

New Frontiers For Electronic Health Records and Research Databases – Alberta’s Bill 52: Submission of the Health Law Institute on Bill 52

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Intended to “bring the *Health Information Act* up to 2008 standards with the advent of technology,” Bill 52, Alberta’s *Health Information Amendment Act*, was introduced, and referred to the Legislative Assembly’s Standing Committee on Health, late last November.¹ Invitations for oral presentations, then written submissions, followed. By May of this year, by the time the policy field committee’s proposed amendments were tabled and accepted, the concerns of no fewer than sixty-nine groups and individuals had been heard.² Those of the Health Law Institute, as submitted in writing to the Standing Committee on April 24, 2009, are reproduced here.

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Endnotes

1 Alberta, Legislative Assembly, *Hansard*, No. 51 (24 November 2008) at 2018 (George Rogers). Bill 52, *Health Information Amendment Act, 2009*, 2nd Sess., 27th Leg., Alberta, 2009.

2 Alberta, Standing Committee on Health, *Report on Bill 52: Health Information Amendment Act, 2009* (Edmonton: Standing Committee on Health, 2009). For all the presentations and submissions, see Standing Committee on Health, “Submissions Bill 52,” online: Standing Committee on Health <<http://www.assembly.ab.ca/committees/health/submissions2009.html>>. Concerns were expressed outside committee, as well. See e.g. “Patients will lose that ‘last little bit of control’” *Edmonton Journal* (3 December 2008) B7; Jamie Komarnicki, “Loss of patient privacy feared” *Calgary Herald* (5 February 2009) A5; Michelle Lang, “Proposed health law raises privacy concerns” *Calgary Herald* (21 February 2009) B2; Jodie Sinnema, “Doctors fear privacy breaches” *Edmonton Journal* (5 February 2009) B6; “Bill 52 could compromise medical privacy” *Edmonton Journal* (18 March 2009) A16; Miloslav Bozdech *et al.*, “Proposed legislation puts patient privacy at risk” *Edmonton Journal* (27 March 2009) A19; and Sharon Polsky, “Digital medical records put patient privacy at risk” *Edmonton Journal* (9 April 2009) A19. And see Office of the Information and Privacy Commissioner of Alberta, News Release, “Commissioner concerned by amendments to Health Information Act” (1 December 2008), online: Office of the Information and Privacy Commissioner of Alberta <http://www.oipc.ab.ca/Content_Files/Files/News/NR_HIA_Amendment_Dec_1_08.pdf>. Bill 52 passed third reading June 3, 2009, and received Royal Assent the next day.



Health Law I N S T I T U T E

Submission to Standing Committee on Health Bill 52, *Health Information Amendment Act, 2009* April 24, 2009

The Health Law Institute, Faculty of Law, University of Alberta

The Health Law Institute is an academic institute of the University of Alberta established in part to promote positive reform of law and associated health policy. Based upon previous work in the area of health law and the handling of health information, we are pleased to have the opportunity to comment on Bill 52. We look forward to providing further comments and explanation in person if requested to do so by the Standing Committee on Health.

In this submission, we outline aspects of Bill 52 which provide improvements over the current legislation, and comment upon amendments that, in our respectful opinion, tip the balance too far in favour of non-explicit uses of health information without sufficient detail regarding the related mechanisms and duties. There is little weight left on the side of protection of the rights and privacy of individuals respecting access to their health information. We conclude with recommendations regarding next steps.

Purposes of the *Health Information Act*

Alberta's *Health Information Act* (HIA) was enacted in 2001 with certain explicit purposes in mind (as set out in s. 2 of the legislation). All of those purposes are relevant to the amendments that have been introduced in the form of Bill 52. Those purposes are as follows:

- a) to establish strong and effective mechanisms to protect the privacy of individuals with respect to their health information and to protect the confidentiality of that information,
- b) to enable health information to be shared and accessed, where appropriate, to provide health services and to manage the health system,
- c) to prescribe rules for the collection, use and disclosure of health information, which are to be carried out in the most limited manner and with the highest degree of anonymity that is possible in the circumstances,
- d) to provide individuals with a right of access to health information about themselves, subject to limited and specific exceptions as set out in this Act,

- e) to provide individuals with a right to request correction or amendment of health information about themselves,
- f) to establish strong and effective remedies for contraventions of this Act, and
- g) to provide for independent reviews of decisions made by custodians under this Act and the resolution of complaints under this Act.

