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 and Purpose

We need good information to effectively manage our health system. Numerous sources of health data have been used to support decision-making in the past. Many of these traditional sources, such as hospital information systems and medical billing systems, are still valid. However, the conversion of Canada's fragmented, paper-based clinical systems to electronic records creates a unique opportunity to integrate data across the health care continuum and to better understand the health of Canadians and our health system.

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 (*Infoway*) have since collaborated with jurisdictions and stakeholders across Canada to advance this agenda.

At the request of the Conference of Deputy Ministers of Health, CIHI in collaboration with *Infoway* have developed, promoted and refined a vision for health system use of data in Canada. A high-level vision—*better information for improved health*—and a draft framework of key enablers for better use of data to strengthen the health system were endorsed (except for Quebec) at the 2011 Conference of Deputy Ministers of Health.

The high-level vision and framework have been refined into the present vision paper, *Better Information for Improved Health: A Vision for Health System Use of Data in Canada.* This paper 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. In particular, this paper describes

- The drivers of the vision, including a compelling case for taking action now;
- The value and benefits this vision can bring to Canadians and the health system;
- The building blocks required to go from vision to reality; and
- Guiding principles, key considerations and opportunities for moving forward.

The shared vision for health system use of data in Canada discussed in this paper 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 (see Appendix A for lists of members). Stakeholders consulted included care providers, health administrators, policy- and decision-makers, information technology professionals, privacy commissioners, patient advocates and researchers; many of them participated in full-day dialogue sessions in Halifax, Toronto and Calgary in October 2012 (see Appendix B for a list of participants).

1   Introduction

Canada's health system faces a growing challenge: doing more and better with less. Good information is crucial to achieving a high-performing and sustainable health care system that is also safe and responsive to the needs of Canadians. 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, they allow us to create only a partial picture of the health system. The conversion of Canada's fragmented, paper-based clinical systems to electronic records creates a unique opportunity to fill the gaps with new and richer sources of information to inform decisions about our health and health system.

We have a good foundation to build on. Billions of dollars are being spent on a range of information technologies to support the direct provision and coordination of health care to patients. With the rapid emergence of **electronic medical records**[i] and **electronic health records**, data is coming in faster and in larger volumes. Other digital health initiatives, such as the use of in-home health monitoring devices, are also increasing the sources and types of data available. To obtain additional value and benefits from these investments, concerted action is needed now to leverage and use this new digital data to also strengthen the health system.

As well, we must remember that **personal health information** is not *just* data. It is sensitive information provided confidentially by individual Canadians to clinicians in the context of care and, as such, needs to be protected. Health information privacy laws govern the collection, use, management and disclosure of personal health information. These laws generally permit **secondary use of health data**, whether paper or electronic, for management and planning of the health system. 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. The implementation of privacy-by-design principles[1] and other technological advances can facilitate **consent management** and the de-identification of health data to help ensure that health system use of data complies with health information privacy laws.

The value proposition for better information use for health system decision-making has never been stronger, nor has the time for concerted action been more appropriate. Working together toward a shared vision of *better information for improved health* can help us realize an important opportunity to achieve the best possible health, the highest-quality care and a sustainable, efficient health system.

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i.   See Section 1.3: Notes on Terminology.

1.1 A Vision of *Better Information for Improved Health*

Health system use of data, a subset of secondary data use, refers to the use of health data to strengthen clinical programs of care, health system management, and population and public health. It can also refer to using data for health research that informs decisions in these areas.

The deputy ministers of health (except Quebec's) endorsed a high-level vision of *better information for improved health* in 2011. The present paper develops and expresses the 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 considers each of the main building blocks required to go from vision to reality, including the

- Key enablers, such as the policies, governance and technology that support the vision and enable the responsible use of health data;
- Data that is collected, made available and used to inform decision-making; and
- Culture and **capacity** necessary to improve health and the health system through better use of information.

1.2 Report Organization and Case Studies

This report is organized into four major sections. The first describes the drivers of the vision, including a compelling case for taking action now. The second identifies how Canadians, care providers and the health system benefit from accelerated and more systematic use of information for health system decision-making, while the third explains the building blocks required to go from vision to reality. The last section of the report highlights guiding principles, key considerations and opportunities for moving forward.

A number of success stories highlight where data was used to support decision-making and resulted in improved patient experiences, more effective care and a more efficient health system. All the case studies showcased are Canadian and are based on real initiatives. They represent only a few examples of the local innovations that are emerging across the country as a result of the increasing availability and use of electronic health data.

1.3 Notes on Terminology

Words bolded in the text are defined in the glossary (Appendix C).

Some words, such as "access" and "use" of data, can have specific meaning when used in the legislative context. For the purposes of this paper, they are used in their broadest sense.

The term "secondary use of data" is used in the privacy community and in some other countries. Secondary use of data refers to any use of data collected for one purpose (for example, providing health care to a patient, which is considered the primary use of health data) to inform another purpose (such as a quality improvement initiative, which is considered a secondary use of health data). The term "health system use of data" is predominantly used in this report to indicate the subset of secondary uses of health data that aim to strengthen the health system. It also reflects the exclusion from the outlined vision of *better information for improved health* of other possible secondary uses of health data, which may or may not be permissible under Canadian health information privacy laws.

Note that this report distinguishes between "**personal health information**" and "**health information**." In cases where direct patient identifiers or data elements could be used to identify a patient (such as name, unique personal identifier or date of birth), the term "personal health information" is used. Thus, unless noted otherwise, health data and health information are used to designate data and information, respectively, that cannot be used to identify a specific individual (examples are health data that has been de-identified and health information that is based on data that has been de-identified, aggregated and/or analyzed and can no longer lead to the identification of the individual from whom it was collected).

2   Drivers for Action

The time for advancing health system use of data has never been better. Four factors are at play that, in combination, reinforce the case for taking action now:

- The need to improve performance and increase the sustainability of the health system;
- The shifting expectations of Canadians;
- The growth of digitized health data from which we can draw insights and inform actions; and
- The advances that make certain new technologies more viable and easier to use, and traditional ones more cost-effective.

2.1   Sustainability and Performance

CIHI estimates that Canada spends more than $200 billion on health care every year. On average, health care accounts for more than 40% of provincial and territorial government spending.[2] The challenge of controlling costs and putting the health system on a more sustainable financial footing is compounded by social and technological changes that are increasing the need for and cost of health services: Canadians are living longer. The aging population is growing. The incidence of multiple chronic conditions is on the rise, requiring more frequent and integrated care that is managed by teams of care providers. Expectations for better health system outcomes, quality of care and active patient engagement are heightened. Newer—but also more expensive—diagnostic tests and pharmaceutical treatments are available.

