comprehensiveness	Data available for all health care services	Acute care including hospital, emergency procedures	Diagnostic radiology, drug data, lab data fragmented/not available
Accuracy	Information is correct	Surgical procedures provided in hospitals	Demographic information in central registry RPDB voluntarily updated for part of population
Timeliness	Short lag between data collection and use	OHIP and ODB	- Hospital acute care—18 months - Births/deaths—up to 4 years (not available from Registrar General)
Linkable	Connection of data to reflect health care system complexity	Continuity of care for identified cardiac patients	Primary care, mental health, community care
Anonymous	Adherence to Ontario privacy legislation (<i>PHIPA</i> , 2004)	- Prescribed entity designation; policies approved by IPC - Data agreements	- Public education about how health information is used
Usable	Accessible and organized	Provincial initiatives for acute care	- No central data repository; health information fragmented across various sources
Temporal consistency	Data elements consistent to evaluate change over time	Few changes to existing Schedule of Benefits fee codes or drug DINs	- Change from ICD-9 to ICD-10 (after 2002) not easily related for some conditions - Coding inconsistencies found in NACRS

DIN Drug Insurance Number; **ICD** International Classification of Diseases; **IPC** Information and Privacy Commissioner; **NACRS** National Ambulatory Care Reporting System; **OHIP** Ontario Health Insurance Plan; **ODB** Ontario Drug Benefits; **PHIPA** *Personal Health Information Protection Act 2004*; **RPDB** Registered Persons Database

Data Source: Improving Health Care Data in Ontario. ICES Investigative Report, 2005

References

- (1) 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):2218–2227.
- (2) Lakhani A, Coles J, Eayres D, Spence C, Rachet B. Creative use of existing clinical and health outcomes data to assess NHS performance in England: Part 1—performance indicators closely linked to clinical care. *BMJ* 2005; 330(7505):1426–1431.
- (3) Lakhani A, Coles J, Eayres D, Spence C, Sanderson C. Creative use of existing clinical and health outcomes data to assess NHS performance in England: Part 2—more challenging aspects of monitoring. *BMJ* 2005; 330(7506):1486–1492.
- (4) Ministry of Health and Long-Term Care. The Information Management Strategy. http://www.health.gov.on.ca/english/media/news_releases/archives/nr_05/nr_120105_2.html. Accessed December 2005.
- (5) Guru V, Anderson GM, Fremes SE, O'Connor GT, Tu JV, Canadian CABG Surgery Quality Indicator Consensus Panel. The identification and development of Canadian coronary artery bypass graft surgery quality indicators. *J Thorac Cardiovasc Surg* 2005; 130(5):1257.
- (6) Kreder HJ, Grosso P, Williams JI, Jaglal S, Axcell T, Wal ED et al. Provider volume and other predictors of outcome after total knee arthroplasty: a population study in Ontario. *Can J Surg* 2003; 46(1):15–22.
- (7) Anderson GM. Making sense of rising caesarean section rates. *BMJ* 2004 Sep 25;329(7468): 696–7 2004; 329(7468):696–697.
- (8) Alter DA, Naylor CD, Austin PC, Tu JV. Long-term MI outcomes at hospitals with or without on-site revascularization. *JAMA* 2001; 285(16):2101–2108.
- (9) Naylor CD, Szalai JP, Katic M. Benchmarking the vital risk of waiting for coronary artery bypass surgery in Ontario. *CMAJ* 2000; 162(6):775–779.
- (10) Tu JV, Naylor CD, Austin PC. Temporal changes in the outcomes of acute myocardial infarction in Ontario, 1992–1996. *CMAJ* 1999; 161(10):1257–1261.
- (11) Austin PC, Tu JV, Alter DA, Naylor CD. The impact of under coding of cardiac severity and comorbid diseases on the accuracy of hospital report cards. *Med Care* 2005; 43(8):801–809.
- (12) Llewellyn-Thomas H, Thiel E, Paterson M, Naylor CD. In the queue for coronary artery bypass grafting: patients' perceptions of risk and "maximal acceptable waiting time". *J Health Serv Res Policy* 1999; 4(2):65–72.
- (13) Redelmeier DA, Naylor CD, Brenneman FD, Sharkey PW, Juurlink DN. Major trauma in elderly adults receiving lipid-lowering medications. *J Trauma* 2001; 50(4):678–83.
- (14) Rochon PA, Tu JV, Anderson GM, Gurwitz JH, Clark JP, Lau P et al. Rate of heart failure and 1-year survival for older people receiving low-dose beta-blocker therapy after myocardial infarction. *Lancet* 2000; 356(9230):639–644.
- (15) Dhalla IA, Anderson GM, Mamdani MM, Bronskill SE, Sykora K, Rochon PA. Inappropriate prescribing before and after nursing home admission. *J Am Geriatr Soc* 2002; 50(6):995–1000.

