


HEALTH CARE'S EPIC FAIL



The federal government promised to give every Canadian an electronic health record. Eleven years and \$2 billion later, we're still waiting. Lives are hanging in the balance.

PAUL WEBSTER

Last winter, Judith Morley's survival hinged on a sheaf of dog-eared computer printouts. The 58-year-old Thornhill, Ont., resident had booked a trip to Mexico with her sister to celebrate her successful treatment for rectal cancer. But during the flight she developed severe abdominal pains. She was assisted from the plane after landing in Baja, and whisked to a private hospital in the area.

Staff, at first, were stymied. "They were unsure what to do with me," Morley says. Suspecting a blocked or burst intestine, Mexican doctors began to discuss surgery.

Alarmed, Morley told the doctors about her cancer and pulled her latest health records out of her handbag. She then provided an Internet address that held even more detailed information. After poring over her

online chart, hospital staff learned all they needed about Morley's complex medical history. They reached a correct diagnosis for her pain—intestinal blockage, best treated with medications via IV—and opted against an unnecessary operation that might have had tragic consequences.

Morley's electronic records—which she suspects saved her life that day in Mexico—were made available via MyChart, a website launched in 2006 by Toronto's Sunnybrook Health Sciences Centre. Through the site, patients can retrieve lab results, ultrasound images and MRIs, and track prescription refills. They can set up appointments and email their doctors. Patients can also grant access to anyone they choose, including outside physicians, pharmacists and family caregivers.

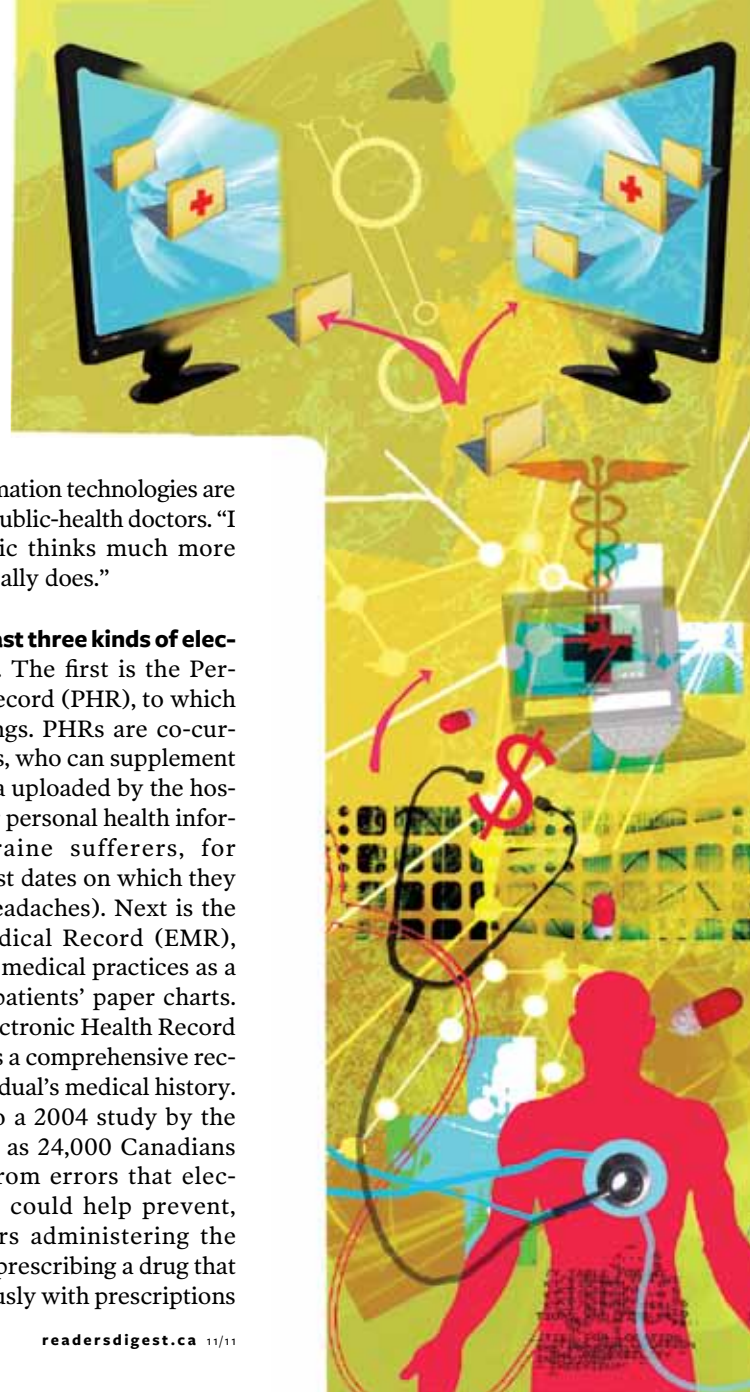
MyChart's popularity—the site has 15,000 registered users—isn't a surprise to Sunnybrook staff. "Critics warn that patients may be overwhelmed by too much information," says Dr. Andy Smith, the cancer surgeon who treated Morley. "But that's offset by the positives—patients who are informed and empowered."

