

Unlocking the Value of Data

Creating a Unified, Informed, Proactive Community

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Executive Summary

There is a growing need for improved patient experiences and seamless interactions between providers and patients, all at a reduced cost. Patients, providers, researchers, vendors and decision-makers would collectively benefit greatly from data sharing across health care systems. Innovative tools have enabled organizations to collect and use patient-provider data to promote more informed, rapid decision making. However, these same innovative tools can make data sharing across organizations challenging, especially when the data are not standardized to ensure compatibility across organizations. These perceived barriers associated with technology, privacy and processes are deterrents that have hindered the interest in data sharing. Moreover, there has been increasing risk and concern on ethical data usage across industries. Cases of data breaches, data-driven manipulation, and other data-driven threats have increasingly shaken the trust and confidence on how organizations securely access and share data. This inhibits the facilitation of data sharing for the purposes of quality improvement, system governance and population health management.

Despite these challenges, many data sharing solutions have been successfully implemented within Canada, on a smaller scale, and outside of Canada, on a larger scale. Some examples discussed include implementations from eHealth Ontario, Australian Digital Health Agency, and the Centres for Medicare and Medicaid Services. Each example provides an opportunity to learn from the successes and challenges. There is a cost to the continued inability to share data within Canada and across borders that needs to be acknowledged. We are not a leader in this field and instead need to focus on acting quickly to become successful followers of those that have models in place.

As part of Digital Health Canada's Call to Action on Unlocking the Value of Data (See Appendix, page 29), this report is one of three actions enlisted to help individuals and organizations collaborate to tackle this collective, mounting problem. Its purpose is for readers to understand the importance of addressing the problem as a community and what immediate actions can be taken to transform the problem into an opportunity.

Introduction

From early on it was identified that technology could have a profound effect on healthcare. In 1949 Gustav Wagner established the first professional organization for informatics in Germany to coincide with the introduction of the computer. However, it was not until 40 years ago that the first personal computer arrived and a decade ago the smart phone did not even exist. In healthcare, it is only in the last 20 years that we have seen a significant investment in the development, deployment and adoption of health information systems to automate workflow and capture information about the patient. Many of the benefits associated with this investment were identified in a 2006 report by the Agency for Healthcare Research and Quality:

- Improve health care quality or effectiveness
- Increase health care productivity or efficiency
- Prevent medical errors and increase health care accuracy and procedural correctness
- Reduce health care costs
- Increase administrative efficiencies and healthcare work processes
- Decrease paperwork and unproductive or idle work time
- Extend real-time communications of health informatics among health care professionals
- Expand access to affordable care

...In healthcare, it is only in the last 20 years that we have seen a significant investment in the development, deployment and adoption of health information systems to automate workflow and capture information about the patient.

Many of these benefits still resonate today, with the addition of one critical overarching benefit, which is to improve the patient experience and outcomes. Although there have been significant strides in achieving some of these benefits, the opportunities to fully realize and sustain the benefits over time are untapped. The reason for this is simple—efforts need to not only focus on technology but on gathering, analyzing, acting on and optimizing the use of appropriate data. At the Fall 2018 CHIEF Symposium, the need to unlock the value of the data was a prominent theme. As a result, a Data Access Working Group was created and a Call To Action defined (see Appendix, page 29).

At the Fall 2018 CHIEF Symposium, the need to unlock the value of the data was a prominent theme.

To enable the unlocking of the value of the data, it was agreed that three key actions were required:

- **Action 1: Create a Unified, Informed, Proactive Community**
- **Action 2: Establish a Connected Healthcare Data Ecosystem**
- **Action 3: Seek and Invest in Partnerships**

This white paper will explore the necessity to “Create a Unified, Informed, Proactive Community”. It will define the need and mandate of the community as well as recommend six Community Actions that can be adopted immediately by individuals and organizations:

- 1. Understand the Value**
- 2. Reframe Barriers as Opportunities**
- 3. Learn from Others**
- 4. Ready Your Data**
- 5. Educate & Align Your Stakeholders**
- 6. Take Action**

In order to create a unified, informed, proactive community, thought leaders must understand the value and risks of converging to a collective vision with their partners. We will first explore the interests of the patients, health providers, researchers, vendors, and health system planners. We will highlight barriers that hinder or prolong the progress of collective efforts to a data sharing community. We will yield examples of successful models and strategies to learn from, while including tactical approaches to preparing organizations as they move towards collectively unlock the value of their data.

The Power of a Unified, Informed, Proactive Community

The ability to unlock the value of the data does not come with one single action done in solitude. Unlike healthcare technology, which can be independently implemented and used within an organization, the true value of data can only be realized when data is shared. A larger more comprehensive data set on an individual, disease/condition, population, and/or service will enable better analytic results that can lead to better decisions and outcomes. In most cases, data is stored by multiple individuals and organizations and managed differently which hinders the realization of this benefit. It is critical that bridges between silos are built to enable a comprehensive view of a patient's health journey and to harness the true benefits data analytics can bring to healthcare.

The first step to building bridges is to foster a unified, informed, active, pan-Canadian data sharing community. The actions of the community must be defined with careful consideration to our existing healthcare landscape, the people that act within it and the possibilities that successful data sharing presents. Although there may be hurdles encountered throughout the set-up and implementation, the benefits are already being realized from other regions that have already participated in a similar endeavor. By unifying as a community with a common purpose, shared values, and a defined action plan, the vision of a unlocking the value of data will become a reality.

