The value of Ontario's electronic health data infrastructure

A brief report from the perspective of the Institute for Clinical Evaluative Sciences

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About ICES

The Institute for Clinical Evaluative Sciences (ICES) is a publicly funded, not-for-profit, independent research institute and has been Canada's leading health services research center for almost 25 years. A key focus of ICES' work is to evaluate Ontario's health system, to look at how it performs in terms of patient outcomes, efficiency, equity and cost. This work is done by analyzing data that are routinely collected by the Province to *administer* health services provided to Ontarians. This *health administrative data* includes information about Ontarians and their use of the health system, such as physicians' visits, hospitalizations, emergency room visits, home care utilization, long term care stays, and use of prescription drugs. These data often exist in separate files or databases and are maintained by separate organizations. However, when information about the same individual from different datasets is brought together, these highly comprehensive data may be used to answer important health system questions such as: Are Ontarians who require a specific service getting it? Is the care provided timely and of high quality? What organizational aspects of the health care system could improve care?

More information about ICES and the use of administrative data for research, planning and evaluation are presented in the appendix to this report.

Important advances in electronic health data infrastructure from a research, planning and evaluation perspective

Over the past few years, there has been important progress made in terms of implementation of electronic data systems in Ontario's healthcare system. In addition to the benefits that these infrastructure elements have brought to practice, there are benefits related to how the data from them can be used for research, planning and evaluation.

Electronic Medical Records

An electronic medical record (EMR) is a digital version of a paper chart that contains all of a patient's medical history from one practice. An EMR is mostly used by doctors for diagnosis and treatment, and currently, more than 4 out of 5 family doctors in Ontario have an EMR system in their offices for patient care. The EMRs in thousands of physician offices across Ontario are a tremendous data asset for Ontario. Data contained in these EMRs include information that cannot be measured using any other routinely available administrative data, like weight, blood pressure, and symptoms. EMRs will not necessarily contain information on events that occur outside of the doctor's office, such as when a patient visits an emergency room or is hospitalized, however this data is gathered in health administrative data. Getting a more complete picture of a patient's health experience therefore requires bringing together, or linking, the EMR record to Ontario health administrative data. ICES has now linked primary care EMR records for about 1 million Ontarians to their administrative data.

Hospital Electronic Records

Ontario hospitals have invested in replacing paper hospital charts with electronic records containing doctors' notes, clinical assessments, medical imaging reports, lab values etc. These hospital records are now being linked electronically in provincial networks so that patient records from one hospital can be immediately available to medical staff treating the same patient at another hospital. This detailed data allows ICES and other research centres to ask new questions about the quality of care patients get in hospitals. ICES has begun to receive this detailed data from hospitals in the south-west Ontario region, and is working toward bringing in similar data from other regions.

Ontario Laboratory Information System

The Ontario Laboratory Information System (OLIS) is an electronic system that contains the results for about 95% of all laboratory tests conducted on patients in Ontario. These laboratory result data provide a first-ever glimpse at things such as how severe a patient's disease is. For example, using routine administrative data, researchers can generally identify who has kidney disease, but with the addition of lab test data, they will be able to determine whether it is mild or severe kidney disease. This year, ICES began to receive and link OLIS lab data to other datasets, and will soon be conducting more detailed studies of the quality of care for patients with kidney and heart disease as a result.

Healthy Babies Healthy Children Data

ICES has initiated partnership discussions with Public Health Ontario to acquire the Healthy Babies Healthy Children data which is collected by family health teams at each of the 36 public health units across Ontario. These data capture information about children under the age of six years and their families. Every child born in Ontario should be captured in this data. If and when there is agreement to bring these data into ICES, it can be used to identify risk factors of healthy child development in Ontario children.

Narcotic Monitoring System

Opioid drug addiction and excess prescribing is an important public health crisis in Ontario. The newly established provincial *Narcotic Monitoring System* provides electronic data on all prescriptions for opioids written by doctors anywhere in Ontario. In contrast with most ICES data for drugs which is limited to people 65 and older and people on social assistance, the *Narcotic Monitoring System* data is available for all patients (regardless of the patient's age). ICES has received a copy of these data and has already begun to use it to better characterize the opioid crisis.

Mental Health and Addictions Data

As part of work to evaluate the mental health and addictions strategy for the Ontario Ministry of Health and Long-Term care (MOHLTC), ICES is bringing together data related to mental health care delivered in hospital and in the community by local agencies. This has previously been very challenging due to the multiple agencies and organizations involved in the delivery of mental health and addictions care, and that much of the care delivery occurs outside of hospitals and doctors' offices. To address this, ICES has integrated several new datasets from community based organizations as part of ICES' work (see next section), which are providing a

first-ever ability to characterize mental health services for large segments of Ontario's population.