Faced with these pressures, provincial, territorial and federal governments have to constantly balance the health needs of their populations against the overall costs of delivering care. Having the most effective and efficient health system possible is critical to maintaining that balance and ensuring its sustainability into the future. Yet international comparisons have shown that despite relatively higher per capita health expenditures, the performance of Canada's health system is behind that of other Commonwealth countries on a number of measures of system performance, including access, efficiency, quality and coordination of care.[3, 4]

Governments, health system administrators and health care providers continue to be challenged to innovate and transform health care delivery to improve outcomes of care and overall health system performance. To support a patient-centric care system and holistic view of health, it needs to become possible to integrate data from across a range of sources, including public health, primary care, specialists, pharmacists, laboratories, diagnostic imaging centres, emergency rooms, hospitals, long-term care homes and community programs. Not only do the juxtaposition and integration of information from different sources support patients across the continuum of care, the secondary use of data from these sources would also enable health system managers and health care providers to consider typical patient pathways, evaluate outcomes of care, plan services to meet the future health needs of the population and allocate resources throughout the health system as a whole. This support is needed for the health system in key areas such as the following:

- **Performance and efficiency:** We need to be better able to calculate performance indicators and other measures of system cost and productivity. We need to be better able to establish the value of health care innovations and identify which are best practices and which can be replicated in other settings. We need answers to questions such as

  – Where are the pressures and bottlenecks in the system?

  – Where are time and money wasted through missed opportunities, duplication of services and inefficiencies?

  – Which care models best support patients with integrated care, and which are most cost-effective?

- **Quality, safety and patient experiences:** We need to be able to measure and analyze activities, processes and outcomes of care to understand the effectiveness of health interventions and to better support the integration of care for high-needs users of the health system, the aging population and patients with chronic diseases. We need answers to questions such as

  – Which patients are not receiving the most appropriate services and cost-effective treatments for their needs? Why not?

  – Which initiatives are most successful at reducing wait times and improving access to care?

  – Which interventions are most effective, and which should be avoided because of their low success rates?

- **Resource Allocation and Health System Planning:** We need to be able to estimate financial and human resource needs and utilization both retrospectively, to evaluate them, and prospectively, to plan future health services based on projected needs of the population and optimize the allocation of resources across the system. We need answers to questions such as

  – 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?

Partial answers to some of these questions are possible now. However, fragmented data sources and issues with data availability, quality and comparability mean that extracting and analyzing the necessary data is complicated and time-consuming; even then, the answers are often not complete.

Meet Robert. [ii]

A few days after his back surgery, Robert no longer needed to be in the hospital but still required care while he regained his mobility and his ability to care for himself. On the same day he was discharged from acute care, Robert found a temporary home at the Jackson Creek Retirement Residence. Not only did the residence have the staff and equipment to support his recovery needs, it also met his care preferences, including being close to his daughter so she could visit.

Robert's quick match was made possible by the Resource Matching and Referral Program,[5] which helps facilitate transfers between acute and rehabilitation hospitals and alternate care settings in the community. Patients waiting to be transferred from the hospital to a more appropriate care setting are a significant problem for the Canadian health system: in 2009, it was estimated that 1.7 million hospital days were for patients who no longer required acute care services. Nearly half of these patients were waiting for a transfer to a long-term care facility.

Facilitating discharge of patients to a suitable setting increases integration of care and makes sure patients have access to appropriate supports after discharge. This in turn ensures high-quality care and reduces readmission rates. Facilitating discharge also liberates costly acute care beds for other patients.

By reusing data collected from patients such as Robert, health system planning and resource allocation can be better supported. For example, health system managers can better project which services are and will be most in demand. It is also possible to identify where bottlenecks are preventing patients from successfully reintegrating into the community and where local innovations are leading to successful outcomes that could be replicated across the system.

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ii. Robert is fictional, but the Resource Matching and Referral Program is real. The program is a multi-stakeholder initiative that brings together the Toronto Central Local Health Integration Network, the University Health Network, the Ontario Ministry of Health and Long-Term Care, as well as participating service provider organizations and the Toronto Central Community Care Access Centre.

2.2   Shifting Expectations

Canadians want and deserve the best care. They have a keen interest in being more engaged in their own health and well-being, and in doing so with the best and most current information available. When they need health care, they want to discuss options with their care providers and have access to good information that supports their decisions and helps them understand the alternatives. For example, they want to know what the best treatment is for their particular diagnosis based on their personal health history and on where they live, the local health services available and the experiences of others with similar characteristics. They want to know what the wait times are and what risks might be involved based on real, current and local information (for example, the success rates of various procedures or average lengths of stay at their local hospitals). In addition to expecting medical expertise, Canadians increasingly expect their care providers to have this information at their fingertips or to be able to direct them to it.

Canadians also increasingly recognize the value of making their own health information available to strengthen the health care system. Opinion surveys conducted in 2012 show that, compared with 2007 and 2010, more and more Canadians support the secondary use of information from electronic health records to plan, monitor or evaluate the health care system; to anticipate and address public health issues; and to prevent improper uses of the health care system (support for these uses ranges from 68% to 70% of respondents).

Canadians are also increasingly comfortable with sharing their own health information across settings and for research. In fact, more than 75% of Canadians were comfortable with sharing their health information with other health organizations, with the health department in their province, with statistical organizations such as CIHI and Statistics Canada, and with health researchers. Support for health research increased from 80% to 88% of respondents if individuals were assured that their name and address would be removed and they were promised anonymity. This support has increased significantly since 2007.

The one objection? More than 80% of Canadians are not comfortable with sharing their health information with private and for-profit organizations, such as pharmaceutical and insurance companies (unpublished surveys commissioned by CIHI and *Infoway*).

2.3   Growth of Digitized Data

The amount of digitized data available is growing rapidly. Federal, provincial and territorial governments are spending billions of dollars on a range of information technologies to support the direct provision of health care to patients and its coordination. More than half of Canadian primary care physicians now use electronic medical records in their practice, compared with slightly more than a third in 2009 (from 37% to 56% in 2012).[6]

The deployment of other digital health initiatives is also increasing the availability of electronic data. For example, electronic records are increasingly used at the **point of care** in clinics, hospitals and long-term care facilities. Results from patients' diagnostic tests, such as laboratory work and diagnostic imaging, are now being digitized in many locations. Technological advances are enabling the capture of digitized data from sensory and monitoring devices in clinical and home settings, as well as from new sources such as genome analyses and social networking sites.

