Empowering Ontarians with Their Health Data:

A Five-Part Roadmap to Improve Health While Catalyzing the New Health Economy

October 31, 2016

Context: Ontario's Opportunity to Lead in 21st-Century Healthcare

The digitization of healthcare is well underway. However, it will not have a positive impact on the health, wealth and prosperity of Ontarians—the very citizens who fund this newly digitized system—if they are not in control of their own health information and decisions about their personal health.

In Canada, citizens have a legal right to access and control their health data. They are also increasingly seeking to share that data with trusted third parties outside of the formal medical system (e.g., family members, allied health professionals or health app developers). And yet they currently cannot access or share their personal health data in a streamlined and seamless way (that is, without a really good fax machine!). While there is a global movement to liberate health data to allow citizens to be in better control of their health (*see GetMyData.Org*), Ontario is a laggard in Canada and globally to make this happen in a meaningful way (despite a lot of rhetoric that claims otherwise).

The unique opportunity for Ontario is to **shift from a global laggard to a global leader** in consumer access to health data. This is possible given its (largely) integrated health data sets, its e-health infrastructure and its rich ecosystem of innovative, young digital health companies. Together, these assets can be leveraged to drive both better health outcomes *and* grow the economy. The province has recognized this potential and declared its commitment to providing an accountable, efficient and transparent healthcare system focused on patient-centred care. Similarly, the Ministry of Health and Long-Term Care has prioritized health promotion and wellness, and the creation of a healthcare system that **empowers Ontarians to be more involved in their own health**. Achieving this vision will not be possible if consumers are not cognizant and in control of their own health information, in a context that is relevant to their unique situations.

The Challenge

The value of consumer e-health to the citizen and the broader health system has been universally recognized; and yet historically, Ontario's e-health investments have focused on enabling institutions, clinicians, researchers and administrators to use the data … rather than its citizens. Going forward, the **province (rightly) seeks to establish the conditions and environment required for market-led consumer health innovation to occur**.

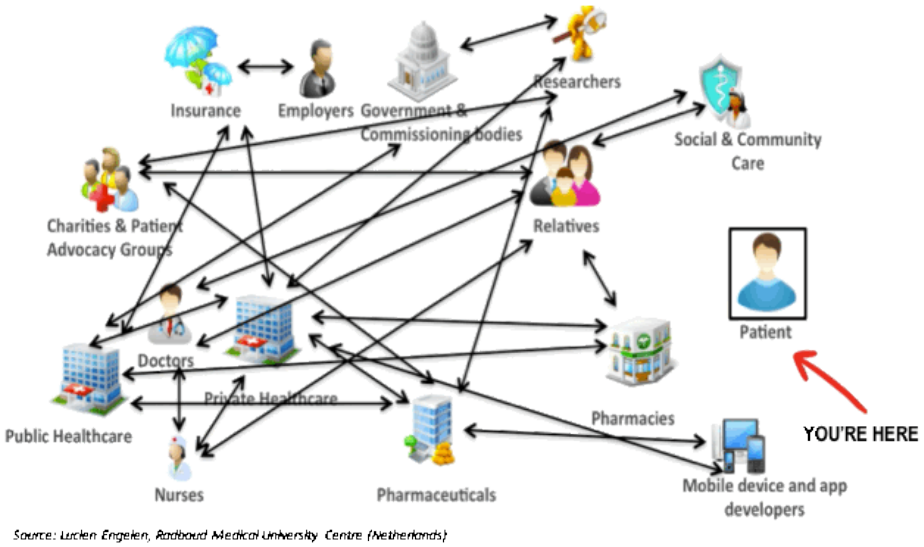
> "*There are some technical barriers [to patient access to their full medical record], but they are not the big problems. The big problems are economic and cultural*." - David Blumenthal, President of the Commonwealth Fund, in *"The Biggest Obstacle to the Health-Care Revolution"* (*The Wall Street Journal*, June 2016)

The roadmap to get there is a lot less clear and is fraught with challenges as it represents an unprecedented culture, capability, methodology and mindset change relative to legacy approaches. The uncertainty and variability characteristic of the consumer e-health space mean that the province would be better served by taking on the role of enabler as opposed to a centralized architect or solution provider (which it had done in the past enterprise-focused model). An effective and efficient approach, consistent with leading jurisdictions globally, would be to focus on putting full control of the data in the hands of consumers with relevant security and privacy conditions in place, while empowering innovators to rapidly build and deploy consumer-relevant solutions via new business models that leverage that data.