Vaccination data

The success of a health system is dependent in part on the prevention of disease, including vaccination services. Vaccinations can occur in various environments (e.g., pharmacies, doctors' offices, schools) and data on vaccinations have been fragmented. In the past, Public Health Ontario Laboratory Services data has been linked to provincial health administrative data at ICES to assess the effectiveness of particular vaccines (e.g., for whooping cough). Research studies have also been able to examine the effectiveness of flu vaccination in preventing influenza-associated hospitalization and death. With the roll-out of *Panorama*, a national communicable disease surveillance and management tool, the ability to examine the effectiveness of various vaccines and duration of immunity from these vaccines increases. The first phase of *Panorama* deployment includes the immunization module which tracks immunization of children attending school and daycare, and those vaccinated at public health clinics. *Panorama* is part of the initial data partnership discussions between Public Health Ontario and ICES. These data linked to the health administrative data at ICES are essential to enable researchers to more completely examine the relationship of diseases and vaccination with health outcomes.

Examples illustrating how specific elements of Ontario's electronic health data infrastructure provide value from a research, planning and evaluation perspective

EMR data to inform and improve Primary Health Care

EMR data has been critical in identifying health conditions, informing health care planning and improving patient outcomes. These data can be used to determine which patients have a chronic condition, but more importantly they add to the value of administrative data once linked. In the past, the administrative health data collected for the purpose of physician payments (claims) were used to identify patterns of health care use that could reasonably indicate a person had a particular disease or condition. To double check that these patterns were accurately identifying patients with disease, researchers would access a limited sample of family physician paper charts to verify that the patterns seen in the administrative data were accurate.

With EMR linked to administrative data several of these chronic diseases patterns in administrative data (known as algorithms) have been verified to be accurate using family physicians' EMR data at a greatly reduced cost as compared to accessing family physician paper charts. These include several neurological conditions (dementia, Parkinson's disease, and epilepsy), arthritis, and heart disease (atrial fibrillation and chronic heart failure). Once developed, these patterns can then be used to look at disease across the entire population of Ontario. As an example, using both administrative data and EMR data, ICES recently produced a report for the MOHLTC on health service utilization patterns and costs for individuals living with dementia in Ontario. This research, which was presented to Deputy Minister Robert Bell

and other stakeholders this year, has provided important information for health care planning activities needed to plan for and improve services for Ontarians living with dementia.

Multi-sector data related to mental health services to establish baseline information about current services, and inform planning for priority improvements

An important health system priority in Ontario is to improve the care of people with mental health and addictions problems. As a leading cause of disability, mental health and addictions impacts multiple aspects of life including school and employment, housing and social services, among others. These services are currently provided by multiple government ministries based on whether the services are community or hospital based and whether the services are provided to adults or children. As a result, the health administrative data held by ICES represents only a small proportion of all of the mental health and addictions services that are provided in Ontario, and do not fully describe the impact of mental health and addictions on the lives of those affected. When the MOHLTC asked ICES to develop a report on mental health and addictions care in Ontario, ICES recognized that more data was required to fully describe the problem and the related health care in the province. ICES worked with many community partners, Ministries and agencies to acquire and or multiple electronic data sets at ICES to fill knowledge gaps in the area of mental health and addictions. Some examples include:

- Aggregate school-level education data from the Ontario Student Information System (OnSIS) was used to develop outcome indicators relevant to child and youth mental health such as the rate of students identified with behavioural issues. These indicators were reported in the child and youth mental health baseline scorecard that was released in March 2015.
- Data from Kinark Child and Family Services, a community-based children's mental health service provider that serves the Greater Toronto Area, were used to examine care pathways between community and hospital-based services that were not otherwise captured in ICES data.
- Data collected using the Early Development Instrument from the Ministry of Education, an assessment tool for early childhood development, is currently being linked to ICES data and will be used be used to determine health outcomes in the early years and to predict development later in life.
- Telemedicine is increasingly being used as a way to provide mental health services to people living in rural and remote regions of Ontario. The Ontario Health Insurance Plan (OHIP) data that ICES holds captures only a portion of the telepsychiatry services that are provided to children and youth. The TeleLink Mental Health Program contains information on telepsychiatry services that are funded by the Ministry of Children and Youth Services and that are not captured in OHIP. Combining this data with OHIP data will provide a better picture of how telepsychiatry services are used by children and youth in Ontario.
- The Community Business Intelligence data set contains client-level service utilization information for adults for all health service providers funded by Toronto Central Local Health Integration Network across three sub-sectors: community mental health, community addictions and community support services. Similar to how ICES has used the Kinark data, the Community Business Intelligence data has been used to increase

our understanding of how and when clients use hospital- and community-based services.