Vignette #1 - Data Access through collaboration between government and academia

Canada's Data Liberation Initiative (DLI) is a partnership between Statistics Canada and post-secondary institutions across the country to improve access to Canadian data resources. The DLI Community gain the benefit of accessing major Canadian datasets collected by Statistics Canada and special collection of aggregate tables. It also provides data and statistical literacy to student and faculty and training on usage of Microdata files and tools with dedicated research assistance to its members. As a result, the availability of the data has increased research activity to the DLI and wider communities. Statistics Canada gains active feedback on the relevancy of its data to Canadian society and in its educational outreach.

The first step in creating a community is to identify a common purpose. A common purpose is what drives us forward and enables collaboration. An example of a common purpose that could be adopted by the community interested in unlocking the value of data could be:

"...to make health data accessible and available to authorized users to improve healthcare delivery, care and decision-making and to promote innovation, entrepreneurship and economic growth."

It is also critical to have shared values to guide the group around data. Examples of shared values that could be considered by the community include:

- **Data is valued** – Data has measurable actual and potential value that can be leveraged.
- **Data is managed as an asset** – Consistent practices are applied to manage data throughout their lifecycle.
- **Data is reused** – Data is captured, created and managed so that it can be used for multiple current and future authorized purposes.
- **Data is fit for use** – Data supports their intended use.
- **Data is protected** – Controls are applied to ensure that access to personal level data is adequate, relevant and limited to what is necessary for the purpose.
- **Data is shared** – Data can be easily accessible for authorized uses and will be made available to health system partners and the public with appropriate controls.

Finally, a defined Action Plan both at the local and national level would prove beneficial. The plan should include tactical steps that can be followed to establish a connected healthcare data ecosystem and how to seek and invest in partnerships to leverage the ecosystem.

Community Action 1: Understand the Value

Data is the foundation for improved value based healthcare delivery. Over the years, industries have benefited from using data analytics to identify informative results that improved accountability/transparency, enriched performance, and enhanced customer service. However, while organizations invest in stronger computing power or development of AI/ML capabilities, the availability of the high-quality data that can appropriately explore or support novel means of analyzing information is often overlooked. By sharing data, organizations can streamline costly data collection, processing, extrapolation, and linkage while creating a foundation for improved clinical outcomes and patient experience.

All stakeholders can benefit from data sharing through the access of a greater quantity of more accurate data on a patient specific and/or aggregated data set. The value of unlocking the data can be articulated by looking through the lens of the various stakeholders and how data sharing can be beneficial to all parties. Following is a summary of how each stakeholder values data-sharing throughout the community:



Patients

Patient-driven healthcare transformation has been the goal for nearly all healthcare institutions across developed nations (Swan, 2009). The dream of patient-driven healthcare models is centered on availability and accessibility of data (Blumenthal, 2019). Since the start of the widespread use of electronic health records, patients have complained about the lack of data liquidity and the inability of the record to follow the patient throughout their health care journey (Blumenthal and Chopra, 2018). Providing patients with access to their health data could empower patients to take control of their own health and the care they receive while reducing current frustrations (Blumenthal, 2019). A seamless, accessible record would ensure that patients are notified of their health changes, risks, and even potential data breaches in a timely manner (OECD, 2019). For example, in British Columbia, an exploratory study was conducted to better understand patients' experiences in accessing web-based laboratory test results. The results yielded that most patients expressed that they were satisfied with the electronic service (Mák, Fowler, Leaver, Hagens & Zelmer, 2015). Patients felt that it helped them to have more informed discussions with their regular doctor, improved their knowledge of their health, and increased the confidence to take care of their health.



Healthcare Providers

Access to data enables healthcare providers to better understand and treat patients by making improved clinical decisions, regardless of where care is provided. The goal of patient-driven health system transformation is to unlock data access and share capabilities to help achieve the IHI Quadruple Aim of better access and better care at a lower cost, while attaining joy in work and equity (IHI, 2017). In 2018, Canada Health Infoway conducted a physician survey that found high physician satisfaction with the use of EMRs to support patient care. Not only did a high percentage of physicians respond that they were satisfied with the EMR's ability to support care, but over 90% of primary care physicians reported increased efficiency due to the use of multiple EMR functionalities. Data sharing between and within healthcare organizations reduces duplicative medical testing and procedures—an outcome measure shared by the MyHealthEData program.



Healthcare System Planners & Administrators

Making health data more widely available can support efficient health system and program planning, public engagement and awareness, and coordination among organizations (OECD, 2019). To support successful healthcare planning, organizations such as ministries, health agencies, departments of health, and other public and private entities, require the ability to access sufficient, complete, accurate, and timely data to promote informed evidence-based decision making. Using data that has been aggregated from multiple sources can add much needed context around specific regional and demographic care needs. This can be used in conjunction with predictive analytics to assess and prepare for public health events in a timely, efficient and effective manner.