Investments in e-health are the foundation that is increasing the availability of digitized data that, if leveraged, can drive deeper insights and guide decision-making to improve health system performance. The emergence of these new sources of electronic health data is creating new opportunities to use health data to personalize medicine, improve patient outcomes and support health system decision-making. Because of its volume, all this digital health data must be analyzed and transformed into information that enables decisions in real time (or nearly so) to benefit patients, clinicians and the system.

Sofia's story below illustrates how the large volumes of health data collected to monitor a patient's vital signs while providing care can be captured and reused to support care providers in the future, improve clinical outcomes and the quality of care for other patients, and avoid unnecessary human and financial costs.

Meet Sofia.[iii]

Sofia was born prematurely at Toronto's Hospital for Sick Children. Shortly after birth, she was taken to the intensive care unit where, like other premature and low birth weight babies, her breathing, heart rate, blood pressure and body temperature were constantly monitored. A few days later, although Sofia looked well, her caregivers were alerted that subtle changes in her vital signs indicated that she might be developing late-onset neonatal sepsis (an infection of the blood that is normally hard to diagnose). Much to the relief of Sofia's parents, her doctor was able to investigate further and take corrective actions before serious complications developed that would have required a lengthy stay in the intensive care unit. Sofia was lucky—sepsis is often life-threatening in premature babies and only slightly more than half of those who develop the illness survive.[7]

The improved quality of care that Sofia received and the decision-making support provided to her caregivers were made possible through Project Artemis.[8] Using computers to aggregate and examine the large streams of vital signs data collected from other premature babies who later developed sepsis, researchers were able to find patterns in the data that could predict—up to 24 hours in advance—when sepsis was developing. By using real-time monitoring and analysis to detect these same patterns in babies currently in the intensive care unit, sepsis can be identified early and the hospital's most vulnerable patients, like Sofia, can be protected.

Systems that monitor vital signs are normally used for real-time or short-term information only because of the large volumes of data they generate. However, by saving this health data and reusing it with **analytics** and **big data** technologies, patient care and caregiver support are improved. The health system also benefits. In addition to reducing significant human costs, hospitals can avoid important financial costs: nearly 30,000 Canadian babies are born prematurely every year. One in 10 low birth weight babies and one in four very low birth weight babies develops sepsis. The average length of stay in the intensive care unit varies from weeks to months, depending on weight at birth and responsiveness to treatment.[9] Each day spent in intensive care costs on average $10,000 (2003–2004 costs).[10]

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iii. Sofia is fictional, but Project Artemis is real and has been in place since 2009. It is a collaborative initiative involving Toronto's Hospital for Sick Children, the University of Ontario Institute of Technology and IBM Canada. It has been expanded to other hospitals in Canada and internationally.

2.4   Technological Advances

Think of the ways in which information technology and corresponding advances in privacy and security have changed the banking industry, airlines and online shopping. These industries have taken great strides to simplify interfaces so that their (non-expert) clients can fulfill some of their own needs. At the same time, behind the scenes, these industries have leveraged newer and more powerful technology to analyze and identify patterns in the large volumes of data created by each interaction their clients have with their services. This allows them to better understand their customers and their needs, as well as to continuously tailor their services and identify more efficient ways of delivering them.

Opportunities for using data to improve the health system are partially driven by similar technological advances. Compared with just a few years ago, information technologies are cheaper and more powerful and offer more ways to process information from virtually anywhere. New analytical methods, more efficient processing, and automation of routine analyses and analytics, for example, make it easier to draw insights from health data and to present the resulting information in an actionable format. Innovations are enabling systems that learn, that support real-time and predictive functions, and that can process **unstructured data** (such as through natural language processing). Thus today's technology is more able to cope with the increased volume, flow and diversity of information associated with digitizing health data.

Technological advances will also support better use of health data for health system decision-making in the future by increasing privacy and security options. Collecting personal health information electronically when care is provided has raised important questions about the privacy and confidentiality of health data. The good news is that tools are becoming available to maintain the security of health data and support the privacy and confidentiality of personal health information. For example, consent management solutions will help ensure that patients' wishes are followed regarding the secondary use of their personal health information. Statistical and technological tools could automatically de-identify data behind the scenes, while administrative tools can help manage who has access to which data and under which circumstances.

3   Value and Benefits

The vision for better secondary use of electronic data by the health system is based on four basic categories of use that bring value to Canadians, care providers and the system itself. To simplify the presentation, the categories of use and examples below are described in discrete groups, but in reality, many uses of health data and their benefits may span multiple categories.

3.1   Categories of Health System Use of Data

The following four categories of health data use provide an overview of the various ways in which data from digital sources can be used to support better programs of care, better allocation of health system resources, and better management and prevention of outbreaks—all of which can result in better health outcomes for Canadians.

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 aggregate and reuse data from their patients to evaluate their own performance against clinical practice guidelines. The data can also provide insights that lead to revised care protocols.

For health system management, health data can be used to manage and improve the effectiveness and efficiency of the health system by informing program, policy and funding decisions. For example, costs can be reduced by identifying ineffective interventions, missed opportunities and duplication of services. Access to care can be increased and wait times reduced by understanding patient journeys across the continuum of care, ensuring that patients receive the services that are most appropriate for their needs, accurately projecting future health care needs of the population and optimizing the allocation of resources across the system.

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 can 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 can be integrated to find early markers of disease, the cost-effectiveness of different interventions can be evaluated, and historical data can be used to simulate and model trends in long-term care needs and evaluate different policy options to meet those needs.

3.2   Opportunity Areas for Better System Use of Electronic Data

Opportunities abound for better use of information within the health system. To bring the vision of *better information for improved health* to life, tables 1 and 2 present a series of actual and potential cases of electronic health data use aimed at improving the health system. They focus on the value and benefits that are expected in two key domains: improving quality, safety and patient experiences; and enhancing system sustainability by increasing performance and efficiency and strengthening planning and resource allocations. Note that these examples do not list all possible secondary uses of health data; rather, they provide an overview of the possibilities that are emerging from the growth of digitized health data.