- The Ontario Common Assessment of Need (OCAN) tool is a needs assessment tool for persons with serious mental illness that is used by community-based mental health agencies in Ontario. In addition to filling a knowledge gap of how adult community-based mental health services are provided in the province, it also provides functional assessment data that is currently not found in any other data set at ICES. Researchers at ICES are currently exploring a number of research questions using the OCAN data to shed light on mental health care needs among Ontarians, including understanding patient characteristics, assessing follow-up care and outcomes after hospitalization, evaluating access to community care, identifying high-needs patients, and understanding patterns of health care use over time. The OCAN data are also essential to measuring the reliability of other sources of mental health data currently held at ICES.
- The Ministry of Community and Social Services (MCSS) data set contains information on clients to who access the Ontario Works and the Ontario Disability Support Programs. The MCSS information will help us better understand the burden of mental health and addictions in Ontario.

How Ontario's electronic health data infrastructure provides value from a clinical perspective

Many ICES scientists are also practicing clinicians, and experience first-hand the utility of some of the new electronic health record infrastructure that has been put in place in recent years. EMRs are now routinely used for every patient seen by the vast majority of family doctors in Ontario. Every time a doctor sees a patient, their EMR provides them with information on the patient's current and past medical history, family history, risk factors (e.g., smoking), allergies and immunizations, laboratory test results, clinical measures (e.g., blood pressure, height, weight), medications prescribed for their patients, diagnostic tests ordered and their results, referral letters to consultants, reports back from consultants and hospital discharge summaries. In hospitals, many doctors now regularly work on hospital electronic charts, which are now linked to the records of other hospitals through electronic networks.

Three such networks now exist in Ontario and are being used every day by doctors and other providers. Such systems provide significant advantages over paper charts in terms of real-time retrieval of critical information, and avoiding duplication (for example, avoiding the need to repeat a laboratory test when a physician can access prior recent lab results done at a neighboring hospital).

Similarly, electronic Picture Archiving and Communications Systems (PACS) now allow physicians to retrieve medical imaging results and reports (e.g., x-ray, ultrasound, CT scans, MRI scans etc.) from multiple hospitals across Ontario, providing critical diagnostic information in real-time, and often avoiding the need for unnecessary and potential harmful repeat imaging.

Another advance is the availability of real-time information about Ontario Drug Benefit medications prescribed to patients through an electronic drug profile viewer in hospitals. This is important because when patients are ill and need to go to the Emergency Room they are sometimes too sick to remember to bring all their medications with them, or to tell the doctor what prescriptions they are taking. This creates a dangerous situation for a doctor who might need to prescribe a new medication. Since 2005, the drug profile viewer has been available 24/7 in all Ontario hospitals and gives doctors the critical information they need about the medications being taken by their patients, when they need it.

Finally, patients themselves can now increasingly access their own medical records electronically. A new innovation, called MyChart, is an electronic platform which provides patients with online access to a secure and privacy-protected portal where they can view and/or share with their doctor information from their electronic hospital record. This means that, for example, a patient from Sudbury on holiday in Toronto or Florida could, if needed, access their medical record online while away and share it with a local doctor if they wished. MyChart is now being used by ~11 organizations including hospitals, home care services, and commercial laboratories. Maximizing the benefit of such systems to patients will require that they be adopted by more sites, and ultimately brought together into a single electronic health record (EHR), so that patients may, if they wish, see their entire record through a single web portal, even if they have records at several hospitals.

Conclusions

ICES uses multiple elements from Ontario's electronic health data infrastructure to answer important questions that help improve the health system, make for better health policy, and healthier Ontarians. For many years, ICES relied primarily on administrative data that was produced through routine interactions of individuals with the health care system. Such data remain a critical resource, but **providing answers to the complex problems facing today's health care system requires enhancing administrative data with new kinds of health information available in electronic records**.