The Vision: Ontarians Access *& Share* their data, Empowering Personal Health Choices

This vision translates into a shift.

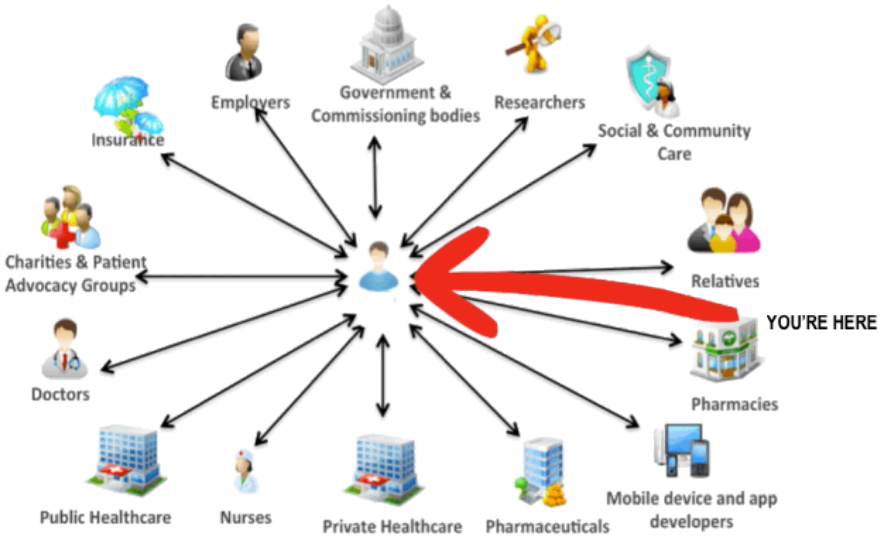
FROM: ***Everyone but the patient gets to see and use their health data***



Source: Lucien Engelen, Radboud Medical University Centre (Netherlands)

Millions of public dollars have been invested in e-health infrastructure that allows internal data connection and exchange, but the tremendous value of enabling the data to be used by citizens, who reside outside of the formal health system, lies untapped.

TO a NEW PARADIGM: Consumer Access + Control



Source: Lucien Engelen, Radboud Medical University Centre (Netherlands)

Access: Ontario citizens have digital access to their entire medical record.

Control: Ontario citizens can seamlessly authorize a third party *of their choice* to access and use their health data to help them make better choices about their health.

Recommendations for Realizing the Vision: A Five-Point Roadmap

1. Access: Give consumers access to all personal health data by default

Implement a mandatory requirement for publicly funded/paid providers to provide access to a standard machine-readable digital record to the consumer after each interaction.

Current state: Consumers must ask for records→retrieve from a records office (often paying a considerable fee and waiting hours or days) → receive the data in paper or .pdf format (usually via fax) → records are often not updated with the latest healthcare interaction → quality/utility of personal health record data is often considered low because it is only a snapshot of time, and often inaccurate.

Future state: Ideally, consumers are in control of their health information, enabling them to do more for their own health:

- Consumers see health records in use, and have confidence in the care delivered and in their own ability to self-manage in the face of health challenges;
- Consumers can check data about themselves and have confidence in the accuracy/quality of the information recorded, acting as the "third line of defense" to audit against errors or omissions;
- Concern about information recall is eliminated – consumers can see what just happened to them and know what they should do next, and this information can accurately be communicated to the individual's informal circle of care and the broader set of formal care providers; and
- Consumer ownership of data is affirmed with their healthcare providers.

