



WHITE PAPER

Feeding the digital health revolution:

How government can help small private companies transform health care in Canada

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Introduction

Hundreds, if not thousands, of small private companies are currently engaged in the development of digital health technologies, which will revolutionize health care in Canada, improving health outcomes, and reducing health costs. Recognizing the value of these innovations from an economic perspective, the government is already assisting these companies with various funding programs – an invaluable resource. But there is a further way that government health ministries and departments can help these private companies to succeed in their health care missions, by facilitating access to relevant data for development and testing.

This white paper presents some thoughts from MEDIC, the digital health research and development team at Mohawk College. MEDIC predominantly serves small to medium private enterprises, and the thoughts in this paper represent needs that MEDIC finds to be common across all of their clients.

1

The role of data in health care

The most important resource in the delivery of health care is people; the doctors, nurses, personal support workers and other practitioners providing care, and the patients themselves. Then, practitioners need the equipment and supplies, including pharmaceuticals, and the spaces, to perform their delivery. After that, we would argue health data is the most important resource. Without health data the effectiveness and efficiency of health care could be severely compromised. Diagnoses and actions would be based solely on what can be seen in front of their faces, right now. Equipment and supplies needed for treatment would not be available. Operating theatres would not be booked or cleaned. And so on.



It is critical for the right data to be delivered to the right people, at the right time, in the right place, perhaps more so in health care than in other industries; what happened to an individual yesterday can be critical to health decisions made today.

Of course, everyone connected to the healthcare system, including patients, knows this. But access to the right data is often a challenge in the current system. Key patient data can be imprisoned in institutional databases, such as clinical or hospital electronic medical records (EMRs), and not easily shareable across institutions to the point of need. This is significantly exacerbated by the widespread use of faxes for transmitting health data across the

health system. Governmental health organizations are working to centralize data through records such as laboratory test databases, drug databases, and the various Patient Summary efforts being pursued. These are all important, but we are a very long way from where we should be. Ask anyone dealing with a health condition requiring consultations across multiple hospitals or clinics: data is not shared between physicians, hospitals make patients request and sometime even pay for their data, data is out-of-date, and more. Consequently, patients often have to take charge of their own data if they are to ensure their health. But the health industry still has an arcane view that patient data belongs to practitioners, not patients.

My-Health-My-Way

One positive element to come out of the COVID-19 pandemic is the growing understanding by the general public that they can have more control over their health. With the health care system being forced to allow physicians to practice telehealth, patients encountered a far more efficient primary care experience. The technology for telehealth had been around for years, but the pandemic pushed both providers and patients to use it, making it now ubiquitous. Simultaneously, a larger part of the population became more comfortable with mobile technologies, having been forced to use them to connect with their loved ones, go to work, to shop, and so on. At the same time there has been a rise in the availability and use of consumer health devices, such as activity tracking watches or apps connected to blood pressure monitors, providing feedback on one's own health. As a consequence, there is now a rising swell of people who

want more control over their health and their related health data.

Health care professionals understand that patients having more commitment to their own health has massive benefits. If this commitment can be supported, or even enforced through digital health applications and devices, there will be better health outcomes. For example, digital health apps can be used for managing type-2 diabetes, or monitoring the process of recovery from adverse health events. These applications increase the capacity of the health care system, increase the benefits to patients, and reduce the number of health system admissions and readmissions.

For all of this to be realized, everyone involved in health care, including patients, need real-time access to accurate, up-to-date health data. Public health organizations, including hospitals and other institutions are all trying to make this happen, but so are thousands of private companies.



2

The role of private, small to medium enterprises (SMEs) in digital health innovation

Based on pre-pandemic statistics from the Government of Canada¹, SMEs (1-500 paid employees) are a major force of the Canadian economy, contributing around 52% of GDP, with small businesses (1-99 paid employees) making up over 72% of that. Those small businesses also make up almost 98% of all employers in Canada, with almost three-quarters having only 1-9 employees. Of these, the fourth largest sector is health care, and of GDP generated in healthcare, 85.7% is generated by SMEs.



