Summary and Recommendations for Moving Forward From *Better Information for Improved Health: A Vision for Health System Use of Data in Canada*

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Prepared by the Canadian Institute for Health Information, in collaboration with
Canada Health Infoway, on behalf of the Conference of Deputy Ministers of Health

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Background

Improving the secondary use of health data to strengthen the health system—often referred to as health system use of data—was identified as a priority at the 2008 Health Information Summit in Kananaskis, Alberta. The Canadian Institute for Health Information (CIHI) and Canada Health Infoway have since collaborated with jurisdictions and stakeholders across Canada to advance this agenda.

Better Information for Improved Health: A Vision for Health System Use of Data in Canada expresses a shared vision for the health system use of electronic health data that will both protect the privacy and confidentiality of patients and serve Canadians and Canada's health care system well into the future. It was founded in consultation with more than 125 health leaders across the country and with the guidance of the Health System Use Deputy Ministers Steering Committee and Technical Advisory Committee.

In May 2013, the Federal, Provincial and Territorial Deputy Ministers of Health endorsed the vision and guiding principles for future health system use of data, as well as the recommendations for moving forward with the health system use of data agenda outlined in *Better Information for Improved Health: A Vision for Health System Use of Data in Canada*.

Better Information for Improved Health

Canadian jurisdictions face a growing challenge: doing more and better with less. Health care providers, governments and health system administrators need to achieve fiscal sustainability, and they continue to be challenged to innovate and transform health care delivery to improve efficiency and health system performance. They do so in the face of an aging population and a growing burden of chronic diseases; newer but more expensive diagnostic tests and pharmaceutical treatments; and heightened expectations for better health system outcomes, quality of care and active patient engagement.

Good information is crucial to achieving a high-performing and sustainable health care system. In the past, numerous sources of data, such as hospital information systems and medical billing systems, have been used to support health system decision-making. While these traditional sources are still valid, the conversion of Canada's fragmented, paper-based clinical systems to electronic records creates a unique opportunity for new and richer sources of information to inform decisions about health and health systems.

Billions of dollars are being spent on a range of information technologies to support the direct provision and coordination of health care to patients. To obtain additional value and benefits from these investments, concerted action is needed now to leverage and use this new digital data— in a manner that respects privacy and confidentiality—to also strengthen the health system.

By utilizing new sources of electronic health data to support health system improvements, jurisdictions will realize an important opportunity to achieve the best possible health, the highest-quality care and a sustainable, efficient health system. With the support and leadership of government championing work and fostering collaboration in each of the three key areas, Canadians can begin to reap the benefits of better information for improved health.

Value and Benefits

A number of opportunity areas for health system use of data exist. Better use of information for **health system management**, for example, would permit answers to key questions, such as the following:

- **Productivity and efficiency**
  – Where are the pressures and bottlenecks in the system?
  – Where are time and money wasted through ineffective interventions, missed opportunities, duplication of services and inefficiencies?
- **Quality, safety and patient experiences**
  – Are patients receiving the most appropriate services and cost-effective treatments for their needs?
  – Which initiatives are most successful at reducing wait times and improving access to care?

- **Allocation of resources**
  - How are local patterns of disease changing? What resources will be needed to meet the associated health care needs in the future?
  - Which human and financial resources are most needed and where are they likely to have the greatest impact?

In the clinical setting, secondary use of health data can improve quality initiatives and the effectiveness of front-line care. For example, administrators and front-line clinicians can be alerted when measures related to quality and patient safety fall outside a normal range and can be notified of factors that may be contributing to the deviations. Clinicians can make secondary use of the data to evaluate their own performance against practice guidelines or to revise outdated care protocols.

For population and public health, health data can be used to understand the burden of illness and quality of life of the population, and to manage and evaluate public health interventions. For example, in addition to timelier public health surveillance of influenza and other viral outbreaks, data from point-of-care systems could be used to identify unanticipated side effects and contraindications of new drugs.

To facilitate health research, health data can be used to support research that informs clinical programs, health system management, and population and public health. Such research spans multiple fields. For example, multiple sources of data could be integrated to find early markers of disease, the cost-effectiveness of different interventions could be evaluated, and historical data could be used to simulate and model trends in long-term care needs and evaluate different policy options to meet those needs.

The full report *Better Information for Improved Health: A Vision for Health System Use of Data in Canada* features more examples and case scenarios demonstrating the value and benefits for Canadians and the health system.