1999 cH-4.8 s2

It is clear from a review of such purposes that the task for the legislature is the striking of an appropriate balance between competing purposes such as protection of individual privacy and the use of health information to provide better health care to Albertans, for example. We respectfully submit that Bill 52, *The Health Information Amendment Act, 2009* will significantly undermine the achievement of an appropriate balance between these important aims if enacted in its current form. The amendments tip the scale in favour of the use, as government sees fit, for any number of purposes (not only to improve the health care system or to provide health care services) without adequate consultation, oversight by the Information and Privacy Commissioner of Alberta, consideration of the wishes of individuals, or appropriate accountability to individuals for the collection, use and/or disclosure of their information.

Expanded Scope of HIA

We support the amendments in Bill 52 aimed at expanding the scope of “health service” and, as a result, information that will be treated as “health information” under the HIA. We make this submission based on the predication that other concerns as set out in our submission are addressed. It has been unwieldy for health care providers that deliver health care services to be subject to more than one piece of provincial legislation depending upon method of payment for those health care services. Expansion of health services regardless of source of payment will enable health care providers to deal with health information of individuals in a consistent manner. A distinction of protection based only on source of payment is not a rational basis for distinct rules.

Electronic Health Record and other Electronic Health Information Systems

The stated intention of these amendments, support for the development of EHRs in Alberta as “a tool that helps health service providers deliver care efficiently and safely” [Legislative Assembly, *Hansard*, No. 52a (25 November 2008) at 2060 (George Rogers)], is laudable. However, the amendments reach well beyond the better provision of health services in this province. The other potential aims of this legislative framework, such as increased ease of access to information for secondary uses, have not been explicitly addressed. This is essential, as is consultation on the acceptability of the use of information from EHRs and other EMRs for purposes other than the improved provision of health care to individuals.

EHRs are indeed an important tool in the improvement of health service delivery, as well as the health system as a whole. It is appropriate to consider these aims as appropriate uses of such information. However, so as to balance the privacy interests of individuals with other important aims that s. 2 of the HIA sets out, it is imperative to maintain some role for individuals in the use of their information. Bill 52 eliminates any such role and renders a balance between these two important aims non-existent. This is the result of a number of amendments.



Compelled production of information

“Prescribed health information” may be “requested” from physicians by the Minister. If such a request is made, the requested information (the character of which is to be specified in the regulations) must be provided to the EHR. Failure to comply with such a request can result in significant fines for health care professionals and others. This seems likely to lead to untenable situations for health care providers. A direction to provide information to the EHR may be in direct conflict with instructions from a patient to keep the information confidential. Given health care professionals’ other legal obligations to their patients, such as their fiduciary duties, as well as ethical and professional duties, this may well lead to serious dilemmas for practitioners. Health care providers should not be faced with having to choose between fulfilling their obligations to their patients and respecting patient rights, or incurring a significant financial penalty. This is particularly the case given that there is no evidence that the aim of improving care and service delivery would be compromised without a section that compels production of information.

Patient wishes no longer a factor

The amendments deem actual disclosure of prescribed health information pursuant to a Ministerial request a “provision of information”. In other words, providing information in compliance with a request by the Minister is not considered to be “disclosure” of health information. In effect, the amendments remove protections for patient privacy that are currently provided by the HIA.

Under the current HIA, patient wishes are not the last word. But they are a factor to be considered prior to disclosure taking place. By deeming the transfer of information a non-disclosure, the amendments eliminate the current duty to consider the wishes of individuals. This has enormous implications for information that the Supreme Court of Canada [*McInerney v. MacDonald*, [1992] 2 S.C.R. 138 at para. 19] has said is essentially held in trust for individuals by their health care providers:

A physician begins compiling a medical file when a patient chooses to share intimate details about his or her life in the course of medical consultation. The patient “entrusts” this personal information to the physician for medical purposes. It is important to keep in mind the nature of the physician-patient relationship within which the information is confided...LeBel J. in *Henderson v. Johnston*, [1956] O.R. 789, ...characterized the physician-patient relationship as “fiduciary and confidential,” and went on to say: “It is the same relationship as that which exists in equity between a parent and his child, a man and his wife, an attorney and his client, a confessor and his penitent, and a guardian and his ward.” Several academic writers have similarly defined the physician-patient relationship as a fiduciary or trust relationship...I agree with this characterization.