Global Precedents:

- *Estonia: Several years ago, implemented full access to all health data by its citizens.*
- *The Netherlands: Targeting 100% access for all citizens by the end of 2017.*
- *US: Meaningful Use Level 2 has mandated that all new EHRs must support the ability for the consumer to "View, Download and Transmit" a copy of their data. By 2015 95% of non-federal acute care hospitals provided at least view access, and over 150 million Americans now have access to their health data. OpenNotes are now operational in 35 states and expanding to the other 15, with >10 million Americans fully accessing their own medical data.*
- *Australia: My Health Record provides a common health record and access for all citizens across all its territorial health systems – the system functions now on an op-out basis due to the realized benefit of ensuring all citizens have access to their data.*

In Ontario the picture is fractured, with an estimated 26 separate hospital and private lab provider portals proliferating and providing fragments of access to different parts of the consumer's record. However, the leaders, such as Sunnybrook MyChart, who thus far have enabled view-only access to hospital patients, have proven it is possible and it has both clinical and patient engagement benefits.

2. Consent: Enable consumers to securely share their data with those they choose

One of the key facets to a healthier Ontario, as described in Minister Eric Hoskins' Health Plan 2.0, is the **creation of a healthcare system that is transparent, accountable and open — one that essentially gives better control to Ontarians over their own health.** Minister Hoskins stressed the need to open up data to transform healthcare and to use the health system to drive innovation and economic growth. It is known that the major drivers of ill health are often best addressed outside the formal healthcare system. Opening access to one's health data can help integrate our social, economic and healthcare systems to balance economic growth, as well as citizen health and wellbeing:

- To reach aspirational performance targets in the health system, we need to enable consumers to connect their data with health solutions that keep them out of the formal health system. Ontarians need

to give the providers of those solutions permission to connect to their formal health data to provide relevant and impactful services.

- To move care into the home and community, we need to enable a seamless experience with a choice of public, private and community providers. Closing the myriad information gaps in these transitions is critical for system effectiveness. With an aging population and the resulting increase in community care and family support, a highly efficient interface between the citizen, their caregiver circle and the formal system will become essential.
- The effectiveness of public health surveillance, promotion and preventative treatments can be better targeted and measured when data is liquid and flows to/through the individual. Healthcare, social, education and employment services can also "wrap-around" the citizens. Consumers sharing their own data can enable this.
- Putting control in the hands of consumers with tangible benefits can bypass issues with enterprise and system deployments – consumers will access their data and healthcare even if the providers' myriad health information systems are not integrated or connected.
- All parties who access the data are logged and auditable by the consumer, including access by healthcare providers. This way the consumer always knows who is – and who is not – seeing or using their data.

Through two years of customer discovery and consultation, MaRS has identified five market-relevant use cases where seamless consumer access to data and smart disclosure to a wider circle of care can have immense benefits to the health of the consumer, as well as that of the health system and the economy. The five scenarios cover the entire 'healthspan' of the Ontario population, from birth to death:

For more details on these five scenarios, please see **Appendix 1**.

There are considerable technical and cultural barriers to overcome, including most notably:

- Accepted methods of consumer identity;
- Standards to allow third parties to easily connect to different data custodians (like *Interac* for banking); and
- Cultural acceptance within institutions and clinician groups.

Fortunately, there are known and proven ways to overcome these barriers.

Global Precedents:

- *The Netherlands: Developed and deployed a blockchain application, in partnership with a national bank, where consumers consent to sharing their medication data with a fully frictionless and secure set of transactions.*
- *Australia: My Health Record enables basic* sharing of health information with family and caregivers – *the patient's real-world circle of care, not just their legal circle of care.*

3. Standards: Set consistent standards for enterprise innovation and scaling pathways

A key enabler for innovation with respect to Ontario's digital health assets is to incorporate clear standards of use, so applications that connect to the data are intuitive and agile enough to adapt in a rapidly changing technology environment.

There must also be appropriate scaling pathways for these assets:

- *Current state*: There is no clarity on what standard an enterprise or clinician-facing application has to meet to deploy and scale across many health institutions. This has led to a fragmented system in which we do not have economies of scale and applications are not intuitive for staff to use. The result is that data is not readily shared across applications, even though infrastructure such as ConnectingGTA theoretically enables this to happen.
- *System change*: There needs to be clear ownership of assets and requirements for access, privacy and security guidelines, in addition to a simplified data-sharing regime and consistent service interfaces.
- *Future state*: Healthcare providers are able to move between applications with greater ease, leading to more effective use and better data exchange, and a much more scalable data platform for consumers to connect into.