Table 1: Improving Quality, Safety and Patient Experiences Through Better Secondary Use of Electronic Health Data

Categories of Use	Examples of Better Secondary Use of Electronic Health Data Aimed at Improving Quality, Safety and Patient Experiences
Clinical Programs	Secondary use of electronic health data can be used to improve quality and patient outcomes throughout the system by reducing practice variability. Variations in practice are to be expected; they occur among care providers, health regions and even provinces/territories according to care provider training, patient expectations and local culture. Unexpected variation, however, may indicate the use of outdated care protocols or interventions, and can result in unnecessary expenditures if the most cost-effective treatments are not adopted. The secondary use of data from electronic medical records can allow care teams to benchmark their performance on a series of quality indicators against the performance of their peers to identify any areas that may be in need of improvement. In addition to improving care for patients, care providers benefit by receiving feedback on their performance and by having the support to keep their practices current in a rapidly evolving environment.
Health System Management	Hospital administrators can assess the quality of their health services and evaluate quality improvement initiatives through better use of point-of-care data. Many hospital performance indicators are generated from patient discharge abstracts. While these are useful for monitoring long-term trends, using health data collected at the point of care can provide information on the quality of care received throughout the hospital stay and can increase the timeliness of quality reports. Administrators and front-line care providers can be alerted when measures related to quality and patient safety fall outside a normal range or when trends that put patient safety at risk (such as hospital-associated and multi-drug-resistant infections) are emerging so that corrective actions can be taken sooner. Finer-detailed and timelier reporting on quality measures can also better support the evaluation of quality improvement initiatives by tracking day-to-day performance against established goals, and by providing timely feedback to care teams and administrators.

Categories of Use	Examples of Better Secondary Use of Electronic Health Data Aimed at Improving Quality, Safety and Patient Experiences
Population and Public Health and Research	Drug safety can be increased by better use of electronic health data and research. Pharmaceutical interventions are a significant cost for the health system, and using them is not without risks. Research based on electronic health data can supplement traditional clinical studies to increase the safety of these interventions and to evaluate their effectiveness. For example, post-market surveillance and better regulation of drugs can be supported by identifying and assessing the extent of adverse drug reactions and unintended side effects, whether these take place in a care facility or in the community. The potential effects of drug interactions, dosage and use over time can also be better understood by tracking drugs' health effects in all patients with prescriptions. This would be particularly valuable when it comes to understanding the effects of poly-pharmacy among seniors or those suffering from multiple chronic conditions, as well as developing better chemotherapy formulas for cancer patients. Better use of health data would also enable us to evaluate the cost-effectiveness of drugs for particular patient populations. In the future, this could lead to more tailored drug regimens and personalized medicine.

Table 2: Increasing Sustainability, Performance and Efficiency Through Better Secondary Use of Electronic Health Data

Categories of Use	Examples of Better Secondary Use of Electronic Health Data Aimed at Increasing Sustainability, Performance and Efficiency
Clinical Programs	Secondary use of point-of-care data can establish the cost-effectiveness of different interventions and allow the comparative evaluation of the performance of different care models. For example, electronic health data can be used to track the management of chronic conditions and determine the best models for preventing relapses or avoidable hospitalizations. Similarly, health outcomes of seniors with chronic conditions can be used to evaluate the usefulness of education materials and the user-friendliness of self-management tools.
Health System Management and Research	System sustainability can be increased by using electronic health data to anticipate future health care needs, plan services and allocate human and financial resources. In particular, data from electronic medical records can show how the burden of illness and quality of life of Canadians changes over time in local areas. This type of information can then be used to project the future needs of the population for health services and to ensure that financial and health resources are allocated appropriately to meet those local needs. Using forecast models, various possible scenarios can be developed and assessed to find the optimum distribution of resources across health services within a health region.

Categories of Use	Examples of Better Secondary Use of Electronic Health Data Aimed at Increasing Sustainability, Performance and Efficiency
Population and Public Health	The effectiveness of policies and public health programs can be assessed through better secondary use of health data. For example, population-level social policies aimed at supporting vulnerable populations can be assessed for their health impacts. Examples include the following: • Food supplements for children of low-income mothers can be assessed against markers of child growth and development; • Publicly funded prescription drug programs can be assessed for changes in patient compliance and the avoidance of health system costs; and • Public health interventions such as the yearly flu vaccine can be assessed for effectiveness by tracking immunization records against the use of health services (such as hospital admissions and/or visits to a family doctor).

4 Building Blocks of the Vision for Health System Use of Data

Canada's health system cannot continue to be data rich and information poor. To remedy this situation, a high-level Canadian vision of *better information for improved health* was endorsed by the deputy ministers of health (except Quebec's) in 2011. Figure 1 outlines a framework to realize this shared vision for health system use of data. While each component is important on its own, the framework's three building blocks must come together in a cohesive and holistic manner to achieve the value and benefits of using electronic data to strengthen and improve the health system. Fulfilling the vision's value and benefits will be difficult without these key building blocks and, as such, each should be a priority for the country.

4.1 Enablers

As illustrated in Figure 1, the vision's foundation rests on key enablers that support the appropriate and responsible collection and use of electronic health data. The enablers include the governance mechanisms that establish leadership and accountability, the legislation and policies that identify how data should be used and protected, as well as the technology that allows us to collect, exchange, integrate and analyze health data and turn it into actionable information.