There are 514,000 small businesses in health care and social assistance, and a further 200,000 medium-size businesses. Obviously they are not all developing digital health technologies, but thousands are, and that number is growing every day (PwC Canada expects digital health spending to more than double in the next 7 years)².

There are thousands of startups and early stage companies who are currently attempting to change the face of health care; from simply fixing supply chain issues or bed reservation systems, to extraordinary breakthroughs in diagnostics or assistive devices. Their founders come from all walks of life: doctors and nurses who have seen failures in the system, patients or relatives of patients who have been victims of the

system, researchers with breakthrough ideas, engineers and software developers who see an opportunity to make a difference. By harnessing the potential of this massive resource, we can significantly expand our country's capacity to address a great number of the challenges in our health care system.

But there are some critical data challenges hindering many if not most of these companies in their missions.



The data challenge for digital health innovators in small businesses

This paper focuses on a key challenge in digital health technology development: access to data for development and testing.

Data is required to:

- Develop insights into the causes of health problems;
- Evolve solutions to those problems;
- Train machine learning algorithms;
- Develop robust interfaces between health systems;
- Test applications and devices;
- Prepare for validation and certification.

This is especially problematic for small businesses. Large hospitals and healthcare networks accumulate a mass of data through their day-to-day health transactions but, in Canada, small

business has little to no such access. This has a number of consequences for health care innovators:

- They must make assumptions during development which, if incorrect, will be costly to fix once the technology goes live and the errors are exposed. This can also lead to lengthy certification cycles, which can bankrupt small businesses before they make their first sale.
- They can miss breakthrough opportunities since they might not fully understand the problem domain.
- Frustrated by the lack of required data, they walk away from problems they are capable of solving – a waste of talent.
- They take their talent to a jurisdiction where there is better access to data, and they don't come back.

3 **How government can help**

Federal and provincial governments currently provide multiple excellent funding opportunities for SMEs. These include outright grants, grants with a required contribution from the SME, employee and student funding, SR&ED, assistance with commercialization and marketing, and more. Without these, there would be little to no development among small businesses. Government has recognized this gap and responded.

But here we are addressing the data challenge, where government can make a huge contribution to digital health innovators with relatively small investment. Further, many if not most of these innovations save lives and/or reduce costs. For example, digital systems that manage post-intervention care reduce readmissions. The following, proposed, small, data investments will likely pay for themselves:

1. Digital health sandboxes
2. Anonymized big data
3. Patient data

1 Digital health sandboxes

An important resource for development and testing is access to a sandbox of representative data. Most health applications do not operate in a vacuum, they commonly need to fetch data from health systems, such as a hospital encounter or a lab test, and/or push data to other systems, such as to a primary doctor's EMR. For the most common systems, being the major EMRs, such as Epic or Cerner, and the major provincial health databases, such as OLIS or DHDR, this access can be very limited during development.

For example, every second innovator working with MEDIC at Mohawk College seeks to integrate to Epic, becoming one of the most prolific hospital information systems in Canada and the USA. Epic provides a free, public sandbox, but it contains a limited set of data which, at MEDIC, has proved to provide little benefit for serious development and testing. Unfortunately most of the major vendors of hospital systems or lab systems do not have the time to deal with small innovators, unless the development is part of a larger hospital project.

An excellent example of how government can help with sandboxes is the MEDIC Innovation Lab. From May 2016 to the start of the pandemic, eHealth Ontario (now

part of Ontario Health) worked with MEDIC to host a public sandbox representing key Ontario Health databases, including the massive Ontario Laboratory Information System (OLIS). The Lab was hugely successful, attracting developers from 220 organizations, with over 1,500 site visits each month, from right across Canada, not just Ontario. Not only did this assist innovators in developing their interfaces to the Ontario systems, but it allowed them to do this prior to committing the funds required to certify their products for access to the data, through OntarioMD.

Provincial governments should build, or sponsor as was done with MEDIC and eHealth Ontario, sandboxes representing the key provincial systems and databases. As with the MEDIC Innovation Lab, it should be a free resource to digital health innovators.