Researchers

Researchers are key players in driving the advancement of the health system through the discovery of new solutions that can be used for improvement in care and cross functional collaboration (OECD, 2019). It is essential for researchers to have appropriate access to granular data to complete analysis and validation to produce accurate findings. This requires a sufficient set of timely, linkable, and understandable health records in order to generate the evidence to inform and advance healthcare and clinical practices (Hripcsak et al., 2015). Furthermore, researchers have indicated that sharing health data is necessary to enable a thriving health data economy which could produce more innovative solutions than can exist within a siloed data environment (Tang et.al., 2018). To fully realize the power of preventative medicine research within the fields of genomics, clinical imaging and more, data from EHR systems must be made easily available to researchers and third-party vendors, which would require patients to permit access to their health data (Tang et.al., 2018).



Vendors/Innovators

The wider availability of healthcare data could also aid in the promotion of technology development by driving innovation within the consumer-driven marketplace. By removing data-sharing barriers and ensuring the availability of interconnected records, vendors and innovators will be able to further enable data availability, re-use and analysis. This will not only lead to the development of novel solutions to guide decision making around one's health, but also promote continuous improvement in health system management, research, and development (OECD, 2019). Liberating and sharing health data could provide more evidence-based information that can be used to build stronger, more reliable AI-based clinical decision-making solutions that contribute to more accurate, personalized advice. (Blumenthal and Chopra, 2018). Advances in AI technology will be dependent on our ability to collaborate and link diverse data sets to drive the development of complex algorithms that factor in socio-economic status, lifestyle, family history, lab results, etc., to generate more personalized healthcare recommendations.

Thorough understanding of each stakeholder's interest and value in having access to shared data will help to improve collaboration among these stakeholders to work towards improved shared data. Gaining perspectives on each persona-based vision, examples of organizations in action, and where these potential partners intend to proceed next will help the community to identify opportunities for collaboration to data sharing.

Community Action 2: Reframe Barriers as Opportunities

With a rise in value-based healthcare within Canada, it is becoming increasingly important for care providers to be able to enhance patient experience, improve population health and patient outcomes, and reduce costs (Bodenheimer and Sinsky, 2014). The evolution of technology has also mirrored the expectation of optimizing health system performance, and there is growing pressure for data to be leveraged effectively and collaboratively to improve service delivery and healthcare planning. In response, although some organizations have succeeded through modernized tools that enable patient-driven decisions in their care, much of the data currently collected still remain in silos and is constrained by data sharing barriers. These barriers often discourage organizations from attempting to build a connected healthcare data ecosystem. It is critical that the community acknowledge the barriers, dismantle the misunderstandings, and identify solutions to minimize resistance and to enable a path forward. The three common barriers to overcome are: technology; privacy; and process, which should be tackled head on by the healthcare community.

Barrier #1: Technology

Disparities in the way that data is collected, retained and disseminated exist among health care organizations partially due to technology. The type of technology, hardware or software, that is implemented at each organization creates a new set of barriers to be overcome in order to share usable and relevant data across organizations. Interoperability issues exist between legacy and more modern software and in some cases, data is still captured in paper format. Having multiple ways of capturing data within a singular organization adds another layer of complexity when it comes time to share. Finally, technical solutions that collect, process, integrate and share data are still maturing. All of the technologically-based barriers can act as opportunities to create a seamless sharing by ensuring organization data-sharing readiness.

Barrier #2: Privacy

In Canada, healthcare services and privacy legislations are established and governed at a provincial levels, with exception to provision of health care for First Nations, which is provided at the federal level . As a result, sharing data has been limited between provinces, healthcare organizations and consumers. An example of this was outlined by The Council of Canadian Academies (CCA) in the research community during its review on timely access to health and social data for health research and health system innovation (2015). It cited that variance in jurisdictional considerations affect the quality, scope, and impact of possible pan-Canadian research.

A culture of mistrust has been established as there is the anticipation of potential misinterpretation, misuses and/or internal abuse of the data. The discovery of bias and discrimination in data-driven technologies, that reinforces biases that excludes certain groups of people or weighs too heavily on existing trends also create uncertainty in enabling data-driven practices, such as data sharing (Government of Ontario, 2019). Legal and ethical considerations to data access and usage have therefore become a concern to Canadians in maintaining trust and confidence to their information. Data users and access providers hesitate to move forward as there is a lack of consistency and clarity in Canada's ethical and legal framework as well as differing interpretations of policies and key terms across the country (CCA, 2015). The barriers identified around privacy and data sharing disenable organizations, provinces and consumers from becoming properly educated on data rights and creating pan-Canadian data sharing legislation and agreements with privacy at the forefront.

Barrier #3 – Process

To enable data sharing, there does need to be commonly accepted guidelines surrounding data sharing principles and steps. Currently, they do not exist, or among the ones that do exists present unclear or inconsistent guidelines. In particular, the lack of data content standards and commonly used processes to assess data quality and capture metadata has had a negative impact on the pursuit of sharing data. While standardized and enriched administrative datasets and surveys that are nationally managed by the Canadian Institute for Health Information and Statistics Canada provide comparable data across provinces and territories, data outside of these sources are often neither sufficient nor feasible for time-sensitive bodies of work. The proper design and implementation of standard processes for collection, storage and use of data will act as an opportunity for organizations to standardize the data made available for sharing.