Risks of Inaction

An important opportunity to increase the sustainability and performance of the health system will be lost unless there is concerted action to leverage rich new sources of data in electronic systems. Without a coherent, shared approach to using data from electronic medical records (EMRs) and electronic health records (EHRs), there is a risk that some of the valuable information produced to help manage the health system and track its performance over time will not be available in the future. It is crucial that the data elements and standards needed to generate existing information be retained or updated. In addition, should secondary use of data requirements not be built into the electronic health systems currently being deployed throughout the health system, jurisdictions will face large retrofit costs in the future. The data and standards necessary to support health system decision-making are also used to support the delivery of front-line care; not having them in place also puts some of the expected benefits of e-health systems at risk.

Building Blocks

Figure 1 outlines a framework to enable the shared vision of *better information for improved health*. The framework's three building blocks must come together if we are to realize the value and benefits of using electronic data to strengthen the health system.

Figure 1: Framework to Enable the Shared Vision of *Better Information for Improved Health*
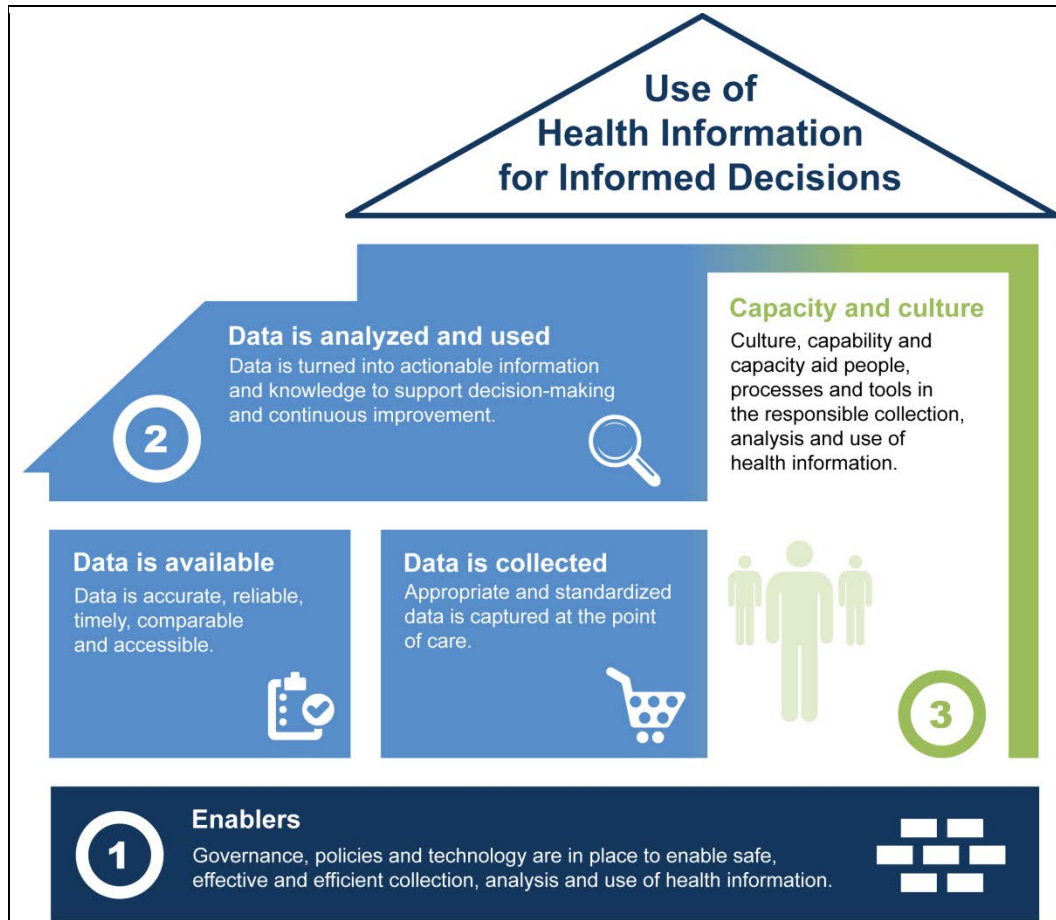
1. Enablers: The Foundation

The transition to electronic records significantly increases the volume of health data that could be potentially shared and made accessible. A solid foundation of governance and technology is essential to efficiently manage and utilize the valuable information that can be derived from point-of-care health information systems.

As well, personal health information is not *just* data. It is sensitive information provided confidentially in the context of care and needs to be protected. Health information laws in Canada generally permit secondary use of health data, whether paper or electronic, for management and planning of health systems. In most instances, this use is—and will continue to be—based on data that has been de-identified to respect the privacy and confidentiality of patients.

Clear governance structures are required to establish leadership, responsibility and accountability for the proactive management of activities related to the use of health data.

