



The President's Letter

Dr. Noel W. Grisdale



Patients First® Patients First® is a registered trademark of the Alberta Medical Association.

March 24, 2009

Dear Member:

Since the Alberta Medical Association (AMA) publicized its concerns about Bill 52, the *Health Information Amendment Act 2008*, we have been trying to create a situation that would meet the needs of the government and, at the same time, protect the privacy and confidentiality of Albertans' personal health information.

As expected, last week the Provincial Government reintroduced Bill 52 with an updated title, the *Health Information Amendment Act 2009*, but with identical content to the 2008 version. The new bill was fast-tracked to the Legislature's Standing Committee on Health. The standing committee has three options: approve the bill as is; propose amendments to the bill; or recommend that the bill not proceed.

The Minister of Alberta Health and Wellness has acknowledged the need to consult with physicians. The chair of the Standing Committee on Health, Fred Horne (PC Edmonton-Rutherford), has expressed his willingness to continue working with the AMA; his efforts and those of the other committee members are appreciated.

It's apparent that the government has heard and understands the concerns and objections from the AMA and other organizations such as the Office of the Information and Privacy Commissioner, College of Physicians and Surgeons of Alberta, Alberta College of Pharmacists, Consumers' Association of Canada, Canadian Mental Health Association, AIDS Calgary and HIV Edmonton, and the Sheldon Chumir Foundation for Ethics in Leadership.

So, the obvious question: Will the amendments address the deficiencies?

The deficiencies included an over-reliance on regulation; an enhanced ability for the minister to compel the provision of patients' personal health information; and a reduction in the need for physicians and other providers to consider the expressed wishes of patients in the sharing of information. Significant changes to the bill will be required to address these concerns.

... 2

With the provincial budget due April 7 and the subsequent budget debate and review of departmental spending estimates, it could be May before the standing committee reconvenes to formally deliberate on possible amendments.

Moreover, the committee, as it had committed to do, is calling for submissions from the public. The AMA believes this is a positive step. Members of the public, including individual AMA members, can provide their comments. For more information, go to <http://www.assembly.ab.ca/committees/health>.

As explained in my February 4 *President's Letter*, Bill 52 as it now stands would have negative outcomes for patient care and will be counter-productive to Alberta's achieving an effective e-health system. The result would be the wasting of hundreds of millions of dollars it has already spent to computerize Alberta Health Services and Alberta Health and Wellness.

The trust of patients and physicians is essential if Alberta is to achieve its goal of "a patient-focused health system" where "use of informational technology (IT) will improve information flow, improve access to patient information, and encourage patient safety regardless of the care setting." (*Vision 2020*, December 2008, Alberta Health and Wellness).

The 11-member, all-party Standing Committee on Health has a wonderful opportunity to design legislation that will meet the expectations of Albertans. Other countries have successfully balanced patient privacy with the value that can result from an electronic health system. So can Alberta.

Albertans overwhelmingly support the intent and direction of the comments made by the AMA and others. According to the results of public opinion research commissioned by the AMA and recently conducted by NRG Research Group:

- 98% agreed "Doctors have an ethical responsibility to respect the confidentiality of the patient-doctor relationship."
- 97% agreed "I should have the right to know who has looked at my personal health information."
- 97% agreed "There should be rules on who can see my personal health information."
- 96% agreed "In building Alberta's electronic health system, it is important that I can know who has looked at my personal health information."
- 94% agreed "I trust my doctor to keep my sensitive information about me confidential."
- 93% agreed "When it comes to looking at a patient's personal health information, there should be different levels of access for different health care providers such as doctors, nurses, pharmacists, physiotherapists, dentists, etc."
- 92% agreed "Confidentiality of personal health information is the most important issue to keep in mind when setting up an electronic health record."
- 82% agreed "There are some things that I tell my doctor that I don't want anyone else to know about."
 - When presented with the type of information that might be included in an EHR, 81% of respondents identified at least one or more of the 16 topics.

The President's Letter
March 24, 2009
Page 3

The fine balance between the potential benefits of information sharing and privacy is at the heart of this debate. While it is easy to get lost in many intricacies of legislation, technical capabilities and so on, there are some basic tenets that will serve to guide the AMA.

First, when it comes to personal health information, Albertans deserve to know what their rights are and to know who has looked at their personal health information, when and for what purpose. New approaches to serving these ends – a patient bill of rights, patient portals, public involvement in the governance of information sharing – should be pursued.

Second, when it comes to the sharing of information for clinical purposes, this should be guided by two considerations: the expressed wishes of patients and the professional duty of the provider to act in the patient's best interest. The ability of patients to mask information in the electronic health record, e.g., Netcare, should not only be continued but the capabilities refined to provide more options as to what information is masked. It also needs to be recognized that there is some information that will only reside in the physician's electronic medical record and technologies, such as "lock boxes," introduced to fully protect that information.

Third, when it comes to the secondary uses of information for health or health policy research, the strictest rules of patient anonymity must apply. The use of identifiable information for these purposes should only be permitted with written consent, no exceptions.

Physicians are among the strongest advocates for a vibrant and robust electronic health system. The AMA is open to working with the standing committee, the department and anyone else to achieve a system that will put Patients First®.

Yours truly,

Noel W. Grisdale, MD, CCFP
President

P.S. My thanks to those physicians who have contacted or met with their MLAs about Bill 52. If meeting with your MLA isn't your cup of tea, you could telephone or email him or her. Contact information is available at http://www.assembly.ab.ca/net/index.aspx?p=mla_home.