Ontario's Digital Health Assets CCO Response

October 2016

EXECUTIVE SUMMARY

Since 2004, CCO has played an expanding role in Ontario's healthcare system, using digital assets (data, information and technology) to enable the linking of funding to the quality of care as well as evidence-based decisions that drive performance and quality improvement.

Based on infrastructure CCO has developed, including digital assets, the Ministry of Health and Long-Term Care (MOHLTC) has asked CCO to support broader health system improvements beyond its core mandate of overseeing cancer and renal care as well as measuring access and wait times for key health services.

For example, in response to the 2010 Ontario Auditor General's report on inconsistencies in emergency room triaging of patients, CCO was asked by the MOHLTC to develop and introduce the Electronic Canadian Triage & Acuity Scale system (eCTAS). Building on CCO's Wait Times Information System, eCTAS will ensure every patient arriving at an emergency room is triaged following a standard process. This will result in higher quality emergency room care and more efficiently operated emergency rooms.

CCO continuously develops its digital assets in order to achieve greater value, making regular investments to improve the design, deployment and management of these assets. It explores ways to measure the actual and potential economic value of its digital assets, and actively seeks partnerships with other organizations where it sees greater potential value through integration. An example of these efforts is CCO's collaboration with eHealth Ontario.

There are elements of CCO's operations that use eHealth Ontario's infrastructure and data. CCO builds upon eHealth Ontario's OneID system, which provides identity proofing, registration and authentication for physicians and nurses. As well, OneID improves the end-user experience by providing a single log-on approach to multiple systems. CCO also uses eHealth Ontario's Ontario Laboratories Information System to provide high-quality, relevant and timely lab data for health system planning. CCO cannot acquire this laboratory data through other means.

CCO's extensive data holdings are used to plan for the health system needs of the whole population at the provincial, regional and local levels. For example, CCO has produced analyses for the Ontario Renal Network to estimate inpatient and outpatient dialysis needs for patients with chronic kidney disease. Analyses have also been conducted to determine the availability of Magnetic Resonance Imaging (MRI) scans so that funding for additional scans can be allocated to meet the needs of patients and decrease wait times. These types of analyses help with the planning of health system operations, capital construction and major equipment investments, all with a focus on putting patients first.

To continue to improve our health system, the province requires a system-wide approach to the integration of digital assets that addresses accountability, governance and funding. This integration must support the design, implementation and maintenance of digital assets that span all settings where patients receive care, whether in hospital, through primary care, community care or at home.

This integrated approach can be realized through a government-led initiative to develop a digital healthcare vision and strategy that will transform our current healthcare system to one that is more aligned and responsive to the needs of our growing and aging population.

CCO OVERVIEW

WHO WE ARE

CCO was formed in 1943 as The Ontario Cancer Treatment and Research Foundation. More than a half-century later, in 1997, the organization was formally launched and funded as an Ontario government agency. CCO is governed by the Cancer Act and is accountable to the MOHLTC. As an agency of the MOHLTC, CCO serves as the Ontario government's principal advisor on cancer and chronic kidney disease care in the province.

CCO directs and oversees approximately $1.9 billion of healthcare funds for hospitals and other cancer and chronic kidney disease care providers, enabling them to deliver high-quality, timely services and improved access to care. It employs approximately 1,100 staff members who work with partners to improve Ontario's healthcare system, and has a strong network of clinical leaders across the province to develop and support the implementation of CCO's quality and performance improvement plans.

CCO relies on partnerships to achieve its goals. The success of these partnerships depends on its ability to be transparent and accountable in the way it monitors the province's health systems, to share information and to allocate funding. Its healthcare partners rely on CCO to provide the tools, resources and data to enable them to continuously improve the delivery of care.

Although CCO's mandate focuses at a system level, it works to address the health needs of the people of Ontario. CCO partners with more than 100 volunteer Patient and Family Advisors from across the province who have had lived experience with cancer or chronic kidney disease. Patient and Family Advisors are integrated throughout CCO's program areas to help ensure that its work to support health system improvement is centered on the needs of patients and the public.