Community Action 3: Learn from Others

One great way to accelerate achievement is to get curious about the achievements, lessons learned, and experiences of others. By understanding success factors and how others have overcome challenges and hurdles, it can help organizations avoid pitfalls and optimize projects in a hugely positive way. For example, in 2017, Rosi et al., (2017) completed a deep dive into five existing personal health data sharing platforms to examine how data has been collected and shared on a large scale in different countries, and the core values that each platform aims to uphold. Already, there have been significant strides within Canada and around the world in creating a healthcare environment conducive to the successful uptake of data sharing, access and utilization.

In Europe, **Finland** presents an example of change management via changes in their law. In 2017, Finland made electronic prescription mandatory by law with doctors no longer writing prescriptions down or prescribing over the phone, although this does continue to occur in extraordinary circumstances (Hypponen, 2017). Due to the success of the electronic prescription program in Finland, Estonia has been working alongside Finland to create a way to exchange digital prescriptions and allow cross-border flow of data between EU member states. As of January 2019, electronic prescriptions written in Finland can now be dispensed in Estonia, marking the first instance that a prescription can be filled in a different country than where the prescription was created (Kanta, 2019). In addition, Finland has also enabled a national data sharing platform called Taltioni to encourage health management and promotion (Riso et al., 2017). Taltioni is able to connect a person by their Finnish social security number with various tools, such as free mobile applications, medication and appointment schedule management, weight management tools, and other resources to generate a tailored service for each person. In addition, by enabling the services to be available on mobile applications, information collected on Taltioni can also be uploaded and securely accessed by medical teams from anywhere with an internet connection.

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Another example in which government oversight and changes to policies created an environment for success is the **Swedish National eHealth Strategy** (Armstrong, 2017). The goal in Sweden is to offer all patients universal access to medical records, a decision made at a national level. Despite the autonomous councils having the ability to choose and deploy their own variations on eHealth services, it has been made a national Strategy that “all residents from 16 years should by 2020 have access to all information documented in country funded health and dental care.” All of this is expected to be enabled by a national patient portal and a national health information exchange platform.

The goal in Sweden is to offer all patients universal access to medical records, a decision made at a national level

In other parts of Europe, personal health data platforms have also evolved to include metrics beyond clinical data (Rosi et al., 2017). For example, in addition to clinically-relevant health information, the **Switzerland**-based platform called MIDATA also tracks a person’s fitness, diet, geolocation, and financial data. In **Greece**, an existing platform called ePGA aims to connect health professionals, researchers, and individuals by translating all data into clinically meaningful information to drive research and support clinical decision making.

Similar to the examples above, **Australia** also hopes that digital health data can one day be accessible anytime from anywhere. The “My Health Record” program initiated by the Australian Digital Health Agency (ADHA) (n.d.) allows individuals and approved healthcare professionals to access patient records from anywhere with internet, including via smartphones. By establishing a national digital health infrastructure, the ADHA hopes to be inclusive to as many patients as possible.

In the **United States**, the Centres for Medicare and Medicaid Services (CMS) (2018) announced in March 2018 that their HealthEData program would not only enable data sharing, but would also allow patients to choose the provider who best meets their needs. The system would enable secure access of their data to their selected provider. This example demonstrates a cultural shift within the patient community while creating greater competition and reducing costs. The MyHealthEData program enables patients to recognize ownership of their own data and have the ability to choose who can access the data, thus taking control of their own health and overall health journey. This control also helps to shift the patient-practitioner relationship from being didactic into that of a team approach, providing patients with more accountability over their results.

In addition, a private sector collaborative in the US has also developed guidelines for an open source, standardized API which provides access to data stored in EHRs. By following in the footsteps of US institutions and either developing or adapting such guidelines would allow for the liberation of patients’ data. This would open the possibility for the development of consumer-oriented third party solutions that utilize the data to provide new and useful services that help patients better manage their healthcare (Blumenthal and Chopra, 2018). These solutions may be more friendly, intuitive, and accurate than existing solutions.

Within **Canada**, the ACCESS Health Gateway currently being developed by Canada Health Infoway will serve as a shared digital service platform that enables the provision of products and services that will more easily connect Canadians with their health data and facilitate electronic health services for patients and care teams to connect and collaborate (Canada Health Infoway, 2019). Statistics Canada has also taken several steps to make data more available, such as making its socioeconomic database free to use, adopting an open license, and eliminating all royalty and licensing fees. The national agency has also formed the Pan-Canadian Real-World Health Data Network (PRHDN), a partnership with the Canadian Institute for Health Information (CIHI) and several leading provincial research data networks (e.g. Population Data BC, the Institute for Clinical Evaluative Sciences, Manitoba Centre for Health Policy, and several provincial Strategy for Patient-Oriented Research Units) to create a coordinated access to distributed health data network across the country. The goal of the research and government communities collaboration is to facilitate and accelerate multi-jurisdictional studies and analysis with harmonized and complementary data (PRHDN, 2017).

In **Ontario**, ConnectingOntario is an initiative overseen by eHealth Ontario. ConnectingOntario acts as a network for providers to access any patient data that has been entered by participating healthcare organizations. Data may include lab results, diagnostic imaging reports, discharge summaries, notes, and prescriptions. As of December 2018, over 99% of Ontario hospitals have connected to ConnectingOntario services, resulting in the submission of over 6 billion patient record contributions to the data repository (eHealthOntario, 2018).