With the Internet revolution now nearly two decades old, electronic links between patients and health-care providers such as those available at Sunnybrook should be widespread in Canada. But that's far from the case. Dr. Brian Postl, chair of the board of directors of the Canadian Institute for Health Information (CIHI), says Canadians are often stunned to discover

that basic information technologies are unavailable to public-health doctors. "I think the public thinks much more exists than actually does."

There are at least three kinds of electronic records. The first is the Personal Health Record (PHR), to which MyChart belongs. PHRs are co-curated by patients, who can supplement the clinical data uploaded by the hospital with other personal health information (migraine sufferers, for example, can list dates on which they experienced headaches). Next is the Electronic Medical Record (EMR), used in private medical practices as a substitute for patients' paper charts. Third is the Electronic Health Record (EHR), which is a comprehensive record of an individual's medical history.

According to a 2004 study by the CIHI, as many as 24,000 Canadians die annually from errors that electronic records could help prevent, such as doctors administering the wrong dose or prescribing a drug that reacts dangerously with prescriptions



undisclosed by the patient. Another federal study estimates that a countrywide EHR system could shave as much as \$6 billion annually from our national health bill by eliminating the time Canadians spend chasing paper records or redoing expensive tests at different clinics.

Unfortunately, Canadians still have an easier time accessing their bank accounts online than their medical records. To be sure, most provinces have started digitizing patients' health information in some way. Hospitals are also getting into the act. Toronto's Princess Margaret Hospital uses InfoWell, a personalized health-information website, to give breast-cancer patients access to test results, and to help them better interpret information about their treatment. But such a project might as well exist in an alternate universe for the nearly 70 percent of Canadian physicians who still keep records in manila folders, communicate with pharmacists via scrawled notes and use fax machines (long obsolete everywhere else) to share test results with colleagues.

The achingly slow progress of e-health in Canada hasn't been for lack of trying. Ever since federal, provincial and territorial governments began discussing electronic recording-keeping back in 1994, over \$2 billion has been plowed into building a national "infrastructure" connecting

every clinic, hospital and physician in Canada. But this objective, mostly quarterbacked by Canada Health Infoway—the federal agency tasked in 2001 with accelerating the country-wide adoption of health-information

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platforms—has been confounded by technological complications, missed implementation dates and budget overruns. A defining moment of this dysfunction was the 2009 spending scandal that rocked Ontario's eHealth program and led to the health minister's resignation.

Kevin Leonard, a University of Toronto e-health researcher, says the stakes for Infoway's success couldn't be higher. Millions of Canadians suffer from chronic illnesses, such as heart disease and cancer, that demand constant monitoring and consultations with various specialists. "Patients with chronic disease account for most of the public health costs," he says, "and their numbers are rising sharply as the population ages."

As Leonard attests from his own experience battling Crohn's disease, life for chronically ill patients can

become a blizzard of files, referrals, prescriptions and not-infrequent medication mishaps. Without a functioning EHR system that allows data-swapping between multiple doctors, efficient treatment may become close to impossible, especially considering our aging population. The chronic disease tsunami on the horizon risks crippling our medical system.

"Lives depend on our ability to pull together and make the system work," says Leonard. "Our failure to join the information age threatens everything."

The plan seemed simple enough. Give every Canadian an EHR and store it in a countrywide network of massive databases. Each province and territory would house one or more of these "interoperable" digital hubs, which could be safely and securely accessed by health-care providers across the country. The hope was that a senior citizen from, say, St. John's, N.L., who falls sick in British Columbia while visiting relatives can expect his complete list of current medications and drug allergies to be instantly available to doctors in a Vancouver ER.

This vision made each jurisdiction responsible for developing its own EHR strategies, with Infoway paying up to 75 percent of the eligible costs of the approved projects. It was laid out in the 2003 Electronic Health Record Solution blueprint, a document that pledged to "help governments and health-care administrations in

Canada develop and deploy EHR systems faster and at less cost and less risk."

A decade later we still have the pledge, but few results. "It's similar to constructing a building," is how Infoway, in its 2010-11 annual report, explains the fact that it is still building data systems that few doctors nationally actually have access to. "The building must be available before the tenants can move in, occupy and use the space as it was intended."

To the ears of many observers, this just sounds like red tape.

Karim Keshavjee, a Toronto-based physician and e-health researcher, is one of them. Keshavjee argues that Ottawa's obsession with a top-down approach has distracted the agency from working more closely with the provinces, resulting in dramatically lopsided EMR and EHR adoption rates. Infoway anticipated that the provinces would design systems that suit their regional health authorities. Yet a lack of clarity seems to have left each jurisdiction in a guessing game about how to plan and monitor their projects, or fix problems when they arise. Ten years after Infoway assumed control of the EHR project, the results are mixed at best. Alberta leads the country with 70 percent of its doctors using electronic records; Yukon, Nunavut and Quebec, in contrast, lag behind.