The repeal of s. 59 of HIA, which required individual consent before information could be placed in an EHR, was one move in the direction away from protecting patient privacy. These amendments, if passed, completely eliminate any last bit of influence an individual might have over the collection, use and disclosure of his or her health information for a potentially unlimited range of uses. The Privacy Commissioner of Alberta has expressed grave concerns over this change.

No meaningful disclosure information need be given to individuals

Classification of this flow of information as a disclosure would also engage the current legislative requirements to maintain a disclosure log and provide such information to individuals upon request. For example, an individual can currently request and receive details about what information has been disclosed from his



or her record and to whom, on what date, and for what purposes. The amendments would allow access to information in an EHR by other custodians and would log the name or number of the custodian. No purpose for the disclosure need be recorded. As well, if a number is the only piece of information that is ultimately passed along to an individual, without purpose information, this will be meaningless to an individual requesting such information.

No Privacy Impact Assessment (PIA) required for new governmental “requests”

The HIA currently requires the government to prepare a privacy impact assessment regarding requests for information, to submit it to the provincial Information and Privacy Commissioner, and to consider any comments made. This requirement is eliminated in Bill 52. There is no apparent rationale for such elimination. Indeed, currently, the government is not bound by any comments that may flow from such an assessment of the impact of the new activity. To do away with this oversight and public accountability without justification is extremely concerning. The oversight of the Privacy Commissioner should remain intact regarding all custodians under this legislation, including government.

Issues unaddressed in the legislation

It appears that EHRs, EMRs and other electronic records will be affected by these amendments. However, as work appears to be underway on this front provincially with the move away from regionalization, and the status of such entities is unclear, the legislative impact of these amendments is potentially increased. It is also unclear, at present, how these EHRs in general will be governed and will inter-relate. In particular, data stewardship rules and representation on oversight bodies must be established. The specifics of such rules will have enormous potential impact on the handling of health information in the province. It is essential that certain overarching requirements are sufficiently addressed in the HIA itself. We would also urge the inclusion of appropriate public representation on such oversight bodies. These amendments are proceeding without some of these key details being established, or at least publicized to Albertans.

“Prescribed health information” which must be input into the EHR, as well as “authorized custodians” able to access the EHR, would be largely defined by Lieutenant Governor in Council regulations—by a Cabinet beyond the full reach of either stakeholder or Legislative Assembly scrutiny (ss. 56.1(b)-(c)). It is unclear why further detail is not set out in the proposed legislation itself. Some rationale for these current gaps would be helpful in assessing the depth of some of the above concerns, among others.

Information Managers and others designated in the regulations can use information in their custody/control

The definition of an “affiliate” has been expanded to include information managers and others as set out in yet to be drafted regulations. This further erodes protection of individual privacy by allowing access to and use of information by persons not previously allowed such use. It also defines such access as a use and not a disclosure, thereby bypassing some of the safeguards to individuals (such as the current requirement to consider a patient’s wishes, or to maintain certain information in a disclosure log).

If information managers are strictly acting as such, there is no apparent justification for such an amendment. If it is contemplated that current custodians may also act as information managers for other custodians, such sharing of information should be addressed through data stewardship agreements and other mechanisms, but not by this contemplated amendment.



Public consultation

We are pleased to have this opportunity to provide comments to the Standing Committee on Health. However, to our knowledge, there have been no previous attempts by government to engage in public consultation on the issues contained in Bill 52. This is concerning given the evidence that does exist regarding the views of Albertans on the use of their information in EHRs in this province. The Office of the Information and Privacy Commissioner of Alberta commissioned a survey in 2003 and the majority of Albertans surveyed had concerns about the use of information from the EHR for anything other than the provision of health care services to them. This does not mean that secondary uses of health information are not appropriate and even crucial in many circumstances; it does indicate that public engagement is important before government action is taken to drastically alter the balance between protection of individuals' privacy and use of individuals' information for purposes other than delivery of health care.

