Plans for e-Health raise huge threats to privacy for Canadians

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Depression, infertility, cancer, addiction, abortion, erectile dysfunction, HIV/AIDS -- whatever our health issues, Canadians value the right to choose who they share intimate health information with. This right is now under threat. "E-Health" is coming.

E-Health will create a giant system of electronic health records that will eventually be accessible across the entire country. These government repositories of citizens' health information are promoted as likely to make health care safer, cheaper and more efficient.

But there's little evidence to support those claims. To the contrary, there is growing evidence that these systems are costly privacy night-mares that undermine even the most basic trust in patient confidentiality.

In a technological age, no one seriously argues that medical information should be recorded only on paper. Electronic health records can have benefits, including the ability to quickly send information to other health care providers who need it for your care. But e-Health isn't a system of sending (pushing) electronic information from one health care provider to another. E-Health pulls information from every health care provider into a giant data distribution system available to tens of thousands of people.

Governments have a terrible track record of safeguarding information on a single laptop, let alone huge concentrations of valuable, highly sensitive data that will attract sophisticated hackers and criminals and be available through thousands of access points.

We are told that the $5 billion (yes, that's a "b") that we have spent on e-Health nationally will pay off in patient safety. The typical examples are of emergency room staff accessing medical records of someone who arrives at ER unconscious. But, a simple medic alert bracelet conveys critical information faster and for almost no cost , and ERs already have access to all our prescription information through PharmaNet.

We are told that the system will save money by creating efficiencies. But when pressed, even Canada Health Infoway, which exists solely to promote the development of centralized electronic health records, admits that most economic benefits are assumed and not proven.

We are told that Canadians support e-health and yet only 33 per cent of Canadians find it very or somewhat acceptable to have some (core) clinical data from a patient record stored and managed by local regional health authorities or agencies.

And here is just a little of what we are not being told. In the words of one renowned security expert, billions of dollars are "being wasted on gigantic systems projects that usually don't work, and that place citizens' privacy and safety at risk when they do."

In the U.K., a pioneer of e-Health, more than two-thirds of the population no longer trust the government with their personal information, after tens of millions of records have been lost or compromised and the prime minister's own health information was illegally accessed and given to the media.

Privacy protections in e-Health systems have an alarming tendency to be here today and gone tomorrow.

E-Health in Alberta started out with promises of patient consent and the ability to keep certain medical information from being generally accessible. Where did everyone's health information go? Into the government databases. And where are the promises? Gone.

In B.C., we don't even really know what our government's "promises" are. B.C.'s e-Health law gives us a vague, unspecified ability to limit who gets to see our medical information by use of "disclosure directives," but we don't know what that means yet because the government hasn't said. It may not mean very much, and even if it does, it may not last long.

A 2007 Canadian Medical Association survey showed that 11 per cent of patients already admit to holding back information from health care providers because of privacy concerns. Without trust, we can't get proper health care. Trust is going to erode even further in the e-Health system. Some people will not get the testing and the treatment they need because of it.

Citizens have been told shockingly little about e-Health. Government is certainly not widely advertising the fact that e-Health is going to be part of a much larger government information-sharing project. Bureaucrats call this the "Information Access Layer" and acknowledge that it will link e-Health data to a vast array of other government ministries.

No one should be afraid to go to a doctor for fear of where their health information will end up. And yet there is real reason for concern. A proper e-Health system must be built on informed consent, and anyone who participates must be able to decide for themselves what information gets shared with whom.

We can reap all the benefits of technology that are needed to improve our health care system without giving up our fundamental rights to privacy, respect, consent and confidentiality. But it won't happen unless we demand it. To start demanding, see: bcoptout.ca.

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