- (16) Juurlink DN, Mamdani MM, Kopp A, Rochon PA, Shulman KI, Redelmeier DA. Drug-induced lithium toxicity in the elderly: a population-based study. *J Am Geriatr Soc* 2004; 52(5):794–798.
- (17) Mamdani M, Rochon PA, Juurlink DN, Kopp A, Anderson GM, Naglie G et al. Observational study of upper gastrointestinal haemorrhage in elderly patients given selective cyclo-oxygenase-2 inhibitors or conventional non-steroidal anti-inflammatory drugs. *BMJ* 2002; 325(7365):624.
- (18) The Commonwealth Fund. First Report and Recommendations of the Commonwealth Fund's International Working Group on Quality Indicators 2004. www.cmf.org. Accessed December 2005.
- (19) Organization for Economic Co-operation and Development. Health at a glance—OECD Indicators 2005. http://www.oecd.org/document/11/0,2340,en_2649_201185_16502667_1_1_1_1,00.html. Accessed December 2005.
- (20) Dartmouth Atlas Series. http://www.dartmouthatlas.org/atlas/atlas_series.shtm. Accessed December 2005.
- (21) Report of the New South Wales Chief Officer. Report of the health of the people in New South Wales. <http://www.health.nsw.gov.au/public-health/chorep/index.htm>. Accessed December 2005.
- (22) Healthcare Commission. 2005 Performance Indicators. http://ratings.healthcarecommission.org.uk/indicators_2005/. Accessed December 2005.
- (23) Nam Bains for Health System Intelligence Project, Ontario Ministry of Health and Long-Term Care. Mortality Geographic Data Quality, 2000–2001.
- (24) Improving health care data in Ontario. ICES Investigative Report. Toronto: Institute for Clinical Evaluative Sciences; 2005.
- (25) Ministry of Health and Long-Term Care. Ontario Wait Times Strategy. http://www.health.gov.on.ca/transformation/wait_times/wait_mn.html. Accessed January 2006.
- (26) Roos LL, Gupta S, Soodeen R-A, Jebamani L. Data quality in an information rich environment: Canada as an example. *Can J Aging* 2004; 24 (Supp. 1):153–170.
- (27) Pinfold SP, Goel V, Sawka C. Quality of hospital discharge and physician data for types of breast cancer surgery. *Med Care* 2002; 38:99–107.
- (28) Iron K, Goel V, Williams JI. Concordance of hospital discharge abstracts and physician claims for surgical procedures. ICES Working Paper Series #42. Toronto: Institute for Clinical Evaluative Sciences; 1995.
- (29) Carson C. What is data quality? A distillation of experience. 2000. International Monetary Fund. www.DPTCS/STA/DRAFTS/DD/SA/DD/Quality/August2000/HOASAFull Paper.doc. Access December 2005.
- (30) Statistics Canada. Statistics Canada Quality Guidelines. 4th edition. 2003. Ottawa, Minister of Industry. <http://www.statcan.ca/english/freepub/12-539-XIE/12-539-XIE03001.pdf>. Accessed December 2005.
- (31) Canadian Institute for Health Information. The CIHI Data Quality Framework. 2005. Ottawa, CIHI. http://secure.cihi.ca/cihiweb/en/downloads/Data_Quality_Framework_2004_e.pdf. Accessed September 2005.