Health Information Repositories

Bill 52 sets out to create new entities, Health Information Repositories (HIRs). If enacted, custodians will be able to disclose health information to these repositories in accordance with the regulations.

No detail provided in Bill 52

For what purposes are these health information repositories being established? What powers and obligations will they have? All of this is left for future determination without debate in the legislature, and without the scrutiny of this Committee.

One can speculate as to possible HIR functions. They may include health system management, surveillance, management of other governmental issues, and so on. Research is clearly contemplated as HIRs are referenced in sections related to such. However, the amendments are certainly not limited in this Bill to research purposes.

Research and HIRs

While the use of HIRs for research purposes is likely something to be supported, we do not support the creation of such entities without any detail of the duties and conditions under which they will operate. Of great concern is the fact that research conducted using health information obtained from such HIRs is not subject to many of the current protections contained in the HIA. While researchers who obtain information from custodians other than HIRs must comply with conditions as stipulated by Research Ethics Boards, as well as the custodians themselves, none of this is mandated in Bill 52 if the information is obtained from HIRs.

Expansion of the definition of "research"

Discussion of Bill 52 in the legislature has also been explicitly related to the improvement of health care. However, the definition of "research" in HIA would be amended by Bill 52 to remove the words "health related." Currently, health information may be used by researchers for "health related" research. This will no longer be the case if Bill 52 is enacted. While worthwhile research projects unrelated to health but of benefit to society can be contemplated using health information, this has not been made explicit to Albertans or to the members of the legislative assembly. This enormous expansion of scope should be addressed, and should be subject to the same ethical and privacy protections as research conducted without recourse to HIRs.



Further, as HIRs are not the affiliates of the custodians they receive information from, they are not bound by any of the policies and procedures of those custodians established to protect privacy and maintain appropriate safeguards, among other things. If the duties of HIRs were set out, this may not be of concern. However, no rules regarding HIR handling of health information are established in Bill 52.

Section 72.3 would leave to Cabinet not only the powers but the duties of such bodies. The latter may or may not include important obligations HIA imposes on custodians—the duty to collect, use and disclose health information with the highest degree of anonymity possible, for instance, or the duty to protect health information via administrative, technical and physical safeguards (ss. 57, 60).

Conclusions

In light of the above, we respectfully submit that Bill 52, *The Health Information Amendment Act, 2009*, ought not to proceed without substantial amendment. We would recommend the following changes:

- ▶ Continued oversight by the Information and Privacy Commissioner of Ministerial and Departmental requests for disclosure of health information, including the requirement to submit Privacy Impact Assessments,
- ▶ Meaningful oversight by the Information and Privacy Commissioner of electronic sharing of health information (in EHRs, other electronic records, and HIRs),
- ▶ Requirement on the part of researchers applying to HIRs to comply with REB conditions, as well as other conditions imposed by the HIR,
- ▶ Classification of provisions of health information to the EHR as “disclosures”
- ▶ Amendments to ensure consideration of individual wishes prior to electronic sharing of health information,
- ▶ Amendments to ensure a right to seek access to meaningful information detailing electronic sharing of one’s health information,
- ▶ Elimination of the mandated provision of information by custodians to the EHR,
- ▶ Removal of penalties for custodians and/or affiliates who fail to provide mandated information to the EHR as a result of patient requests,
- ▶ Inclusion of statutory definitions for terms such as “prescribed health information” and “authorized custodians,”
- ▶ Inclusion of statutory specifications of HIR powers, duties and functions,
- ▶ Removal of “information manager” from the definition of “affiliate.”

All of the above is respectfully submitted with the hope that our comments will assist the Committee and Legislative Assembly in striking the appropriate balance between competing purposes in the HIA. We also submit that government consider further public engagement prior to the further progress of this legislation. In particular, we would suggest that public feedback on use of health information for the provision of health services, as well as secondary uses, be solicited. We also suggest that a more explicit explanation of the expansion of “research” be forthcoming, with the opportunity to debate such an amendment.



We would be most pleased to present orally on both our comments and recommendations to the Standing Committee on Health. Thank you for this opportunity to provide comments.

Respectfully submitted,

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