As the rate of data generation and data sharing increases, it is important to realize the need for technology to keep up and ensure that data sharing capabilities are also ever evolving and advancing in order to leverage the generated data. Moreover, individuals and organizations should be encouraged and empowered to assume the accountability of keeping up-to-date on advancements health data sharing through ongoing developments and learning from others.



Community Action 4: Ready Your Data

Individuals and organizations can immediately start on the journey to unlocking the value of data by establishing internal programs to ready the data. **Data Readiness Programs** can be a significant resource and financial investment therefore it is recommended that they be designed based on the priorities of the organization to ensure the most beneficial impact. These priorities should then be translated into guiding principles for the Data Readiness Program.

Examples of Guiding Principles

- **Availability:** Comprehensive health data should be made available for authorized use to enable effective and efficient health management.
 - Improved availability must address cultural, IP, technology, and other barriers
 - Health data should be available to authorized users for authorized use
 - The principles of privacy by design must be integrated to ensure the protection of patient confidentiality while enabling the use of data to provide value for the public good
- **Accessibility:** Authorized users should have knowledge of where the data is located and the means for accessing health data.
 - Patients should know what data exists about them and where it can be accessed
 - Mechanisms for data access should be made transparent
 - An inventory of the location of the sources of data (i.e. metadata) is required to make data discoverable and accessible
- **Analytical Use:** Appropriately de-identified health data, at an aggregated level, should be used to advance research, public health, planning, and quality improvement efforts.
 - Aggregate data should be leveraged extensively to advance innovation in the areas of research, population health management, and ongoing improvement of the quality of health services
 - Aggregated data must be appropriately de-identified to preserve the privacy of individuals before being used
- **Data Linkage:** Appropriate data linkage, i.e. the integration of information from two or more independent sources that relate to the same individual, must be available to integrate and match data and ensure the development of a single record/ view for an individual.
 - Records should be linked on the basis of common identification data.
- **Data Quality:** To ensure consistency and quality of health data, measures need to be in place all along the data pipeline to assess and improve quality based on the following metrics: accuracy, applicability, understandability, relevance, availability, timeliness, and primacy.

The focus can be identified through a self-assessment tool within CIHI's Health Data and Information Capability Framework (2019)— a guide to improve governance practices and knowledge sharing. The self-assessment tool can help organizations and networks to understand and improve their capabilities in managing and sharing data within and across the enterprise. It is critical for organizations to understand their approach to access, privacy, and associated risks.

Once the focus is identified and the organizations are able to identify the level of their data and information capabilities, effort can be directed at establishing data governance and implementing consistent data management practices with CIHI's Health Data and Information Capability Framework. It can be used to develop plans to improve the organization's practices, and identify which capabilities to harmonize with their partners. It provides a common language and understanding of the scope of work to gain value from data and information, the opportunity to establish a capability exchange for knowledge sharing and expertise, and the opportunity for networks of organizations to identify capabilities to harmonize to simplify interactions, lower cost, and improve trust.

By creating common processes and management practices, higher data quality can be collected, privacy and security considerations can be addressed, and continuous improvement can be achieved.

Throughout the lifecycle, standards for high quality data collection should be established and both the processes created and technology that is chosen should ensure that all data collected is relevant, accurate, consistent, comparable and timely. Digital health records, network interoperability, and technical toolsets must be in place for optimal management and dissemination of health data. Network interoperability must be available to communicate, disseminate, and exchange data accurately, effectively, securely, and consistently across different information technology systems. Technical toolsets should be created for operational management, privacy and security, and data analysis. All technology management tools should be included within the IT infrastructure which spans the entire framework.

Similar to IT infrastructure, security should appear as a framework feature across all lifecycle steps. Security measures that focus on blocking inappropriate access and preventing data tampering will be important for initial user buy-in and continued use. Creating appropriate security measures involves the creation of clear policies and procedures that focus on privacy, confidentiality and security of health data, controlling the access to health data, and, ensuring that data is appropriately collected, in accordance to regulations and laws, and kept private, confidential, and secure.

By creating common processes and management practices, higher data quality can be collected, privacy and security considerations can be addressed, and continuous improvement can be achieved.

Another key consideration is the identification of right data domains. These domains can include patient, provider, payer, location, organization, etc. Structures may be established to define policies and standards across these domains. Common, agreed-upon data standards must be adopted to allow for a consistent way to record and communicate health data and facilitate interoperability. The adoption of health data standards is critical to the effective use of electronic health records as the lifetime patient record is built from data shared across different sites, throughout the patient care journey. Data comparability should be enabled through standard vocabularies, measures, and, principles of privacy and ethics. The interoperability of differing software should be assessed based on function, process capabilities, semantics and technical lenses.

This assessment should be standard across organizations that opt in (if applicable) to the data sharing movement. Metadata can be used to standardize organization specific measures which may include the proper labelling and general organization of the data that is received. Creating clear federal policies around the expectations and standards for data sharing can enable sharing across provinces and territories whereas allowing each region to create their own unique policies will make the walls of interoperability more difficult to penetrate (Riso et al., 2017).

Creating a feedback loop during the initial stages of deployment will be a valuable way to ensure that the privacy and security needs of all involved populations are being met with trust and confidence. Maintaining strong partnerships across involved organizations is important to gain necessary perspectives and improving the model on an ongoing basis. Process standardization can be difficult when many parties are involved but is an important aspect for a data sharing model to be deployed successfully.

