Patient records should belong to patients

The Editorial Board

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Here's a revolutionary idea. Patients should have access to their personal medical information by default. Not after they make a specific request for it, potentially wait up to 30 calendar days for a response and possibly pay a fee for a copy of the records, as currently set out in various iterations of rules across provinces.

By default means that when you go for, say, blood work, it's guaranteed that you, along with your doctor, will get a copy of the test results for free, in a timely manner and convenient format. The fact that this is a novel concept is a problem.

Canadians have right to access their medical records if they wish to, with limited exceptions, according to a 1992 Supreme Court decision.

Enabling patients to see their own information, the court noted, helps to ensure "the proper functioning of the doctor-patient relationship," both strengthening the trust in that relationship and protecting the well-being of the patient.

Yet more than three decades later, being able to exercise that right often remains unnecessarily arduous.

Only four in 10 Canadians currently access their health information electronically, <u>recent data show</u>. And sometimes patients or their authorized caregivers must resort to <u>filing an access to information request</u> to get their own or their family members' full medical records. This is simply unacceptable – and a symptom of the broader issue with how Canada handles medical records.

The system treats doctors and other health care providers as custodians of the patient information that they collect or receive. Sensibly, that role comes with strict obligations to protect the records to ensure patients' privacy. But there generally aren't equally strong obligations to share that information where appropriate.

For example, a doctor in Alberta may face a fine of up to \$200,000 for violating the province's health privacy law. But a physician faces virtually no consequence for failing to share information when needed, <u>a recent report found</u>.

And while sharing information is easier in the digital era, this framework has bred a system in which different bits of a patient's electronic record are held by different health care providers on a multitude of platforms that often can't communicate with each other. And that's not to mention cases where information and medical images are still sent by via fax or <u>downloaded</u> <u>onto a CD</u>.

This fragmentation hinders medical innovation, makes it harder to formulate health policy and creates unnecessary frustration, stress and extra work for health care providers.

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There can be <u>deadly consequences</u> for patients. An emergency room doctor may not have immediate access to the records of patients. A radiology scan showing an abnormality may not make it back to the referring physician. Ultimately, Canadians may not get the care they need.

There are efforts under way to tackle the problem. Some provinces now have centralized online portals where doctors and patients can find information such as lab test results. A federal bill had proposed national standards for electronic health information systems. That bill died when Parliament was prorogued but should be revived.

Those are positive steps. But as Canada works to weave a coherent system for sharing health information, it should also establish the principle that patients are entitled to access their full medical records by default.

Of course, there would continue to be limited exceptions, including in rare cases in which seeing the information would risk harm to the patient or others.

There should be safeguards. No one should learn they have cancer by logging into a web portal. To that end, many of the platforms already delay the release of some information to patients to give doctors a chance to disclose it first.

But electronic information means doctors no longer have to make physical copies of patients' records, in most cases. It no longer makes sense that Canadians should have to ask to see their information, often chasing after different providers for various pieces of their medical history.

Records should be shared with patients as a matter of course, to enable Canadians to bridge some of the information gaps in the system. Patients are the common link among all their caregivers. And they are highly motivated to make sure no information is missed.

After all, it is patients' information – they have a right to it. There should be nothing revolutionary about that thought.