WHAT WE DO

CANCER SERVICES

Cancer Care Ontario – the Ontario government's principal advisor on cancer – equips health professionals, organizations and policy-makers with the most up-to-date cancer knowledge and tools to prevent cancer and deliver high-quality patient care.

It does this by collecting and analyzing data about cancer services and combining it with evidence and research that is shared with the healthcare community in the form of guidelines and standards. It also monitors and measures the performance of the cancer system, and oversees funding for cancer services that is tied to performance and the quality of care provided.

CHRONIC KIDNEY DISEASE SERVICES

The Ontario Renal Network – the Ontario government's principal advisor on chronic kidney disease – is leading a province-wide effort to diminish the burden of chronic kidney disease on Ontarians and the healthcare system.

It provides leadership and strategic direction to fund, organize and manage the delivery of renal care services in Ontario. This includes preventing or delaying the need for dialysis, broadening appropriate patient-care options including home dialysis, improving the quality of all stages of renal care, and building a world-class system for delivering care to Ontarians living with chronic kidney disease.

ACCESS TO CARE

In 2004, Canada's First Ministers made a national commitment to reduce wait times for key health services. In Ontario, this commitment resulted in the MOHLTC's Wait Time Strategy and the subsequent launch of its Emergency Room/Alternate Level of Care Strategy in 2008. The success of these strategies relies on information and technology to collect and report accurate, reliable and timely wait time data.

CCO, under its Access to Care program, was asked to develop and deploy a Wait Time Information System to capture and report this data in near real-time. Subsequently, CCO was given the task of collecting and reporting information to support the improvement of emergency room services and to help reduce the province's Alternate Level of Care problem (patients who are in hospital beds but could be better served through access to community or home care services).

CCO's Access to Care program enables improvements in the access, quality and efficiency of healthcare services. It also helps to reduce wait times by collecting, analysing and providing information that can be used to track patients as they receive health services.

BROADER HEALTH SYSTEM IMPROVEMENT

CCO supports broader health system improvement as requested by the MOHLTC, including for dementia, palliative care, emergency room decision support, mental health and addictions, and health system funding reform.

CCO currently uses eHealth Ontario's OneID service to authenticate several thousand healthcare users for a number of CCO's digital health solutions. CCO is in discussions to expand use of OneID in other digital applications including:

- eReports (Cancer Screening Activity Reports);
- iPort & iPort Access (an online Business Intelligence platform);
- ORRS (Ontario Renal Reporting System);
- eClaims (reimbursement of the cost of cancer drugs used in hospitals); and soon,
- eCTAS (emergency room triage).

CCO uses eHealth Ontario's OneID service, which enables CCO to focus on digital asset service delivery rather than managing user populations. It also provides cost savings for CCO by not having to license and support technologies for user populations already managed through OneID. Lastly, it provides CCO's healthcare partners with a better user experience, as physicians and nurses can use a single access to all CCO systems. eHealth Ontario also provides CCO with a ONE Network connection, which is used by some healthcare partners to send information to CCO. Other partners choose to send information to CCO through the Internet using encrypted

connections. Should CCO no longer have access to the ONE Network, CCO would transition all of its partners to Internet-based connectivity.

In order to effectively plan for the healthcare system, CCO also uses eHealth Ontario's Ontario Laboratories Information System (OLIS) to provide high-quality, relevant and timely laboratory data. CCO cannot acquire this data through other means. In the case where OLIS data was maintained by a different entity, CCO would partner with that host organization to ensure continuous flow of laboratory information. CCO's partnership with eHealth Ontario allows for the use of OLIS data in supporting quality improvement efforts today, with potential for CCO to use OLIS data for future health system planning and research. Some examples of how CCO and eHealth Ontario are working to use this laboratory data to improve patient care include:

- Understanding the number of people with chronic kidney disease in Ontario and its progression;
- Exploring the value of population-level chronic kidney disease screening, earlier case detection and prevention of progression to costly dialysis;
- Understanding the geographic distribution of chronic kidney disease to support health system planning;
- Informing the development and improving the quality of renal care, including provincial standards; and,
- Understanding the renal care outcomes and health service needs amongst remote, rural and First Nations, Inuit and Métis populations.