Global Precedents:

- *UK NHS has an application standards and approval process that sets out clear criteria for the selection and deployment of enterprise applications. This ensures that applications meet the required standards to be deployed at scale, so that vendors know what is expected and institutions can deploy with confidence. A key enabling reason UK NHS was identified as #1 in the world for outcomes and cost was its ability to deploy health IT as an enterprise transformation tool (Canada lags behind our peers at #10).*
- *US-EU Collaboration on eHealth / Health IT: Since 2012 the US and EU have had an MOU and roadmap for collaboration focused on establishing common standards and building a workforce in health IT. In 2016 the MOU was extended to connecting the continents' major health innovation ecosystems to accelerate innovation and commercialization. Canada and Ontario lack formal partnerships that enable the healthcare system to learn from global leaders, build a robust standards base and the capacity to apply those standards, or provide a global advantage and access point for its domestic health IT market.*

4. Infrastructure: Innovate the process of infrastructure development through collaboration with private enterprise

The tech industry offers deep expertise in the deployment of infrastructure services at scale that the province can draw upon to create the enabling infrastructure for the vision of 100% Ontarian access to one's health data:

- The current data exchange and core data assets of eHealth Ontario architecture are struggling to scale given the difficulties of building on what is now legacy technology put in place for exclusive access by selected healthcare professionals, not for patients or consumers.
- The design of core infrastructure and protocols will benefit from a new vision and modern technology that has the assumptions and needs of patients and consumers at its core, purpose-built for sharing, extension and collaboration, and incorporating strong security controls etc. This means considering mobile-first, cloud-based storage and computing, blockchain and other relevant technologies.
- It will be critical to establish a more open and frequent dialogue with a broader set of innovators, thought leaders and vendors of all sizes during the early stages of procurement and infrastructure design activities.
- The approach to digital health system design, development and deployment should take a more Lean Startup approach, which incorporates joint prototyping as part of an innovative procurement process.

- The utility of universal, affordable high-speed wireless access is a critical component in our health system, public infrastructure and economy; yet Canadian wireless service rates are consistently the highest amongst comparable nations. Concrete action toward change, undertaken with the federal government, will be a necessary enabler.

***Global Precedents**:*

Successful examples of this approach to joint infrastructure creation between governments and industry include the US, where tech CEOs routinely advise on how to execute on major infrastructure plays, and cities that partner with and bring technology communities in (e.g., the Health and Human Services IDEA Lab).

5. Platform for Innovation: Back digital health products and services that demonstrate impact to help grow consumer demand and advanced analytics

With the data-sharing standards and infrastructure laid out above, the final plank of the vision can be put into place. The province can work with leading designers, startups and citizens/families to provide access to the platform and fast-track the shift to the new paradigm. This will tangibly place consumers at the centre and in charge of their own health, thereby demonstrating real benefits:

- The Ministry is committed to a patient-centred healthcare system, but it is difficult for our healthcare institutions to overcome decades of culture and behaviour that is oriented around the system and physician. A consumer-centred and consumer-driven health information ecosystem can help change that, with a platform for compelling products and services to be built based on personal health data that consumers want.
- Most consumer products will likely require less than 20% of the currently available clinical datasets. Providing access for consumer products will require less, but the impact of these products could be much greater. Features and requirements important to consumer products will be different than EHR/EMR and other clinical products. It would be a critical mistake to build consumer access in the same way as building access for healthcare professionals. Consumer access should be designed and built in parallel with current interoperability and EHR/EMR systems connect-up efforts, leveraging shared resources wherever possible.
- New consumer-generated data sets (from fitness applications and other devices and programs supporting health and wellness outside the formal system) can be integrated with institutional and provider-sourced data sets to enable robust health system utilization and population health research, as well as the establishment of always-on surveillance systems. The existence of a comprehensive library of accessible health data will lead to new insights from advanced analytics for researchers, administrators, clinicians and policy-makers.
- Over time, pay-for-data-access business models can be designed and tested that could include individual remuneration for data-sharing. This will require that critical components be built to support seamless commerce and payment. While current EHR/EMR systems are designed to support the mission of individual healthcare providers to achieve health outcomes for their patients, realizing a flourishing digital health marketplace would require incentives for data custodians (and citizens) to provide and continuously improve access to data.