Individual doctors' practices, clinics, hospitals, home care and other community agencies have been increasingly adopting electronic records over the last decade, but in too many cases these data reside in stand-alone systems and cannot be readily combined across systems. The full benefits of these investments are therefore not yet being realized. However there are many examples of progress in bringing data from these systems together into networks while ensuring privacy and security. **Continuing to build a more integrated electronic health data infrastructure is critical to ensuring that health data can be used to strengthen the health system, improve health policy, and improve patient care and population health.**

APPENDIX

Appendix: What is the Institute for Clinical Evaluative Sciences and how does it use administrative health data?

The Institute for Clinical Evaluative Sciences (ICES) is a publicly funded, not-for-profit, independent research institute and has been Canada's leading health services research center for almost 25 years. A key focus of ICES' work is to evaluate Ontario's health system, to look at how it performs in terms of patient outcomes, efficiency, equity and cost. This work is done by analyzing data that are routinely collected by the Province to *administer* health services provided to Ontarians.

This *health administrative data* includes information about Ontarians and their use of the health system, such as physicians' visits, hospitalizations, emergency room visits, home care utilization, long term care stays, and use of prescription drugs. These data often exist in separate files or databases and are maintained by separate organizations. However, when information about the same individual from different datasets is brought together, these highly comprehensive data may be used to answer important health system questions such as: Are Ontarians who require care getting the care they need? Is the care provided timely and of high quality? What organizational aspects of the health care system could improve care?

ICES is a "*prescribed entity*" under the Personal Health Information Protection Act, 2004, which allows ICES to collect, link and use personal health information for the purposes of health system evaluation and research. Other organizations that routinely collect this health administrative data securely transfer the data to ICES. A small number of highly trained staff at ICES removes names and other direct personal identifiers as soon as data are disclosed to ICES to ensure that privacy is maintained, and then bring the various databases together to create the ICES data repository of linked Ontario data that does not contain identifying information. This enables ICES to evaluate the health care that Ontarians get over time and anywhere in the province.

ICES uses a variety of sophisticated measures to protect the information entrusted to it. Physical security measures, technological safeguards like encryption and a robust framework of policies and procedures work together to protect information. ICES' staff and scientists at six locations across Ontario have expertise in using these linked data sets to generate new knowledge that has directly informed health policy and improved the safety and quality of healthcare in Ontario. Many ICES scientists are practicing doctors or other healthcare providers, so they are part of the health care system and their research questions often relate directly to the care of their patients.

ICES produces reports in response to questions posed by the MOHLTC and other health system stakeholders, ensuring that ICES data are providing practical answers to help improve health policy and strengthen healthcare. ICES also works in close partnership with many other organizations, such as Cancer Care Ontario, Health Quality Ontario, and Public Health Ontario.

ICES is the steward of a large comprehensive and linkable repository of about 90 databases used for research and evaluation. These data are linkable based on individual Ontarians, can follow patients over time, and cover almost all of the Ontario population.

The ICES Data Repository consists primarily of health administrative data that are created in the day-to-day interactions with the health care system. ICES' data includes most publicly funded health care sectors, and goes back as far as 1991 in some cases. ICES enhances these data by bringing them together with other datasets to further characterize the population and identify specific medical conditions or diseases. For example data on the characteristics of the population (e.g., sex and age) are determined through the Ministry of Health's Registered Persons Data Base and immigration status based on data from Immigration, Refugee, and Citizenship Canada. Several important disease registry collections include Ontario Cancer Registry, the Ontario Stroke Registry, and the Registry of the Cardiac Care Network. Using the administrative data available at ICES and comparing with data from patient charts, scientists at ICES have developed methods to reliably identify Ontarians living with a number of chronic diseases including diabetes, asthma, chronic obstructive lung disease, and chronic heart failure.

ICES does this based on a person's pattern of doctor and hospital visits, but this method is not perfect, and is not detailed enough to identify what symptoms a patient has or the severity of their disease. For example, ICES may be able to identify people with chronic lung disease, but cannot distinguish how seriously the disease impacts their health and life: one individual with lung disease might be able to work despite the disease, while another individual might be confined to bed.

Another limitation is that administrative data tell us little about how risk factors influence health prior to the development of a disease. For example, ICES data can show that an individual has been admitted to a hospital for a heart attack, but ICES' data are not detailed enough to know that the same individual was at high risk prior to having a heart attack due to high blood pressure and cholesterol level. Knowing how important health risk factors are being treated could provide important information for the health system to help prevent serious diseases from developing or worsening. ICES is continually looking to grow and improve its data repository to answer these important questions. A more integrated electronic health data infrastructure is critical to ensuring that health data can be used to strengthen the health system, improve health policy, and improve patient care and population health.