CCO was the first organization to request OLIS data for health system planning purposes, and has been working with the MOHLTC and eHealth Ontario since 2013 to access this data to support chronic kidney disease services. There have been significant challenges with the automatic transfer of this data to CCO, leading to the need for an alternative means of transferring the information. The MOHLTC and eHealth Ontario continue to work together to ensure a sustainable, ongoing transfer of OLIS data to support CCO needs.

Currently, OLIS data is the only eHealth Ontario data asset used by CCO. However, other provincial electronic health records developed by eHealth Ontario could potentially be used by CCO in the future.

HOW WE DO IT

CCO's ability to drive quality, accountability, innovation and value across all care settings is a result of more than 15 years of experience in designing and implementing provincial health systems. CCO has established strong partnerships with healthcare organizations and clinicians across the province through a network of regional programs (aligned with existing LHIN boundaries) and 225 clinical leaders across Ontario. Its information and technology services capabilities can provide agile, tailored solutions that are responsive to an evolving electronic health landscape.

ONTARIO'S CANCER SYSTEM

In 2004, following a number of pressures within the cancer system, Cancer Care Ontario transformed from a service delivery organization to a fund-holding agency with a focus on quality and performance, with purchasing authority for cancer services within Ontario.

Today, CCO is an organization that is integrated, evidence-based and focused on driving quality improvements at the system level. Its evolution to this current state required four significant system-level changes.

First, a link was established from the province to the local level with a **chain of accountability**. This included establishing: a Quality Council, focusing on performance metrics across the cancer system; a Clinical Council, which recommends clinical policies and improvement plans for the cancer system; and, a Provincial Leadership Council with Cancer Care Ontario's Regional Vice Presidents (aligned to each LHIN) to provide advice on planning and coordinating cancer services across Ontario.

Second was the development of **high-quality data**, which enables Cancer Care Ontario to measure and identify opportunities for cancer system improvement across the province, to measure quality of cancer care, and to benchmark Ontario's cancer system against other jurisdictions.

Third was a commitment to **planning** to provide focus and direction on the priorities that will lead to system improvements. Known as the Ontario Cancer Plans, they serve as roadmaps for how health professionals and organizations, cancer experts, patients and families and the government will work with Cancer Care Ontario to prevent cancer while improving the quality of care for current and future patients.

Cancer Care Ontario needed to effectively tie together these pieces to drive change for system improvement, and this was accomplished through the fourth change, CCO's **performance improvement model.** This model uses data and information to generate knowledge in the form of evidence-based guidelines, to conduct research, and for policy analysis and planning. This knowledge is shared with healthcare partners, which leads to developing and implementing improvement strategies. These strategies become part of performance management, linking funding to quality, quarterly reviews and accountability. Performance is regularly monitored, with data fed back into the performance improvement cycle.

ONTARIO'S RENAL SYSTEM

CCO applied a similar approach as above to support improvement of Ontario's renal care system for people with or at risk for chronic kidney disease. Today, the renal care system is comprised of 26 regional chronic kidney disease programs with more than 100 sites providing dialysis or pre-dialysis services.

In response to a number of challenges with Ontario's renal care system, in 2010 the MOHLTC transferred provincial oversight, coordination, and funding of renal care services to the newly formed Ontario Renal Network, under the CCO umbrella. In this way, the infrastructure CCO had developed to support the cancer system and Access to Care could now be used to support improvements in renal care.

The Ontario Renal Network was asked to lead a province-wide effort to diminish the burden of chronic kidney disease and improve coordination, planning, quality and performance of the renal care system. To do so, the Ontario Renal Network had to bridge the gap between provincial policy and clinical practice. This required implementing numerous structures and processes similar to those that had been set up for the cancer system.

A **provincial and regional leadership** network was created to define best practices and to champion these practices with healthcare providers. In addition to the establishment of a solid provincial and regional leadership structure, a focus on **performance management and measurement** was implemented.

Valid, reliable and comparable data were acquired to measure performance and establish greater accountability for quality and performance throughout the renal care system. The Ontario Renal Network used CCO's existing

information management/information technology infrastructure and CCO's status as a prescribed entity within Ontario's Personal Health Information Protection Act to launch its Ontario Renal Reporting System. This system provides timely data for renal care system planning, funding and performance/quality reporting.