Infoway claims it has consulted with hundreds of experts, including medical professionals. Critics say it froze nurses and doctors out of the

early planning stages, and surrendered decision-making to health-care executives without clinical experience. This, critics continue, is reflected in the way the agency implemented its mandate, making patients' health information and history accessible to health-care providers, rather than building links between patients and health-care providers.

"Countries that rank highest on e-health surveys," says Keshavjee, "focused first on getting systems into the offices of family doctors and specialists. There's a good reason for this: Health care is almost always delivered locally." Building a national storehouse of patient information won't be much use to anybody, he says, unless you convince the country's front-line health-care providers—who already store that information on paper—to go digital.

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To get a starker sense of our predicament, we need only look abroad. The New York-based Commonwealth Fund ranked Canadian doctors last among 11 wealthy nations in the EMR adoption rate. New Zealand and the

Netherlands have built electronic health-care systems for a fraction of what Infoway has now lavished on software systems that, as yet, offer little benefit to patients or clinicians on a national level.

Even Belize, a tiny impoverished Central American nation that spends one twelfth what Canada spends per patient, has built an electronic health-care system far more comprehensive than anything yet available in this country—and much of its success is due to Canadian innovators. Dr. Michael Graven, assistant professor of medicine at Dalhousie University, co-designed Belize's national health information system. "Working in developing countries makes you develop lean and mean work habits," he says. "Infoway got very comfortable negotiating among many vendors, with the focus only on software and hardware." The salaries of hundreds of federal e-health officials and computer engineers consume over \$22 million annually—not far from the \$30 million New Zealand spent to connect all its doctors permanently.

In the United States, e-health investments by major institutions are yielding better health care at lower costs—and paint a picture of what a patient-centered EHR could accomplish in Canada. The Veterans Health

Administration (VHA), a government-run system that serves over five million patients, experienced an extraordinary turnaround after adopting EHRs in the mid-1990s. Once saddled with the worst health-care record in the United States, the VHA today is celebrated for its success in keeping illnesses such as diabetes from becoming full-blown crises. This, in part, is due to in-home monitoring devices that measure a patient's vital signs and symptoms round-the-clock. The telehealth innovation harnesses the data in EHRs and allows staff to make timely interventions that prevent expensive trips to the hospital for patients.

Trevor Hodge, an Infoway vice-president, acknowledges that Canada possibly should have taken its blueprint to the whole clinical community earlier in the game and worked harder to consult with health professionals. But Hodge notes that unlike pharmacists, Canadian doctors—particularly solo practitioners—have been slow to spend money of their own on electronic systems. In a 2010 article, Hodge wrote, "Physicians in community practice do not have a strong history of using information technology for clinical purposes."

Unsurprisingly, this rubs many doctors the wrong way. In a recent article responding to Hodge, physician and University of Ottawa professor Dr. Mark Dermer, who served on Infoway's board of directors at one time, notes that doctors have to pay

for the hardware, software and implementation services of EMRs. The investment of time and money is greater than any payback they can anticipate, so the business case for implementing EMRs doesn't exist.

All this might have been avoided, critics say, if doctors had been allowed to drive the process. With only one doctor on the agency's 13-member board of directors, physicians feel they have but a token presence.

Infoway has committed to funding approximately 300 health-information technology projects across the country; planning for about 200 of those projects is complete. It also notes that approximately 50 percent of Canadian hospitals have core elements of the EHR system already in place. And Infoway has pledged to work more closely with physicians. Agency spokesman Dan Strasbourg says that, over the last year, the agency has set aside \$380 million to help physicians acquire and utilize EMR systems, which includes personal training and on-site support. "Physician response to this decision has been positive," says Strasbourg. Dr. Jeff Turnbull, president of the Canadian Medical Association (CMA)—which represents 74,000 physicians—praised Infoway's allocation of the money. "Infoway's initiative shows real commitment to put EMR support where it is needed most: at the front lines of care."

But after all this, Infoway's investment still represents only about 18 percent of its \$2 billion budget. The

rest of the agency's funding is earmarked for large-scale systems.

Graven calls Infoway's "vendor-centric" approach a "clear miss." Graven's experience in Belize has taught him that an easy-to-use and

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easy-to-deploy EHR system needs to be "encounter-centric," that is, focused on the moment of doctor-patient interaction.

If Canada used this as a model, claims Graven, it could design a functional EHR in six months and have it running three months after that. "Those few of us who have been a part of successful deployments—only ten people have been through this more than once, worldwide—know that it is possible to achieve this schedule. It would help if Infoway finally accepted input from people who have actually done it before, rather than exclusively from those that have not.

"Much of what has been developed by Infoway," Graven concludes, "can be retasked to serve the new focus. But it needs to start over again." ■



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