Figure 1: Framework to Enable the Shared Vision of *Better Information for Improved Health*
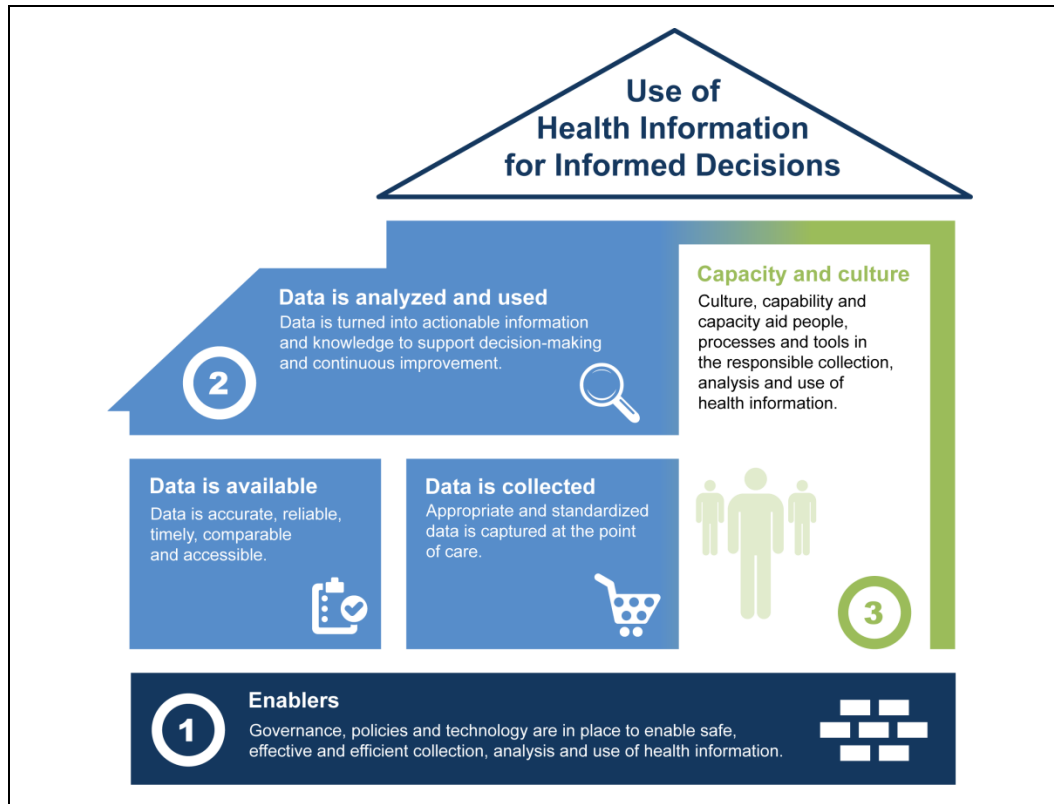
4.1.1 Governance

A strong foundation of governance ensures transparency and accountability, and allows us to proactively manage activities related to enabling the vision for health system use of data. For example, it includes identifying who has decision-making authority related to health system use of data and the roles, responsibilities and authority of stakeholders, including **data stewards** and **data custodians/trustees**. It also defines who is accountable for ensuring that privacy-protective processes for data collection, availability and use are in place and who is responsible for monitoring, evaluating and overseeing these activities.

> To turn the vision into reality, clear governance structures need to establish leadership, responsibility and accountability.

Certain aspects of governance, such as identifying which uses of data are acceptable and for what purposes, are set out in legislation and in accompanying policies and procedures that guide data collection, protection, and availability, and use of health information for secondary purposes. Other elements of data governance are not legislated but need leadership and concerted actions by multiple stakeholders to

- Establish the priorities, roadmaps and plans for coordinated efforts to improve health information use;

- Identify information gaps and prioritize information needs to ensure that priority policy questions are understood and can be supported by good information, both now and in the future;

- Align secondary data use activities with other business drivers to leverage investments and avoid duplicating work (such as aligning them with e-health investments for direct patient care);

- Facilitate capacity-building and learning within the system; and

- Promote and demonstrate the value of using information for health system improvements to patients, providers and system managers.

Thus clear governance mechanisms are essential to assure individuals that their personal health information is being de-identified correctly, used responsibly and protected properly while at the same time ensuring the health system has efficient access to the data needed to manage and plan for publicly funded health services.

4.1.2 Privacy and Security

The transition from paper to digital health systems has led to significant changes in how much personal health information is collected, stored, used and shared, as well how accessible it may be and who may have access to it. Health information laws in Canada apply to all forms of health information, both paper and electronic. These laws generally permit data to be used for management and planning of the health system. However, the laws were created when secondary data use activities were fairly limited in scope compared with what is anticipated for the future.

> To turn the vision into reality, legal frameworks, policies and best practices need to be in place to ensure data privacy and security.

Designing and implementing appropriate privacy and security measures (such as de-identification, anonymization and consent management solutions) directly in health information systems is an important prerequisite for the appropriate use of data for health system decision-making. Privacy specialists are working to identify ways to protect a patient's privacy while still enabling the use of data to guide health system improvements.[11] *Infoway*'s Pan-Canadian Health Information Privacy Group has published a number of common understandings to help design privacy and security features into digital systems, governance and other processes to enable health system data use in a way that protects privacy.[12]

In addition to embedding safeguards directly into digital systems to protect data and individuals from possible misuse, it will be important to ensure that patients are informed of their privacy and confidentiality rights. Education and training also need to be available to reinforce these rights among the health workforce and other data users.

4.1.3 Technology

The vision for health system use of data rests on optimizing processes currently in place or being put in place through e-health initiatives that support direct care to patients, so that information can be collected once and reused for multiple purposes, including strengthening the health system. The technical architecture and business processes that enable health system use need to be designed, developed and implemented with this dual purpose in mind. It is much easier to incorporate the functional, privacy and data requirements by design than to try to retrofit systems at a later date. It is also important that the technical architecture and business processes be flexible and amenable to change as health technology, health delivery models and health information legislation continue to evolve.

> To turn the vision into reality, robust and secure technological architecture needs to be designed, developed and implemented to simultaneously facilitate patient care and use of data for health system decision-making.

Infoway is leading work with stakeholders to develop a blueprint of data warehouse architecture and deployment models that will enable and support the appropriate collection and responsible use of data and information for clinical and health system decision-making. This technological framework depicts best practices and a future state of how technology can be deployed to support new and emerging uses of health data while leveraging existing investments and infostructures.

4.2 Data

4.2.1 Data Collection

New data sources allow us to learn from, and improve with, 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 the health system. The vision for data collection in support of health system decision-making is to first and foremost reuse appropriate data that was collected to deliver care (the primary use of data) without having to enter any additional information into the system. Collecting data once and making it available as appropriate for secondary use by the health system optimizes current processes, reduces duplication of effort and leverages investments being made in e-health systems.

> To turn the vision into reality, the appropriate data needs to be collected in a manner that minimizes effort, maximizes quality and protects privacy.

Some of the data collected as part of the care process needs to be **structured** and **standardized** to support health system uses. Codified data is also required for the optimal use of e-health systems to provide care to patients. This is particularly the case when records are made available for use outside the clinician's office or health institution (such as during a referral or transfer) and when they are used by different members of care teams (such as for chronic disease management), or if clinicians want to maximize the capabilities of their electronic records system by using algorithms that provide alerts, reminders and clinical decision support. To facilitate this uptake and encourage high-quality data collection, standardized collection and input need to become easier and unobtrusive in the clinical workflow, and extraction and analysis need to be simple, timely and of value to patients, care providers and system administrators.