CCO'S DIGITAL ASSETS

CCO views its data, information and technology as fundamental digital assets which need to be deployed and managed effectively to enable the delivery of high-quality care in Ontario.

DATA

CCO is the custodian of more than 75 data holdings (translating to over 250TB of data) and manages an additional 45+TB of data in support of its business functions. These functions include informatics, analytics and business operations in support of the cancer, renal, access to care and other programs.

CCO has experience in translating large data sets into meaningful information that builds knowledge in health system performance and enables directed improvement initiatives. It operates a sophisticated enterprise data warehouse and is investing in the implementation of a data lake which enables the co-location of vast amounts of data that can be easily and efficiently used for analytic purposes to help drive quality and performance improvement.

CCO is unique in its designation as both a "prescribed entity" and a "prescribed person" under Ontario's Personal Health Information Protection Act. With these important designations CCO can quickly respond to deliver new initiatives identified by the MOHLTC as a priority. Beyond the prescribed entity and prescribed person statuses, CCO also acts as a Health Information Network Provider and Agent to providers such as hospitals, supporting the secure sharing of health information. Additionally, CCO is currently moving towards a Privacy by Design model, whereby all future privacy controls will be embedded seamlessly into every data and analytics initiative. Privacy by Design is a concept that was developed by the Information and Privacy Commissioner to support both privacy and the effective use of personal health information that agencies like CCO collect to support health system improvement.

CCO shares its data, through data sharing agreements, with partners such as the Institute for Clinical Evaluative Sciences, fostering further research and exploration of data to maximize value. In addition, through CCO's Data Disclosure program, researchers and other requesters external to CCO can access its vast data holdings to support their work in developing innovative solutions for our health system.

Data is the cornerstone upon which CCO is able to drive continuous improvement in disease prevention and screening, the delivery of care and the patient experience for chronic diseases. For example, established in 1964, Ontario's cancer registry is one of the oldest and most comprehensive population-based cancer registries in North America. Covering a population of approximately 13.8 million people, the Ontario Cancer Registry includes information about all Ontario residents who have been newly diagnosed with or have died from cancer. The registry is used across the province for surveillance, population health, analytics and research purposes.

Another important example of an information system being used to drive continuous improvement is the Wait Time Information System to monitor, measure and publicly report surgical and diagnostic imaging wait times

across the province. This web-based tool is used to collect and to report wait time information for over 190 types of procedures in 13 key surgical and diagnostic imaging service areas as well as Alternate Level of Care information. Approximately three million surgical procedures, diagnostic imaging scans and Alternate Level of Care patient waits are collected per year. Nearly 665,000 surgical cases and more than 2.2 million diagnostic imaging cases were entered into the Wait Time Information System during fiscal year 2015/16, making it the most comprehensive wait time information database publicly available in Canada. As of May 2016, there were more than 2,000 application users in 186 healthcare sites across Ontario. Policymakers and planners use the information collected to inform funding decisions and resource allocation, as well as to identify performance improvement opportunities.

CCO's databases have also enabled it to develop numerous capacity planning models that support the building of a better healthcare system, including models in the areas of cancer services and resources, palliative care and dementia. In addition, CCO has begun implementation of a four-year Data & Analytics Strategy that is focused on deriving the maximum value and insight from its data and information assets. These initiatives are focused in: sourcing, integrating and analyzing data to generate insights; utilizing insights to inform decisions; and sharing insights as a catalyst for change to our healthcare system.

INFORMATION

CCO uses analytics skills to meet reporting requirements, support business decisions and strategic planning efforts, and derive new insights from the data. The scope of analytics services includes linking data sets so that individual patients can be tracked as they receive care in different settings (hospital, primary care, home and community care) and from different healthcare providers. Analytics also drives and supports the development of key performance indicators, operational reporting, data exploration, ad hoc reporting, survey analysis, surveillance and costing/financial analysis. Specific information assets include cancer and renal program provincial scorecards and tracking tools, and wait times for surgical/diagnostic imaging and emergency rooms.