Establishing common data management practices will ultimately enable data sharing and a data stewardship model with clear roles and responsibilities to ensure accountability, sustainability, and scalability. Conscious decisions need to be made on what should be harmonized across organizations and what other capabilities need to exist to have trust between organizations in the network.

Strong data governance ensures standardized processes for the collection, curation, and security of system data. By agreeing to common policies and standards, the healthcare ecosystem can ensure greater interoperability and risk control. This in turn would serve as a key enabler of improved care coordination across the system, enabling the realization of improved patient and provider outcomes and more efficient and cost-effective processes.

Conscious decisions need to be made on what should be harmonized across organizations and what other capabilities need to exist to have trust between organizations in the network.

Community Action 5: Educate & Align Your Stakeholders

Ensuring that stakeholders are knowledgeable and aligned on the benefits of data sharing, what it means for them, how to realize such change, and what supports will be in place are key to unlock the value of the data. Participation and input from different groups have benefited similar initiatives and other eHealth innovations in recent years. Data sharing at a larger scale will require a collection of various approaches to engagement, education, and communication that best fit the type of stakeholders involved. It is important to consider and include a diverse group of stakeholders that can be categorized in the following personas: patients, healthcare providers, researchers, government, vendors, and the general public.

Patients

As technologies continue to evolve and the occurrence of activities related to privacy breaches persist, patients' trust in the use of data continues to decline. A commonly cited concern when other nations have sought to provide accessibility to patient health records is fear. Patients fear that their health data will be seen or used by an individual with malicious intent. However, data sharing is essential for public health, longitudinal patient care, and clinical research. A way to encourage patient understanding and provide the opportunity to learn about the use of data is to create groups where patients feel safe to ask questions and provide feedback.

Patient and Family Advisory groups can organize forums and events that other members of the public can join to learn more about the value, risks, and constraints of data sharing and data usage. Creating an environment of trust and understanding through transparent and thorough education can help to alleviate some of these concerns. Education can build a data culture that will increase the desire for appropriate sharing, protection, and interpretation of data (ISO, 2017). A study conducted in Sweden, following the implementation of their public access EHR, showed that users felt that accessing their data helped them to feel empowered and involved in their health care and security was commonly cited as a positive benefit (Moll et al., n.d.).



Another form of patient engagement includes patients becoming involved in the organization's committees and having a level of accountability. Diabetes Action Canada (DAC) created a Research Governing Committee where half of its members are composed of people living with diabetes or their caregivers (Willison et al., 2019). These individuals bring value, integrity, and continuous quality improvement to the organization as they help provide governance over secondary use of data, private access to data, registry-based clinical trials, and practice-based research. While they do not carry formal authority in the committee, they ensure patient-centered perspective by holding accountability to the DAC for including patient-related outcomes, consider benefits and risks for people living with diabetes, and perform good communication practices with their research participants pertaining to consent and the organization's use of their health information (Willison et al., 2019). Members have the freedom to go public if there is ever concern on particular policy direction. They are also provided with guidance by the DAC to help them understand their influence as digital stewards of their own health data.

As a result, the DAC developed an information governance process that fosters public trust, social license, and patient/public interest in the use of the data within their custody (Willison et al., 2019). The inclusivity brings transparency and confidence from both the data users and providers the culture of sharing and accessing data.

Healthcare Providers

Providers are key influencers to patients and to the communities that they serve. Without clinician engagement, the adoption of technology would not have had as much impact as it does today. Providers can be key change agents to enabling data liberation if they are supported by senior leadership and if they are part of the design of the initiative. While the DAC's research data governing committee had 50% of their members be patients, leadership had also included primary care physicians and researchers to participate (Willison et al., 2019). The inclusion provided further credibility to the committee and formed a powerful coalition.

Similar to the DAC participatory governance model, including providers in the data liberation initiatives provides them the opportunity to provide feedback on how to engage with their peers and the ability to receive education on the value of data access and sharing. As the technology continues to evolve, the providers would consequently use the tools and devices with less barriers to accessing the data that they need and provide further influence to their colleagues and peers on the benefits realized from data liberation initiatives. Overall, their contribution will help ensure transparency and awareness around the use of data at the front line to mitigate concerns about data falling into the wrong hands (Spencer (2016).

Data sharing can be promoted within the broader community by health organizations, agencies, and associations who also support the provision of care. Initiatives such as Canada Health Infoway's ACCESS 2022 and Statistics Canada's Data Liberation Initiative to improve better access to data resources through partnerships with post-secondary institutions, exemplify the organizational commitment that can help drive open data to patients, learners, and providers.

As a start, learning from local, provincial, and national level partnerships, such as the joint initiatives of developing a Social Data Linkage Environment between the Canadian Institute for Health Information and Statistics Canada may encourage further opportunities for linking data from one organization to another. Broader initiatives such as Alberta Health Services' provincial clinical information system (Connect Care) and Ontario's secure provincial electronic health records portal (ConnectingOntario) may also provide best practices and challenges to share when developing data sharing agreements, data policies, and the change management from the users, for successful implementation and adoption.