Additionally, given that big health system vendors are an integral part of the public health care systems, provincial or federal governments should use their influence to have them provide quality, free sandboxes for their systems. Most of these vendors already have their own development sandboxes - they should be strongly encouraged to open them for public use.

If the government or vendor organizations do not wish to host the sandboxes themselves, they can sponsor other organizations to do so, as eHealth Ontario did with the Innovation Lab.

2 Anonymized big data

Analysis of large volumes of health data using advanced data processing algorithms, machine learning and artificial intelligence, has the potential, and is already demonstrating the ability, to revolutionize health care. In simple applications, analytical algorithms can help manage the supply chain of health supplies or access to beds and emergency personnel. At the more complex end, great strides are being made in diagnostics for applications such as detection of cancers far earlier than has been previously possible. The revolution in big data and diagnostics is also propelling us towards precision medicine, where each individual receives a care plan tailored to their unique conditions, including their genetic makeup and predispositions.

A great deal of this innovation is happening in the larger research hospitals, where there is better access to big data. But there are also dozens, if not hundreds, of researchers in small Canadian private companies trying to innovate with big data. **On nearly every digital health project we see at MEDIC, there is a desire by the innovator to develop analytical and machine learning algorithms to extend the health benefits of the application.** The problem is, these smaller companies typically do not have access to the data they need to support their research, development and testing.

Provincial health organizations have this data. Ontario, for example, built the Ontario Health Data Platform (OHDP), a massive, anonymized base of COVID-19 data accumulated during the pandemic. They have made this data available to Ontario researchers, but unfortunately severely limited its value by placing restrictive conditions on the resulting



intellectual property (IP). This makes this extraordinary data asset practically useless to private companies, who will find it difficult to attract significant investors if they do not have outright ownership of the company IP.

Of course, it is important to manage access to such data to ensure it is used for the right reasons. We would not want the data to be used for unethical purposes, such as identifying relationships between employee attributes and mental health conditions so that employers can exclude people with these attributes when hiring. Committees can be created to manage ethical access, although this could be costly. But there may be an optimal opportunity to use Research Ethics Boards (REBs), which already exist to assure health ethics in research.

We must also recognize the right of patients to exclude their data from use in big databases. Many will refuse because of fears that the data will not be truly anonymous and will be misused. But many more will allow their data to be used for research. We cannot focus on those that choose to exclude their data as being the primary reason why we should not seek to build big data sets for innovation.

Related to this, data must, of course, be truly anonymous. There is a fear of data being reverse-engineered, and this can



happen if the anonymization process is not well done. But, again, technology can be part of the solution. We can and should build artificial intelligence technology to test the anonymity of data before it is released for research and development.

What is important for government is to recognize that they *must* provide big data to private companies, unencumbered by IP constraints. The focus must be on achieving this objective, ethically and securely, rather than on reasons why it shouldn't be done.

3 Patient data

A significant problem in the current health care system is the excessive fragmentation of patient health data across institutions and practitioners. Anyone who has had to deal with multiple physicians at different locations will tell you how difficult it is to get up-to-date data into the hands of their health care practitioners. This is a very frustrating issue for patients and their caregivers.

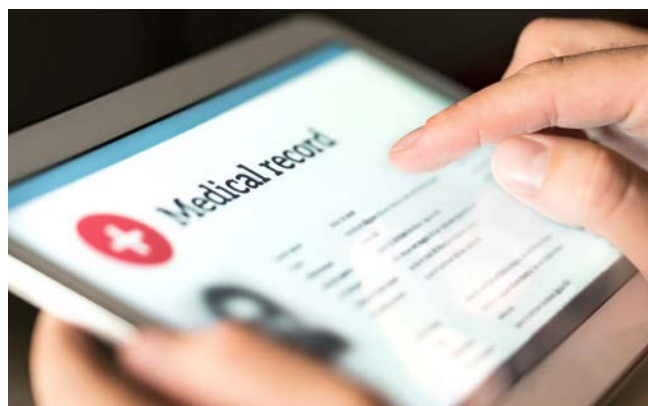
Hospitals and other major (and minor) health institutions are aware of this, and they are all trying to solve the problem as best they can within the confines of privacy legislation such as PHIPA. Unfortunately, this tends to limit the sharing of data to entities who already network, and is not practical for communicating with specialists and others who are not a regular part of the network.