CCO's Strategic Analytics team provides diagnostic and predictive analytics services and assets to internal partners within the organization. These analytics activities support programmatic decision-making to study the clinical or business systems of a CCO program and derive insights needed to assess performance, or set the stage for clinical or programmatic change. Examples of work in this area include:

- Ontario Renal Network's high-intensity end-stage renal disease patient prediction model for explaining drivers of inpatient costs during first year of dialysis;
- Regional analysis of wait times for Alternate Level of Care patients; and,
- Analysis of the types of symptom issues experienced by lung cancer patients.

Strategic analytics are also used to anticipate future outcomes of potential clinical or planning changes and to inform decisions, while recommending the best actions for future performance. Examples of information assets in this area include:

- Ontario Renal Network's planning model to estimate future inpatient dialysis, outpatient dialysis, equipment and infrastructure needs;
- MRI capacity assessment models to determine how to allocate scan hours to improve wait times; and
- Pain models to flag cancer patients for referral to symptom management services.

TECHNOLOGY

CCO manages a diverse range of digital assets and the technology required to operate and support them. Examples include:

Cancer Services

- *My CancerIQ* is an evidence-based online cancer risk assessment tool, developed through a collaboration between the MOHLTC and Cancer Care Ontario. *My CancerIQ* empowers Ontarians to assess their own personal cancer risk and receive a personalized risk assessment and action plan with tips and resources to lower their cancer risk and live a healthier life.
- *InScreen* enables the acquisition, integration and use of data to support Ontario's colorectal, breast and cervical cancer screening programs. *InScreen* receives as many as 250,000 cancer screening results per month from private laboratories across the province and from more than 180 Ontario Breast Screening Program sites. *InScreen* matches the screening results with several data sources from the MOHLTC (including demographic, physician and claims information) and integrates the data to establish an electronic screening record for almost 8 million Ontarians.

Renal Services

The Ontario Renal Reporting System provides the Ontario Renal Network with a foundational data reporting system, enabling measurement and funding of chronic kidney disease programs across Ontario. This information system captures all advanced chronic kidney disease, acute dialysis and chronic dialysis patients in the province and is integrated with hospital electronic medical record systems. This data (over 200 data elements) enables the Ontario Renal Network to measure and report in real time on renal care performance, patient outcomes and expenditure for over 25,000 active patients. Nearly 90 percent of funding for patient care is allocated using the Ontario Renal Reporting System ($500M+ annually), using a patient-based funding model.

Access to Care

The electronic Canadian Triage & Acuity Scale (eCTAS) aims to improve patient safety and quality of emergency room care by standardizing the application of Canadian Triage & Acuity Scale guidelines. The Canadian Triage & Acuity Scale helps define how long a patient can safely wait to see an emergency room physician. This five-level triage scale was designed to ensure that the sickest patients are seen first. However, the 2010 Ontario Auditor General's report noted that there is a lack of consistency in assigning Canadian Triage & Acuity Scale levels and a lack of clear accountability in ensuring standardized application of the guideline. In 2015, the MOHLTC announced that CCO will develop and implement an electronic solution to improve patient safety and quality of care by standardizing how Canadian Triage & Acuity Scale guidelines are applied in Ontario hospital emergency rooms.

CHALLENGES & OPPORTUNITIES

For Ontarians, health is about more than the care they receive from providers. It is about living a healthier life, avoiding getting sick and learning to manage illness when it happens. The fragmented state of Ontario's eHealth infrastructure makes access to information for patients and families a major challenge. It also presents a significant barrier in establishing a structure of clinical connectivity for healthcare providers, linking together patient and broader healthcare quality information in meaningful ways.

Currently, there is significant variation in the information management/information technology maturity of Ontario's digital health assets and the capabilities of healthcare providers to use these assets. This variation is a result of many factors including funding, human resources, support for the ongoing maintenance and evolution of the assets, and time required to build and maintain the data infrastructure to connect to provincial health system improvement initiatives. Addressing these challenges would enable the development of a more integrated health system, resulting in consistent high-quality care across the province.

The following recommendations represent a set of initial steps that should be considered for improving the capabilities that currently exist within Ontario's health system.

