



Why Are Doctors so Concerned About Protecting the Confidentiality of Patient Records?

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Trust is the lubrication that makes it possible for organizations to work.

- Warren G. Bennis

Warren Bennis was a leader in thinking about organizations and while his work focused on leadership within organizations much of his thinking can be applied to large scale operations such as the Canadian healthcare system. His observation that trust is the lubricant that makes organizations work is the cornerstone of the healthcare system.

In the world of the physician, trust is at the heart of their relationship with patients. The guarantee that physicians will keep confidential the health information provided to them by their patients and only share it as needed with other providers for therapeutic purposes underscores this trust. Thus patients view their physician as the guardian or steward of their health information.

As patient information gets collected electronically, this raises important questions about the privacy and confidentiality of patient health information [including who should protect it, where it gets stored and who has access to it and under what conditions]. But as we push forward with the IT agenda in Canada and the drive for the health care system to adopt electronic health records (EHRs), the issue of confidentiality often seems to be downplayed.

We at the Canadian Medical Association believe that if implemented properly, the widespread use of EMRs and EHRs will indeed lead to better care.

But there are caveats, one of most important being the inherent contract between doctor and patient to protect the privacy and confidentiality of patient information. Physicians have a proven track record of managing sensitive health information, which is why they feel an obligation to speak out when they have concerns that what is going on in the health care system might imperil this confidentiality.

Physicians are concerned about the potential erosion of trust. Physicians in other nations have recently been quite vocal in expressing concerns about approaches taken for building EHR systems that focus on creating central data storage of patient records.

In the U.K. at least two recent polls of doctors found that more than 80% have no confidence in the government's ability to safeguard online patient data stored in a central database. The same is true in Germany where an overwhelming number of physicians are calling on the German health ministry to halt all plans for centrally-stored electronic patient health records because of potential risks to patient confidentiality.

Closer to home, similar concerns are raised by the ever-growing number of reports of breaches in security of systems designed to protect patient data. It's the same reason so many Canadians feel uncomfortable when the issue of electronic storage of their health data is raised. The CMA has made clear statements about the need to protect patient confidentiality. Guiding principles for physician EMR adoption recently passed by our board state that "patient data must always be collected and stored in an EMR with the primary goal of improving individual patient care. Data accessibility for clinical care is more important than compiling a large common data set."

These views are strongly supported by what the Canadian public wants.

Polling conducted by Ipsos Reid for CMA in 1999 and 2004 found the majority of Canadians trusted physicians to keep their health information confidential, supported the release of their health information with consent and preferred to have their physician act as data steward for

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their health information. A more recent poll, conducted last year, showed little change in these views.

The 2007 survey shows the majority of Canadians (85%) still trust doctors to keep their information confidential and share it appropriately with others. This is up from 74% in 1999. The majority of Canadians (74%) also believe their consent should be sought before releasing personal health information and just over half (51%) remain concerned even if non-identifiable (i.e. anonymized) health information about them is released without their consent.

Consent remains a critical component for sharing health information and the CMA believes that appropriate consent mechanisms must be built into the design of healthcare databases and electronic medical record systems to ensure patients remain confident their information is properly protected.

Where information is stored and who manages it are also key privacy considerations for the public.

Almost three-quarters of Canadians (74%) feel it is acceptable if they consent up front for their physician to provide electronic access to their health information to other physicians for the purpose of diagnosis and treatment or in situations such as an emergency room. A similar percentage (72%) also feels it is acceptable if a patient's personal health record is stored and managed by their physician with no information released without the patient's consent.

However this percentage drops dramatically to 33% if asked whether they find it very or somewhat acceptable to have some (core) clinical data from a patient record stored and managed centrally by local regional health authorities or agencies. In addition, fully three-quarters of those surveyed feel there are parts of a patient record that should not be seen by third parties such as governments, researchers etc.

As is clear from these findings, the public is very concerned about protecting the confidentiality of their health information. Equally importantly, they are willing to see this information shared if proper consent is obtained.

At the CMA we are concerned with the current trends towards the collection and storage of patient data without appropriate policies and safeguards being in place that satisfy patients and physicians. And the growing interest to access patient information stored in EMRs and EHRs for secondary purposes such as research is also of concern. These trends are becoming so prevalent that the CMA is currently re-evaluating its privacy code to ensure it adequately protects patient confidentiality while ensuring appropriate secondary use of this type of information.

With explicit patient consent and proper safeguards, electronic storage of patient information can indeed help improve health care in ways that are impossible with a paper-based system. But to physicians the care of the patient always comes first.

Lest individuals feel that I am overstating these concerns our 2007 survey showed that a disturbing 11% of patients admit to holding back information from a health provider because they are concerned about who it will be shared with – a practice that can seriously compromise their care. The best care can only be provided if the practitioner has all the information they need and that will not be the case if patients do not have trust in the system to protect their information. Without listening to patients and respecting their views we risk eroding the cornerstone of trust that makes our system work so well.

For physicians, protecting patient privacy remains a clear priority and the CMA has been at the forefront of ensuring that technological advances do not impinge or endanger the privacy of that information. Careful stewardship of sensitive health information protects the privacy of patient information and preserves and even enhances the patient-physician relationship.

These are important messages for government and health stakeholders to keep in mind when making decisions on privacy legislation and local or pan-Canadian electronic health record initiatives. ●