Global Precedent:

In partnership with the NY Digital Health Accelerator, New York State created a platform for market solutions that allows innovative tech companies to connect to state digital health assets via the SHIN-NY dataset.

Conclusion

After decades of investment in building robust e-health infrastructure, Ontario has amassed a foundation of digital health assets that have been used to date for the internal management of health resources and to support clinical decision-making by health professionals. The patient's role in understanding and using data about her own body has been left on the sidelines. Much like what digitization did to bricks-and-mortar retail banking in the 90s, we now have the opportunity to unlock the incredible untapped value from these e-health investments by enabling an entirely new set of uses of the data, one in which consumers are in control. The above recommendations lay out five steps for achieving barrier-free access to one's own health data and control over the sharing of that data. Consistent standards and infrastructure partnerships with private industry will leverage expertise to ensure that digital health assets can continue to seamlessly evolve with external, system and technology change. Together, these recommendations provide a roadmap to 21st-century healthcare that will lead to better health outcomes and a thriving health economy in Ontario. Five concrete examples of relevant market situations could be a logical starting point for getting the vision operationalized quickly.

For further reading, see MaRS' curated literature on the topic of citizen-owned health data: *https://pressly.com/marsdd/landings/search?q=%23patientowneddata*

Appendix 1: Five market-relevant use cases for citizen access and control over their own health data

Scenario 1 – Healthy Moms and Babies

Enable new mothers to effectively track a diverse array of metrics associated with their baby's and their own health.

Value	Mothers with greater control over the health and wellness of their newborns
Dataset(s)	• Baby vital stats • ODSP data • EHR data • Immunization information
Impact	• Changes to number of postpartum visits • Child vaccination rates • Breastfeeding rates and duration
Candidate Partners*	• Children's Hospital of Eastern Ontario (CHEO) • Ontario's Better Outcomes Registry & Network (BORN) • Immunize CA • Bridgeable

Scenario 2 – Youth Mental Wellbeing

Proactive health management in support of university students at a critical life-juncture to maintain mental and physical health.

Value	Long-term student health through interventions at a critical life stage
Dataset(s)	• Campus clinic health data • Family history • Health product and service usage
Impact	• Student stress levels • Change in student weight • Prevalence of STIs
Candidate Partners*	• York University • NexJ Systems • Lawson Health Research Institute • InputHealth

Scenario 3 – Workplace Health

Support employers and employees in maintaining workplace health and wellness by helping employees better self-manage their health.

Value	Boost employee productivity and wellness by promoting better self-management of health
Dataset(s)	• Engagement scores • Activity levels • Family history
Impact	• Workforce longevity • Rates of time off work • Prevalence of chronic disease and/or depression • Insurance claims
Candidate Partners*	• Loblaws/Shoppers Drug Mart • Revera

Scenario 4 – Healthy Unwell

Promote self-care and chronic disease prevention in vulnerable communities by activating a wider circle of care and providing the necessary personalized information and tools.

Value	Implementation of a preventative approach to chronic disease management
Dataset(s)	• Formal clinical datasets (e.g., cGTA, CHRIS, etc.)
Impact	• Changes in patient health (BMI, etc.) • Average number of hospital visits
Candidate Partners*	• Black Creek CHC • NexJ Systems • InputHealth

Scenario 5 – Dying Well

New model of end-of-life care that enables aggregation of an individual's health data and puts it into the hands of the patient and home care provider

Value	Facilitate bridging of the gap between policy prioritizing palliative care and implementation of these goals
Dataset(s)	• Formal clinical datasets (e.g., cGTA, CHRIS, etc.)
Impact	• Changes in number of hospital visits in terminal phase of life • Location of death (i.e., home or clinical setting)
Candidate Partners*	• Saint Elizabeth • QoC Health • InputHealth • Lawson Health Research Institute

*Note: Indicated candidate partners are at different stages of confirmation.