Advancing Provincial Architecture and Standards

Harmonization and expansion of the electronic architecture and standards work currently underway within the province is a fundamental requirement for the future. The province's eHealth Blueprint (2015) provides a future state, high-level electronic health record focused view for Ontario. Solving the complex problems of our health system requires tackling many components, but starting with electronic health records makes most sense. However, each electronic health record covers only one component of the "continuum of care" (e.g. family doctor, hospital, community care etc.) and so there will remain a need to advance standardization of data in the broader health system. Integrating data from primary care, community care, and mental health and addictions agencies will reinforce the province's commitment to patient-centred care.

CCO acknowledges that there must be a balance of innovation and design freedom within the bounds of a shared architectural vision for the province. This vision should include capabilities to support health system decision support, use of data for purposes other than as originally collected and intended (secondary use), as well as research and innovation. A common architecture vision, aligned with industry best practices and reflective of the needs of the broader healthcare sector, would accelerate advances in the integration of digital assets and improve efficiencies by reducing duplication.

With this standardization, CCO and all other agencies and providers could develop the strategic partnerships that will both lead to the efficient integration of our digital assets and allow us to better carry out our individual mandates in support of our health system. To ensure the architecture is effectively applied, it would be beneficial to institute an architecture governance board led by the MOHLTC with representation across the health sector and province. Additionally, there would need to be a strategy to support adoption and ensure compliance and adherence, perhaps through linking adoption to information management/information technology infrastructure funding. By having one unified system-wide architecture vision, opportunities for better system integration will soon become evident which in turn will lead to efficiencies, system-wide performance improvement and therefore greater value.

Provincial Data Standards and Integration

A second opportunity exists to expand and accelerate the work being done within the province to integrate data. This includes the establishment of data standards, adoption of consistent management practices, and the promotion of and ability to share data. eHealth Ontario has established standards to promote interoperability between electronic health record solutions. However, the standards are limited in scope, do not address use of data for alternative purposes and are not collectively adopted. These variances have also made it difficult to share and integrate data; this impacts the quality, timeliness and use of data within the province.

A key to improved data integration is addressing challenges with data sharing. Currently, Ontario's healthcare system has a siloed data environment in which there is duplication in data collection tools, data repositories, data practices (such as data quality assessment) and data sets. This fragmented approach leads to inefficiencies and risk in the quality and integrity of data which in turn can affect the quality of decision-making. There is a significant opportunity to capitalize on recent work done by the Government of Ontario on data integration to build a robust and consistent health system data management approach and platform. Exploring opportunities such as leveraging the electronic health record repositories and/or creating a "data commons" to facilitate the flow of data for reuse could enable the centralized application of privacy and security controls (such as de-identification). It could also allow for the enrichment of health data with other data such as socio-economic or environmental data, which may lead to new insights regarding population health and the utilization of health services.

Finally, while privacy, legal and security requirements are essential to protect and govern the use of personal health information, a review of the current legal and privacy frameworks may uncover opportunities for sharing data in a more timely and efficient manner, resulting in better and broader use of Ontario's data assets.

Provincial Technology Integration

A third opportunity is to accelerate the work being done within the province to integrate technology. Significant effort and resources have been invested in the development of an electronic health record. However, these systems must be integrated to facilitate the extension of that record across all care settings. CCO's patient advisors continually provide feedback regarding frustrations with the lack of coordination of care in our health system. Much of the deficit in coordination can be attributed to the lack of technology and data integration between primary care, specialists and hospitals as well as home and palliative care. This continues to translate into poor system performance, often in terms of duplication and/or delay of services. The lack of integration has also led to duplication from a technology perspective, as data feeds and interfaces often must be created to meet each specific purpose. This has resulted in increasing demands on healthcare providers' resources to develop and maintain a patchwork of data and technology solutions. There is opportunity as part of the LHIN Renewal and Patients First Act to improve the integration of technology within the province.

As a committed partner and advisor, CCO supports the government's interest in maximizing the value of its digital assets by supporting the changes required to realize a more patient-centred and high-quality approach to care. As together we take a more integrated approach, the true value of those assets to the people of Ontario can be unlocked.