Care associations, including but not limited to hospital or long term care associations, may be particularly influential to facilities in highlighting particular technology standards to ensure consideration of interoperability in system changes, such as incorporating standards, or having the ability to connect third party applications to medical records through Application Programming Interface (API).

While policies and technology may help set guidelines and parameters to the process and machinery to data access and sharing capabilities, it is equally important for the community to engage with patients/public and care providers through consultations with related committees (e.g. patient and family advisor councils, local medical advisory boards, etc.). Without engagement, the effort will not be optimized, risking immobilization and diminished value of data-driven care. Engagement may also include investment in training and education within the organizations to encourage the socialization of data liberation.



Researchers

Researchers represent a key stakeholder as open data initiatives enable them to side-step financial barriers to access and make use of large, expensive-to-collect, or previously inaccessible datasets. Data sharing initiatives enable the use of large or even relatively small datasets to contribute to big data initiatives and fuel future scientific discoveries. The availability of such large and diverse datasets can allow for meta-analysis that can reveal numerous novel findings (Gewin, 2016). Data sharing would thus improve reproducibility and robustness of findings while driving research and innovation.

Given the strong benefits to the research community, researchers may be enthusiastic in their initial engagement into open data initiatives. The development of a distributed network to accelerate multi-jurisdictional research through the Pan-Canadian Real-world Health Data Network (PRHDN), may be the beginning of such initiative. Composed of partners from not-for-profit and research organizations, this endeavor seeks to collectively increase dedicated resources and necessary policy and governance coordination to achieving a pan-Canadian health data platform that can be accessed and leveraged locally, nationally, and internationally in the broader research and systems planning community (PRHDN, 2017). Its seven major strategic objectives support data access services, data harmonization and standardization, data linkages within clinical information with the potential to expand to social data, patient engagement and indigenous health data support, and building strong governance to enable national coordination.



Government

The role of the government can be highly sensitive and deeply powerful to drive change. A data access and sharing initiative may incite the government to review and modernize legislations and by-laws that may be preventing data access and sharing to its fullest potential with other health organizations. Government's involvement can encourage more parties in the sector to be willing to share data with previously unknown parties, while retaining control of the data and access to it. As the supervisory authority, the government could decide to oblige dominant organizations to share specific, indispensable data that all partners agree is an imperative part of sustaining a data sharing community.

As an example, businesses in the Netherlands noted to their government that the sector as a whole would become more productive and efficient if there were secure and uniform exchange of data based on a single set of agreements (Government of Netherlands, 2018). The Dutch Ministry of Infrastructure and Water Management therefore provided a broad facilitating role in the initial stages via financial and organizational assistance.

Data sharing could have the aim of easing access for new and current health service providers to enter the sector, with the confidence that government will always seek a balance between exploiting opportunities and protecting data subjects' other interests—in areas, for example, like privacy and control (Government of Netherlands, 2018). The U.S. government developed the U.S. Core data for Interoperability task force to collaborate with the Office of the National Coordinator for Health Information Technology in supporting interoperability of multiple devices at levels impacting policy, technology, and people. In Canada, examples of private-public partnership with innovators to enable data sharing and access is the collaboration between TurboTax and Canada Revenue Agency through Netfile certification. Banking and identifying tax information are auto-filled to tax forms and tax returns are automatically deposited to a person's financial account of choice.

Data sharing could have the aim of easing access for new and current health service providers to enter the sector, with the confidence that government will always seek a balance between exploiting opportunities and protecting data subjects' other interests—in areas, for example, like privacy and control.

- GOVERNMENT OF NETHERLANDS, 2018

Vendors & Entrepreneurs

The vendor community and private start-up companies have created much innovation in healthcare technology, but it continues to be fragmented as it creates interoperability barriers to the users who use a decentralized web model. Reducing these barriers will enable the new paradigm for electronic health information to be shared by the patient (Gordon et al, 2018). For example, Apple's Health App enables consumers to directly retrieve medical data from the EHRs of participating providers that adopted that standard through consumer-facing API. Apple also developed a Health Record API to enable 3rd party ecosystem of consumer facing applications to be built using data in Apple iOS products. A common standard language would also enable data sharing across organizations. Standard accelerating effort involving the major EHR vendors, realized an industry developed open API build on HL7 Fast Healthcare Interoperability Resources (FHIR) standard to be made freely available to any application developers or EHR vendors.

Collaboration between data providers and vendors through their participation in a governance structure will provide timely communication as well as direct engagement and education with senior leadership that will foster a data-driven culture throughout organizations. Humber Regional Hospital's governance structure for the Command Centre includes representation from GE as they incrementally evolve the initiative to increase its capabilities. The Canadian Institute for Health Information has also realized benefits through the creation of a Vendor Working Group during the development and implementation of InterRAI's Integrated InterRAI Reporting System (IRRS). The goal of such engagement will provide consistent and transparent communication between stakeholders and vendors, which will provide more clarity to new or expanded products with faster implementation and operational support.