There are numerous data sources in a health system that can be used to inform decision-making. Many are traditional and still-valid sources like hospital information systems or medical billing systems. Solid progress in areas such as diagnostic imaging, laboratory information systems, drug information systems and electronic medical records has been made—although integration of this data is not yet optimal. As noted in Section 2.3: Growth of Digitized Data, there are also many emerging sources of health data, such as those from home-based patient monitors, social media and sequencing of the human genome. Medical devices, such as diagnostic and home monitoring equipment, require no additional manual entry of data (see Sofia's story on page 7).

4.2.2 Data Availability

To draw maximum benefits and value from health information systems, high-quality data that is useful, integrated across the care continuum and relevant to decision-making must become more widely available. As most of the information required to improve the health system does not come from health data that is personally identifiable, processes and technologies can be employed to automatically de-identify data. Similarly, user authentication can be used to restrict the availability of health data and give access to different levels of detail according to a patient's consent directives or a user's access levels.

Given the increased volume of possible data to analyze, it will become necessary to identify and prioritize which data is needed to support health system decision-making. While patients and different stakeholders may need different types of information to inform different decisions, they all need the underlying data to be

- Accurate: the data reflects the reality it was designed to measure;
- Reliable: the data can be trusted;
- Timely: the data is current enough for the intended use and is available to those authorized to use it when they need to use it (including in near real time, if that is the need); and
- Comparable: the data is standardized so that it can flow from one location to another and maintain its meaning, and/or it can be aggregated or linked with other data to increase users' confidence in the conclusions drawn from it.

4.2.3 Data Analysis and Use

Data that is collected and available does not on its own support better care, improve system performance or inform health policies. As noted, the volume of health data being collected and made available is increasing, and its nature is changing; this is transforming how data is analyzed and used. The presentation of results and information is also evolving—from reports and papers on a desk to smart phones, tablets and other technologies that put information at users' fingertips in any location.

> To turn the vision into reality, high-quality information needs to be available in the right format, to the right people, at the right time.

To reduce the risks of information overload, the results of data analyses and their presentation need to be contextualized and tailored to make it easy for clinicians, system managers and policy-makers to interpret them and gain insights into what works and what doesn't. A shift also needs to occur from the traditional reporting of what happened in the past to the analysis of health data to determine what is happening today and what is likely to happen in the future.

There is still tremendous value in using data to analyze what happened in the past. This is most often referred to as "retrospective analysis" and is often used in research to uncover relationships among complex sets of variables. In the clinical setting or for system management, retrospective analyses are generally presented as part of ad hoc reports, dashboards of key performance indicators, graphs or charts. In both cases, the value of retrospective reporting can be increased by enriching it with new data sources and using more sophisticated analyses and new visualization techniques to reveal new insights from the data.

New data sources, along with the availability of new tools, will allow some information to be made available and analyzed in near real time. Insights can be derived as data is being created and provided in context to guide decision-making, actions and change. We can use this type of rapid feedback to adjust or optimize a process, to alert clinicians or patients about important information, or to detect and analyze the spread of an infectious disease as it happens.

The capability to analyze data to forecast or predict what might happen in the future is becoming easier, faster and more accurate. Prospective analyses have the potential to support health system improvements by allowing us to take preventive actions (for example, determining if someone is at risk of readmission to hospital after discharge based on the experiences of similar patients) or to evaluate and compare different treatment or policy alternatives (such as making investments in more long-term beds versus more home care support).

4.3   Capacity and Culture

4.3.1 Culture

If the key enablers of governance, policies and technology underpin the approach and processes for success in the use of health information, then culture will create the environment necessary for success. Overall, the vision must be built on a culture of accountability, willingness to collect and use data, and willingness to continuously learn and improve, while using health data responsibly and in a privacy-protective way.

> To turn the vision into reality, a shift in culture needs to take place, and the skills, processes and tools to make the best use of data need to be available.

A culture of privacy-protective use, sharing and reuse of data will be crucial in transforming the ways in which health system data is used every day for insights and decisions. In many ways, the biggest challenge will be not technological but behavioural: stakeholders across the health system need to learn to ask the right questions and act on the results. As with any transformation in organizational culture, creating a culture of measurement, data sharing and use, and continuous performance improvement will need to be promoted, reinforced and rewarded if it is to become pervasive at all levels and in all sectors of the health system.

Throughout the health system, those making decisions need to be empowered to apply the information and knowledge gained to improve patient care and health system performance. Stakeholders across the system, including the public, also need to see and understand the value of collecting high-quality data to support the direct provision of patient care and of reusing it to also support health system decision-making.

4.3.2 Capacity and Skills

Capacity refers to both the skills and abilities to understand and take advantage of information to support decision-making, and the tools and processes that facilitate that use. Even with a shift in organizational culture and a willingness to increase information use for decision-making, we will need to update traditional tools, processes and skills to be able to make the most of the opportunities created by the growth in digitized data and continued technological advances.

Not everyone will need to become an analytical expert, but care providers, system managers and decision-makers will all need to possess general health information literacy skills to be able to ask the right questions, understand the answers and act on insights generated by good information. This may include supplementing their skills to effectively make use of new and emerging electronic tools to gain access to, visualize and interpret the information they need at any given time. The tools that best support this type of non-specialist user are ones that communicate information in a people-friendly way and fit within existing processes with no increased work. They have interfaces that make it easy to input data and maintain its quality, and they have intuitive functions so users can analyze data and view the generated information. Non-specialist users also need to be provided with feedback from information systems in a manner that is timely, straightforward and customized. In this case, less of the right information to the right people at the right time is more powerful than lots of untailored information.

Specialized skills and knowledge are also needed to empower a smaller group of workers within the system. They need expertise and tools to support complex information requests (such as those that require integrating data from multiple sources and analyzing point-of-care data), efficiently analyze data, correctly interpret it and present the results in a manner that is compelling and actionable. Expert health data analysts also need to support and empower non-expert data users to independently access the information they need. This can be achieved by creating easy-to-use self-service tools and by automating simpler analyses. Finally, specialized skills and knowledge will be needed to leverage tools based on analytics and big data.

Specialized knowledge and skills are currently scarce; health organizations and regions may need to pool resources or partner to learn from one another and gain access to these specialized skills. Partnerships with academia or others with analytics experience may also be advantageous. In the longer run, academic support is necessary to train the next generation of health data analysts.