Guiding principles for building strong governance

- The roles, responsibilities and authority of multiple stakeholders are defined to ensure transparency and accountability for the responsible use of data for health system decision-making. Current governance structures are leveraged and supplemented as necessary.
- Mechanisms are in place to identify information gaps and prioritize information needs.
- Guidelines and policies are in place to facilitate health research and collaboration between organizations.

In addition to governance, legal frameworks, policies and best practices that ensure data privacy, confidentiality and security must be in place and adhered to.

Guiding principles for privacy and security

- Best practices for privacy, confidentiality and security are applied and supported by technology to control what data can be accessed, when and by whom. Procedures for managing a privacy breach and the consequences of a breach are known.
- Education and training programs communicate legislated obligations, privacy policies, and data collection and use responsibilities.
- Canadians understand how their data is used, what safeguards are in place to protect it and what rights they have to limit its use or gain access to it.

Finally, technology that can integrate data from multiple sources and easily turn large volumes of data into actionable information is essential.

Guiding principles for technology

- The secondary use of data is considered when developing e-health strategies and making investments.

- Systems used to provide direct care to patients are designed for interoperability, using common approaches and content standards, to also enable health system use of data.

- New analytical techniques and emerging technologies are leveraged to gain actionable insights from large volumes of data that are linked over time and across multiple data sources.

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2. Data Collection, Availability and Use

New data sources can be leveraged to learn from each patient's interactions with the health care system. Getting value from this new data depends on collecting the right data once as part of the care process and transforming it into actionable information to support health systems.

To make the most of these opportunities, appropriate data must be collected in a manner that minimizes effort by care providers and maximizes its reusability (that is, collection is standardized). The analysis of health data must help determine what is happening today and what is likely to happen in the future, in addition to the traditional reporting of what happened in the past. Finally, high-quality information needs to be available in the right format, to the right people, at the right time.

Guiding principles for data collection, availability and use that support health system decision-making

- Data is made available (in compliance with health information privacy legislation) to adequately manage and plan for all publicly funded health services.

- Guidelines are in place to ensure that data is standardized to maximize usability for both primary use of data (caring for patients) and health system purposes.

- Results are contextualized and tailored to manage information overload. Information is presented in a way that can be easily understood and interpreted by clinicians, system managers and policy-makers to enable action and change.

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3.   Capacity and Culture

Capacity and culture play a crucial role in creating an environment in which health information is systematically used to support decision-making at all levels. Traditional tools, processes and skills need to be augmented to make the most of the opportunities created by new and emerging information sources.

Guiding principles to support capacity and culture

- A culture of measurement, information use and continuous performance improvement is promoted and reinforced.

- Skills and abilities to understand and take advantage of information to support decision-making are developed. Tools and processes that facilitate information use are adopted.

- Education and skills development strategies are developed to increase information literacy among the health workforce.

- Stories of innovations, successes and lessons learned about information use are shared broadly.

- Canadians recognize that the secondary use of health data has a role to play in strengthening the health system.

Recommendations for Moving Forward

Some of the strategic issues and guiding principles identified to better use electronic health data to improve the health system will require provinces and territories to determine the best course of action according to what is already in place in their jurisdiction. However, there are a number of shared challenges across jurisdictions, and similar interdependencies with key stakeholder groups, that require concerted action at a pan-Canadian level.

The vision paper marks the final deliverable of the 2009 electronic health records and health system use initiative, yet more work is needed by jurisdictions and others to ensure that electronic health systems across Canada can collect, make available and use health data for a variety of health and health system benefits. In particular, there is a need to address key factors necessary to turn the vision into reality, including:

a) Engaging and communicating with key stakeholder groups, such as
   - The Canadian public, to maintain trust and gauge shifting expectations;
   - Health professional organizations, to demonstrate the benefits to clinicians and patients, and to increase buy-in and uptake from front-line care providers; and
   - Privacy commissioners, to enact or maintain legislation for secondary data use aimed at strengthening the health system and to educate workers within the health system on their obligations and responsibilities.

b) Building a strong knowledge base and facilitating knowledge sharing, starting with

- Evaluating initiatives in progress, to assess the benefits and share best practices; and
- Calculating the return on investment of current and future health system use activities, to inform future investment decisions.

c) Ensuring that high-quality information is available and used in front-line care and for secondary uses by

- Championing the adoption and use of content standards to ensure front-line clinical value and comparability of the information across the country and internationally;
- Confirming with e-health agencies that secondary use capabilities are built into systems, both for work in progress and future work;
- Ensuring minimum data sets are identified and that systems require the coding of data during its capture; and
- Articulating priority information needs to proactively design, build and use systems in a manner that allows key questions to be answered.