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Medical data debates: Big is better? Small is beautiful?

Canada Health Infoway's plans for highly-centralized electronic health records (EHR) systems within each province containing patient records that can be shared nationwide may not be feasible, a chorus of experts say.

That "shared record" model which Infoway has adopted was in large part discredited and discarded in the United Kingdom, note the critics, who say that inadequate consultation with the medical community has also been a key problem in the development of the system. They suggest Infoway has forged a "Soviet-type" over-centralized approach based on a top-down vision of a "federated set" of "health information data warehouses" with highly centralized access to "shared records" (figure 2, www2.infoway-inforoute.ca/Documents/EHRS-Blueprint-v2-Exec-Overview.pdf).

Infoway's strategy has delivered few, independently-verified benefits to patients or health care providers, and may not even be achievable as designed, the analysts say.

"Massive centralized systems almost always fail," warned Norman Archer, ehealth policy analyst with the eBusiness Research Centre at McMaster University in Hamilton, Ontario, during a Jan. 25 ehealth conference in Toronto, Ontario.

Archer argues that the national ehealth focus should be on manageable solutions serving local patient populations no larger than those in each of Ontario's 14 local health integration networks, or about one million patients, with patient information residing not in massive data warehouses, but "with the family physician."

The idea of "one provincial centre with all the data in it is asking for trouble," he says.

But Infoway rejects the notion that a shared records model is a centralized behemoth that is somehow incompatible with, or antithetical to, sharing of patient information at the physician level.

The model supports both data sharing (obtaining information from a repository) at the provincial or national level and data exchange between clinicians, Kirk Fergusson, Infoway's vice-president, corporate affairs, writes in an email. "The Infoway Blueprint is a conceptual architecture and through the middleware layer — commonly known as the Health Information Access Layer (HIAL) — the architecture supports both data exchange and data sharing,"

"How a HIAL gets physically implemented is often where the confusion starts to creep in. The technology at the centre of a HIAL is an 'integration broker'. An integration broker can facilitate data exchange and we've seen examples of this in practice for the past 15 years," Fergusson adds. "An integration broker with additional services can also allow data sharing. So whether the same integration broker is physically used to do both data exchange and data sharing is a local deployment decision. In Canada today we have situations where in some jurisdictions the provincial integration broker is used for both data exchange and data sharing. In other jurisdictions, especially

the larger provinces, we have the use of two or more integration brokers for data exchange and data sharing. The Blueprint Infoway developed needed to be flexible enough to allow for these regional differences.”

Fergusson adds that from a physician’s perspective, it’s important that Electronic Medical Records (EMRs) serve their purposes and are cost effective. He also notes that repository models are now being effectively used within several provinces to compile clinical drug information and laboratory results.

The international experience with such a centralized approach appears to have been inauspicious.

Trisha Greenhalgh, a University of London researcher who was commissioned to review the UK’s approach to building a national infostructure, notes that there’s been a hasty retreat from the shared record model because it lacked demonstrable benefit; suffered “wicked” problems such as technical glitches and security concerns; and was less likely to succeed than smaller scale initiatives (www.ucl.ac.uk/news/scriefullreport.pdf). In short, she argues, small is beautiful.

“I’ve never yet seen a healthcare IT [information technology] programme in which government has a central driving role where that elementary principle is recognised,” says Greenhalgh, adding that Infoway’s blueprint is in the “same genre” as the UK’s now-repudiated master plan. Such approaches “are likely to be less efficient, less cost-effective, less safe, and the information they contain less trusted than smaller, more local systems.”

New Zealand, using a bottom-up patient-physician approach and a mere \$35 million was able to achieve to craft a far more effective system, Greenhalgh and a colleague recently argued ([Health Serv J.](#) 2010;120:12-3). “In New Zealand, a general practitioner is automatically sent all laboratory results, hospital discharge summaries and specialist letters electronically,” they wrote. “Any healthcare provider with a relevant interest may seek remote access to laboratory reports, discharge summaries and other document-based data from any public-sector hospital in the country. The amount of information exchanged electronically between general practices and other healthcare providers has increased by 33% annually since 2000. Patients can and do access information from a personal health record attached to their GP’s electronic medical record system.”

Archer cites the \$200 million Ontario Laboratory Information System as a prime example of a centralized effort gone awry. “This is a mess that I cannot believe,” he says, noting that it has yielded almost no clinical benefits and that the province’s auditor-general says it’s bedeviled by technical problems (http://69.164.72.173/en/reports_en/ehealth_en.pdf).

Meanwhile, some provinces are already moving to chart a new course. Brenda Jameson, chief operating officer for Saskatchewan Health’s Information Solutions Centre, says the province is developing its own ehealth strategic plan and intends to take control of an issue “that lacked clear ownership.”

While Infoway laid the groundwork for the creation of very large data repositories, without patient data from clinicians “they aren’t much use,” she says. “Throwing more money at this is not necessarily the answer.”

Karim Keshavjee, a Toronto-based physician and ehealth researcher who has provided advice to Infoway on its ongoing efforts to rewrite its blueprint, says the agency

has an old-fashioned “Soviet” approach to harnessing health data, and needs to work much harder to consult with the medical community.

“They should take their proposal for a new blueprint to the whole clinical community,” advises Keshavjee, who frets that money is being thrown “at the wind” in a rush to spend government stimulus money on projects that have not been independently assessed. Under the federal government’s economic action plan, Infoway received \$500 million “to speed up implementation of electronic medical record systems in physicians’ offices, and to develop electronic systems that connect points of service” such as hospitals, pharmacies and community care facilities (www.actionplan.gc.ca/initiatives/eng/index.asp?mode=7&initiativeID=63).

One physician who recently left Infoway’s ranks says privately that a lack of input from physicians is a major problem. With only one doctor on its 11-member board of directors, physicians have but a “token,” presence, he says.

As a consequence, Infoway’s blueprint, the technical plan by which the agency maps national interoperability, “is fundamentally wrong from a clinical perspective” because it puts the needs of patients and physicians last, he says, adding that interoperability should be “the icing on the cake,” not a starting objective. “It’s upside down, They should have started with primary care.”

Fergusson counters that value for clinicians and patients has always been at core of Infoway’s mandate and that physicians have had considerable input. Among doctors who now serve, or have served on Infoway’s board of directors are Dr. Anne Doig, past president of the Canadian Medical Association (CMA), Dr. Brian Postl, dean of medicine at the University of Manitoba and Chair of the Canada Institute for Health Information, and Dr. Michael Golbey, chair of the CMA board of directors.

“We also have standing physician, nursing, and pharmacy reference groups which bring together clinical leaders from across the country,” Fergusson writes. “Their members provide us with valued advice based on their diverse expertise and experience. For example, many participated in our recent ‘Blueprint 2015’ visioning process, helping to shape our future directions.”

“It is also important that we ensure a strong clinical voice within our various investment programs,” he adds. “For example, the Canadian Association of Radiologists and many of its members have been involved in our diagnostic imaging program and we have recruited physician leaders to participate in our work on standards, telepathology, consent directives and e-prescribing. Our programs have also been informed by broad surveys of clinicians and focus groups with direct care providers.” – Paul Christopher Webster, Toronto, Ont. and Wayne Kondro, *CMAJ*

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