5   Moving Forward

5.1   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 and electronic health records there is a risk that some of the valuable information produced to 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, provinces and territories 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.

5.2   Guiding Principles

Better information to improve health is possible. However, the transition from traditional sources of health information to responsible use of data from electronic records is not as easy as it first seems. Questions of governance, privacy, capacity, data standardization and integration across organizational boundaries remain important hurdles to delivering on the early promise of e-health to strengthen patient care and our health system simultaneously. The following section outlines guiding principles for putting in place the necessary enablers, data and capacity to broaden the use of electronic health data for health system decision-making at all levels.

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.

Guiding principles for privacy and security

- Legislative frameworks and policies for privacy and confidentiality are up to date and enable health system use of data.

- 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.

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.

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.

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.

5.3   Recommendations

This vision paper marks the final deliverable of the 2009 electronic health records and health system use initiative mandated by the Conference of Deputy Ministers of Health, 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.

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 the country and similar interdependencies with key stakeholder groups that require concerted action at a pan-Canadian level. In addition to adopting the vision and guiding principles, there is a need to address key factors necessary to turn the vision into reality, such as the following:

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.

6   Conclusion

By utilizing new sources of electronic health data to support health system improvements, we will realize an important opportunity to achieve the best possible health, the highest-quality care and a sustainable, efficient health system. This report strengthens the value proposition for better use of electronic health data that respects privacy and confidentiality. It also demonstrates the benefits it can bring to Canadians and to the myriad stakeholders within the health system who rely on good information to make the best decisions. These stakeholders include first and foremost patients and their families, but also

- Care providers who advise on, and deliver, the most effective treatments for patients' health concerns;

- Policy- and decision-makers, administrators and managers who plan for, manage and allocate resources to deliver the highest-quality health services and ensure the system is sustainable in the long term;

- Public health officials who survey and put in place programs to protect against emerging health threats; and

- Researchers who evaluate care and policy options and who find answers to complex health questions.

The time is right to supplement the incomplete traditional sources of health information, such as hospital information systems and medical billing systems, with more comprehensive electronic point-of-care health records. More and more clinicians are adopting e-health systems, and we have made significant technological advances to securely share and efficiently analyze this data. An important opportunity to realize the value and benefits that our system needs and Canadians deserve will be missed if we do not leverage these rich new sources of information.

As described, three key building blocks are required to realize the shared vision for health system use of data—*better information for improved health*:

- Key enablers, such as the policies, governance and technology that support the vision and enable the responsible use of health data;
- Data that is collected, made available and used to inform decision-making; and
- The culture and capacity necessary to improve health and the health system through better use of information.

By adopting the guiding principles outlined in this report and taking concerted actions aimed at developing and strengthening each of these building blocks, the benefits of better information for improved health can be accelerated, and the benefits of investments fully realized.

7   Appendices

Appendix A: Health System Use Deputy Ministers Steering Committee and Technical Advisory Committee

Health System Use Deputy Ministers Steering Committee

Richard Alvarez	President and CEO	Canada Health Infoway
Kevin McNamara	Deputy Minister of Health	Nova Scotia
John Wright	President and CEO	Canadian Institute for Health Information
Glenda Yeates	Deputy Minister of Health	Health Canada

Health System Use Technical Advisory Committee Members

Mike Barron (Chair)	President and Chief Executive Officer Newfoundland and Labrador Centre for Health Information	Newfoundland and Labrador
Liam Whitty	Executive Director, Health Information Management Health PEI	Prince Edward Island
Cheryl Hansen	Executive Director, Innovation E-Health New Brunswick, Department of Health	New Brunswick
Susan Logue	Executive Director, Business Intelligence, Analytics and Privacy Nova Scotia Department of Health and Wellness	Nova Scotia
Alison Blair (Chair, Knowledge Exchange Network)	Director, Information Management Strategy and Policy Ontario Ministry of Health and Long-Term Care	Ontario

Roger Girard	Chief Information Officer Manitoba eHealth	Manitoba
Neil Gardner	Strategic Advisor eHealth Saskatchewan	Saskatchewan
Susan Anderson	Executive Director, EHR Delivery Services Alberta Health and Wellness	Alberta
Charlyn Black	Professor School of Population and Public Health; Associate Director Centre for Health Services and Policy Research, University of British Columbia	Researcher
Brendan Seaton	President ITAC Health	Information Technology Association of Canada
Paul Chittick	Senior Advisor, Health Information Chief Information Officer Branch, Information Technology Division Treasury Board of Canada Secretariat	Treasury Board of Canada Secretariat
Glenn Irwin	Acting Director General Public Health Agency of Canada	Public Health Agency of Canada
Brent Diverty (Vice-Chair)	Vice President, Programs Canadian Institute for Health Information	Canadian Institute for Health Information
Dennis Giokas (Vice-Chair)	Chief Technology Officer Canada Health Infoway	Canada Health Infoway
Scott Murray	Chief Technology Officer Canadian Institute for Health Information	Canadian Institute for Health Information

Appendix B: Participants in Dialogue Sessions Held in Halifax, Toronto and Calgary (October 2012)

Raza Abidi	Dalhousie University	Nova Scotia
Owen Adams	Canadian Medical Association	Ontario
Ewan Affleck	Great Slave Medical House	Northwest Territories
Debra Allen	College and Association of Registered Nurses of Alberta	Alberta
Susan Anderson	Alberta Health and Wellness	Alberta
Mike Barron	Newfoundland and Labrador Centre for Health Information	Newfoundland and Labrador
Alison Blair	Ontario Ministry of Health and Long-Term Care	Ontario
Mark Brisson	Alberta Health and Wellness	Alberta
Patricia Campbell	Ontario Hospital Association	Ontario
Sandra Cascadden	Nova Scotia Department of Health and Wellness	Nova Scotia
Jill Casey	Nova Scotia Department of Health and Wellness	Nova Scotia
Maureen Charlebois	Canada Health Infoway	Ontario
Gail Crook	Canadian Health Information Management Association	Ontario
Mélanie Josée Davidson	Canadian Institute for Health Information	Ontario
Nancy Day	Toronto Public Health	Ontario
Stafford Dean	Alberta Health Services	Alberta
Gail Dobell	Ontario Health Quality Council	Ontario
Mark Dobrow	Health Council of Canada	Ontario
Lee Fairclough	Canadian Partnership Against Cancer	Ontario
Theresa Fillatre	Canadian Patient Safety Institute	Alberta
Brian Forster	OntarioMD	Ontario