General Public

With a widespread change aimed at an entire community, using a campaign style approach can be an effective way to increase public knowledge. In 1990, Australia conducted a mass media campaign aimed at increasing awareness on the importance of physical activity. Using television, professional educational activities, promotional materials and community events, they found that 75% of the population recalled seeing the campaign materials following the campaign's completion (Booth, Bauman, Oldenburg, Owen & Magnus, 1992). A similar example using a radio campaign in Ethiopia, found that entertainment education increased the listeners knowledge on the topic, changed their attitude on the topic based on their current perceptions and increased their self-efficacy on their ability to implement the changes being suggested (Farr, Witte, Jarato, & Menard, 2006). Using this same approach in current times, where social media is already used heavily for knowledge dissemination, would likely have a similar, positive effect. The public engagement and campaigning transformative changes made to the Canada's Food Guide through traditional (e.g. TV, news, public consultations, etc) and modern means (e.g. Twitter, Facebook, online website, etc) demonstrate the success in change behaviours realized using various forms of media.

Social media has also encouraged the public to become more aware of the use of their health information and leverage online presence (e.g. Patients like me, patients Canada, #MyDataMyProperty) to share their opinions on the parameters to which their data may be used. This approach can promote the value of data sharing and access from a health care perspective. For example, it can provide transparency in its practices on data usage, highlight passages of consent documentation, and educate the public of information such as privacy policies to demonstrate willingness to build a data culture at a public level. More importantly, organizations will be able to understand and communicate with patients through their feedbacks on social media.

Using television, professional educational activities, promotional materials and community events, they found that 75% of the population recalled seeing the campaign materials following the campaign's completion.

- BOOTH, BAUMAN, OLDENBURG, OWEN & MAGNUS, 1992

Community Action 6: Take Action

Overall, it is critical that individuals and organizations not be observers, but be active participants in the community. Together, a universal data-driven culture can be fostered and built on the principles of trust, transparency, and collaboration. In conjunction with the actions through engagement, education, and communication, here are some ways to get involved and advance the agenda to unlock the value of data:

- **Connect** with others to exchange ideas & experiences
- **Educate** your leaders and community
- **Share** information on risks and best practices and align where possible
- **Encourage** the sharing and reuse of data

Promoting a community to foster balance, openness, fair procedures, and consensus, can encourage and support early adopters in gathering and modeling the path to a common, harmonized standards and processes for data access and privacy protection. Similar to organizations supporting its peer sectors, such as Institute of Electrical and Electronics Engineers (IEEE) to the electricity industry, or the Society for Worldwide Interbank Financial Telecommunication (SWIFT) to the finance sector, the network would encourage consistency across the healthcare sector, creating an industry standard and a hub for peer organization support and the ability to share learnings on challenges and best practices.

Conclusion

Despite the known benefits of technology use in healthcare, the last twenty years represent a significant change in the way it has been leveraged. Investments in hardware and software development and deployment across health sectors has been shown to improve the quality of healthcare delivered, increase efficiency, prevent medical errors, reduce healthcare costs, and more. Benefits can be further amplified through appropriate use of health data.

Despite existing and perceived barriers, using collaboration across organizations to enable sharing has been successful in many areas within and outside of Canada. The Data Access working group has presented the value of data, as well as some of the barriers and successes that exist today.

This white paper provides organizations with the tools to unlock the value of their data and help stakeholders to take action to Create a Unified, Informed, Proactive Community by understanding and participating in the six Community Actions:

- 1. Understand the Value**
- 2. Reframe Barriers as Opportunities**
- 3. Learn from Others**
- 4. Ready Your Data**
- 5. Educate & Align Your Stakeholders**
- 6. Take Action**

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Appendix

Call to Action

Creating a Unified, Informed, Proactive Community

The Opportunity

Data sharing among organizations across Canada was identified as a top priority at the CHIEF Executive Forum Fall Symposium 2018. Health data access on an integrated basis is an essential element to enhance health service delivery and improve outcomes. Sharing data across organizations and sectors—hospital, community, home— moves patients out of the hospital faster while giving them access to care in their communities and homes. The opportunity exists to enable a shift in mindset and policy to promote active sharing of current data within and between organizations while also planning for new forms of future data.

The Challenge

Healthcare system challenges create barriers to data sharing, leading to patient disengagement from their own care, inefficient management of chronic disease, and increasing costs.

The Call to Act

It is time to take action to unleash data locked within healthcare organizations and move towards a system that will provide better health for Ontarians. Individuals are encouraged to leverage the resources provided by CHIEF to create a sense of urgency within their own organization.

- **Ready your data** Ensure data is of high quality and is linkable to other data sets.
- **Enable a culture of sharing** Align your processes to simplify sharing of data while taking into account appropriate privacy protections.
- **Educate your leaders and community** Many decision makers in Canada's health system have expertise in health, technology, or planning, however, few have expertise in data and analytics. We must help those leaders understand what it takes to generate sustained and optimal value out of data.

Resources Available from Digital Health Canada

To support your call to action, Digital Health Canada has made the following resources available to members:

- CHIEF White Paper *Unlocking the Value of Data: Creating a Unified, Informed, Proactive Community*
- Community of Action White Paper *Canada and Shared Information Governance – Expanding on Governance Standards – Steps to Enabling Canada's Digital Health Ecosystem*

For any questions or comments please contact CHIEF@digitalhealthcanada.com

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Canada's Health Informatics Executive Forum (CHIEF) is an interactive, trusted environment for senior professionals and leaders in digital health and healthcare. CHIEF Members collaborate, exchange best practices, address professional development needs, and offer their expertise in setting the agenda for the effective use of information and technology to improve health and healthcare in Canada.



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