Governments are also trying to find solutions, such as federal and provincial implementations of the International Patient Summary standards, which will be a big health care asset when they are eventually implemented.

Private company innovators are trying to build interfaces between digital solutions across the full spectrum of digital health. But they too are confined by privacy legislation, along with the other data access problems noted before.

However, there is a window of opportunity afforded by the rising swell of people who

want to have more control over how they interact with the health system, noted earlier as one of the positive outcomes from the pandemic. As part of this *my-health-my-way* wave, people are beginning to demand access to their own data. By facilitating this, instead of having to rely solely on the health institutions to connect with each other, health care systems will now have another source of critical data, the patients themselves. In the current fragmented system, physicians often rely on their patients for health data, but commonly patients do not have it, or do not have the complete picture necessary for physicians to make the right decisions. But if patients have complete electronic data provided to them, they can be a more effective part of the health data process. This does not require major changes to privacy laws as patients currently have a right to their own health data. Of course, we must strongly encourage health institutions to continue their journeys to connect and share data – this is more effective than relying on patients. And we must also bear in mind that a large portion of the population will not take charge of their own data, for many reasons – this should not exclude them from equitable access to health care.



There is a particularly egregious inhibitor to sharing of data across institutions and with patients - the widespread use of faxes across the health care system. Transmitting data through a fax destroys any reasonable opportunity to share that data efficiently and effectively. The reason given by those who insist on faxing is that faxing is more secure – this is misleading. While it may be true that, during the transmission stage, a fax is more secure than an unencrypted email, this is the only thing that is true. Fax machines can be hacked and their data accessed before or after encryption. Many, if not most, organizations do not actually use fax machines but instead use software for sending and receiving, with many of the inherent insecurities of email. Where physical faxes are used, the paper they are printed on lies on the fax machine and then in an in-tray before being processed, open to all the world to see. In a small clinic, the person entering data from the fax into the clinical EMR is often the receptionist, where the faxes may lie in an in-tray in full view of the general public. And large hospitals are reporting multiple privacy infringements directly related to the use of faxes.

So, with respect to feeding the health care digital health revolution, government needs to move aggressively to eliminate faxes from the health care system as soon as possible; by the end of 2023 seems like an achievable deadline.

To accommodate those who want to take charge of their health data, there should be a **requirement** (i.e. legislation) for all hospitals, clinics and other health institutions to make data available to patients *in any form that the patient wants it*, including email. This will require investigation into secure methods of providing data, including encryption which can make emails and their attachments more secure, and patient portals. There will need to be changes to processes to have the patient understand and accept the inherent risks of electronic communication. Many may not find the risk acceptable, in which case they should still be able to get their data printed, for free (some hospitals have been known to charge patients for their data!). The same applies to those who don't have or want a technology solution. On the other hand, if a patient is happy to have their health data provided through an unencrypted email or a text, who has the right to refuse that?

How will this help the health care system and private innovators?

The more access people have to their own data, the more they will seek applications to help them with their health care. Thus, innovation; and there are masses of innovators who will step up and develop related solutions. And, when people are involved in their own health, they tend to have better health outcomes – a win for the health care system too.

Summary

The Canadian health care system is in crisis. Digital health technologies can be part of the solution. There are thousands of small private businesses in Canada seeking to innovate digital health technologies that will make a difference. To succeed, they need access to patient data, for development, for testing, and for implementation.

The government can help by:

- Sponsoring sandboxes of representative health data.
- Pressuring key third-party system providers to provide relevant sandboxes.
- Providing big data databases of anonymized health records for data analytics and machine learning, with relevant access controls, but no restrictions on IP.
- Requiring health organizations to provide data to patients any way they want it.
- Eliminating faxes from the health care system.

Then stand back and watch the private sector innovate solutions for health care!



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