Dennis Giokas	Canada Health Infoway	
Roger Girard	Manitoba eHealth	Manitoba
Inese Grava-Gubins	College of Family Physicians of Canada	Ontario
Rosemary Gray	Saskatchewan Health Quality Council	Saskatchewan
Caroline Heick	Canadian Institute for Health Information	Ontario
Francis Lau	University of Victoria	British Columbia
Ray Leblanc	Capital Health	Nova Scotia
Adrian Levy	Dalhousie University	Nova Scotia
Shelley Lipon	Canada Health Infoway	
Susan Logue	Nova Scotia Department of Health and Wellness	Nova Scotia
Don MacDonald	Newfoundland and Labrador Centre for Health Information	Newfoundland and Labrador
Mary Eileen MacPhail	Capital Health	Nova Scotia
Alex J. Mair	Canada Health Infoway	Ontario
Deborah Malazdrewicz	Manitoba Health	Manitoba
Shannon Malovec	Provincial Health Services Authority	British Columbia
Michelina Mancuso	New Brunswick Health Council	New Brunswick
Lynne Mansell	Alberta Health Services	Alberta
Ferne Mardlin-Smith	IWK Health Centre	Nova Scotia
Patricia Martens	Manitoba Centre for Health Policy Faculty of Medicine, University of Manitoba	Manitoba
Georgia McDonald	Vancouver Island Health Authority	British Columbia
Anne McFarlane	Canadian Institute for Health Information	British Columbia
Margot McNamee	Canadian Nurses Association	Ontario
Jim Mickelson	Canada Health Infoway	
Linda Miller	Canada's Health Informatics Executive Forum	Ontario

Terry Moore	Canada Health Infoway	
David Morgan	Newfoundland and Labrador Centre for Health Information	Newfoundland and Labrador
Scott Murray	Canadian Institute for Health Information	Ontario
Lynn Nagle	PricewaterhouseCoopers/ University of Toronto	Ontario
Stephen O'Reilly	Canadian Institute for Health Information	Newfoundland and Labrador
Rachelle O'Sullivan	Canadian Institute for Health Information	Newfoundland and Labrador
Dennis Protti	University of Victoria	British Columbia
Michael Routledge	Manitoba Health	Manitoba
Francine Anne Roy	Canadian Institute for Health Information	Ontario
Brendan Seaton	Information Technology Association of Canada	Ontario
Rick Skinner	Cancer Care Ontario	Ontario
Jeremy Smith	Physician Information Technology Office	Ontario
Neil Stuart	Facilitator	Ontario
Don Sweete	Canada Health Infoway	
Brett Taylor	IWK Health Centre	Nova Scotia
Douglas Tessier	Facilitator	Ontario
Gail Tomblin Murphy	Dalhousie University	Nova Scotia
Barbara Wasilewski	Manitoba Health	Manitoba
Liam Whitty	Health PEI	Prince Edward Island
Don Young	Ontario Ministry of Health and Long-Term Care	Ontario
Zachy Olorunojowon	British Columbia Ministry of Health	British Columbia

At the request of the ministère de la Santé et des Services sociaux du Québec, stakeholders from Quebec were not invited to participate in the dialogue sessions.

Appendix C: Glossary

Acronym	Term	Definition
	Analytics	Analytical methods used to identify and visualize trends or patterns in big data.
	Big data	Large and complex data sets that require specialized software to be manipulated and analyzed.
	Capacity	1. The skills and abilities to understand and take advantage of information to support decision-making. 2. The tools and processes that facilitate that use.
	Confidentiality	Ethical and legal obligations that relate to the disclosure or non-disclosure of information obtained in the context of care. See also *Privacy*.
	Consent management	Allows patients to determine who can see what parts of their health information under which circumstances.
	Data custodian/ trustee	Person or organization responsible for securely holding and processing data from health information systems.
	Data steward	Person or organization responsible for defining the content of health information systems and for ensuring the data can fulfill its intended uses.
	De-identification	Removal of direct patient identifiers (such as name or unique personal identifier) or data elements that could be used to identify a patient (such as date of birth or postal code). De-identification is also the assurance that linking data with another data set will not make it possible to directly identify an individual. In this case, identifiability depends on the amount of information held, the rarity of the characteristics, and the skills and technology of the information holder.
EHR	Electronic health record	Secure lifetime electronic record of an individual's key health history and care received, regardless of where health services were received. EHRs are available electronically to authorized health care providers and to the individual concerned anywhere and anytime.
EMR	Electronic medical record	Electronic record used within a single health organization (such as a family physician's office) that captures clinical information at the point of care.
	Personal health information	Health-related information about a specific individual that can be used to identify this individual.

Acronym	Term	Definition
	Health information	Information that is not personally identifiable (for example, data that has been de-identified or that has been aggregated and analyzed, such that it can no longer lead to the identification of the individual from whom it was collected). See also *Personal health information* and *De-identification*.
HSU	Health system use of data	Use of health data collected at the point of care to strengthen the health system. Health system use of data generally comprises the use of health information to support clinical programs (for example, through decision-support or quality improvement initiatives), health system management, population and public health, and health research. Health system use of data is a subset of secondary use of data, a term commonly used in the privacy community. Secondary use of data refers to any use of the data collected for one purpose (for example, the provision of health care to a patient, which is considered the primary use of the data) to inform another purpose (such as a quality improvement initiative, which is considered a secondary use of the data). Health information laws in Canada regulate which secondary uses of health data are permissible. Generally, they permit the use of health data, whether paper or electronic, for management and planning of the health system.
	Interoperability	Ability of two or more systems to exchange and use shared information. Interoperability is a pre-condition for developing electronic health records from the electronic medical records held in disparate health care organizations.
	Privacy	Right of individuals to determine when, how and to what extent they share information about themselves with others. See also *Confidentiality*.
POC	Point-of-care data	Data that is captured during the provision of health services to a patient, without having to enter any more data into the system than is necessary to deliver care.
	Standardized data	Data that has been structured using a controlled vocabulary of predefined and authorized terms.
	Structured data	Data that has been codified and recorded in a pre-determined manner.
	Unstructured data	Data elements that have not been captured using an identifiable structure (in health records, the most common example is free-text data).

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