Twenty-Seventh Legislature
Second Session

Standing Committee on Health

May 2009

Report on Bill 52: *Health Information Amendment Act, 2009*

COMMITTEES
OF THE LEGISLATIVE ASSEMBLY

Contents

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* Committee Member to February 11, 2009.
† Committee Member from February 11, 2009.
‡ Substitution for Jonathan Denis on January 30, 2009.
§ Substitution for Kyle Fawcett on May 13, 2009.
** Substitution for Dr. David Swann on January 21, 2009 and February 4, 2009. Substitution for Dr. Kevin Taft on May 11, 2009, May 13, 2009, and May 20, 2009.
†† Substitution for Rachel Notley on January 21, 2009.
‡‡ Substitution for Jonathan Denis on May 13, 2009.

1.0 Introduction

Bill 52, *Health Information Amendment Act, 2008* was introduced and received first reading on November 24, 2008, and received second reading on November 27, 2008, at which time it was referred to the Standing Committee on Health (the "Committee") for review. Bill 52 was reinstated pursuant to Standing Order 51 on March 17, 2009, through a motion by the Deputy Government House Leader:

> Mr. Renner moved on behalf of Mr. Hancock:
>
> Be it resolved that Bill 52, Health Information Amendment Act, 2009, the contents of this bill being the same as Bill 52, Health Information Amendment Act, 2008, be reinstated to the same stage that Bill 52 had reached at the time of prorogation of the previous session; namely, the bill standing referred to the Standing Committee on Health following second reading.[*]

[*] Alberta, Legislative Assembly, *Hansard* No. 16 (March 17, 2009), p. 437.

2.0 Order of Reference

Excerpt from the *Votes and Proceedings of the Legislative Assembly of Alberta*, Thursday, November 27, 2008:

> **Second Reading**
>
> On motion by Hon. Mr. Zwozdesky, Deputy Government House Leader, the following Bill was referred to the Standing Committee on Health for the committee's review:
>
> Bill 52 Health Information Amendment Act, 2008 — Mr. Rogers

3.0 Recommendations

Pursuant to Standing Order 78.3(1) "[a] Policy Field Committee to which a Bill has been referred by the Assembly after second reading shall be empowered to report the same with or without amendments or to report that the Bill not proceed."

3.1 Proposed Amendments to Bill 52

The Standing Committee on Health recommends that Bill 52, *Health Information Amendment Act, 2009*, proceed with the following amendments:

HEALTH INFORMATION AMENDMENT ACT, 2009

A Section 11 is amended by striking out clause (b) and substituting the following:

(b) by repealing subsection (3);

(c) by repealing subsection (5)(b) and substituting the following:

(b) must consider the comments of the Commissioner, if any, made in response to the privacy impact assessment before disclosing the health information to a custodian referred to in section 1(1)(f)(iii) or (iv).

B Section 20 is amended

(a) in the proposed section 56.1

(i) in clause (c) by adding "a regulated health professional or" **after** "regulations that";

(ii) by adding the following after clause (c):

(d) "regulated health professional" means

(i) a regulated member under the *Health Professions Act*,

(ii) a person registered as a medical practitioner under the *Medical Profession Act*,

(iii) a person registered as a podiatrist under the *Podiatry Act*,

(iv) a person registered as a physical therapist under the *Physical Therapy Profession Act*,

(v) a person registered as an optician under the *Opticians Act*, or

(vi) a person registered under the *Health Disciplines Act*.

(b) by striking out the proposed section 56.3 and substituting the following:

Making prescribed health information accessible
56.3(1) The health professional body of a regulated health professional may in writing direct the regulated health professional to make prescribed health

information that is in the custody or under the control of the regulated health professional accessible to authorized custodians via the Alberta EHR in accordance with the regulations.

(2) If

(a) the Minister determines that it is in the public interest to have certain prescribed health information that is in the custody or under the control of one or more regulated health professionals made accessible to authorized custodians via the Alberta EHR, and

(b) the health professional body of the regulated health professionals has not directed the regulated health professionals to make that prescribed health information accessible via the Alberta EHR,

the Minister may, subject to subsection (3), in writing direct the regulated health professionals to make the prescribed health information accessible to authorized custodians via the Alberta EHR in accordance with the regulations.

(3) Before giving a direction under subsection (2), the Minister must

(a) consult with the health professional body referred to in subsection (2)(b),

(b) prepare a privacy impact assessment describing how disclosure of the health information may affect the privacy of the individual who is the subject of the information and submit the privacy impact assessment to the Commissioner for review and comment, and

(c) consider the comments of the Commissioner, if any, made in response to the privacy impact assessment.

(4) A failure by a regulated health professional to comply with a direction of the health professional body under subsection (1) or of the Minister under subsection (2) constitutes

(a) in the case of a regulated member under the *Health Professions Act*, unprofessional conduct;

(b) in the case of a person registered as a medical practitioner under the *Medical Profession Act*, unbecoming conduct;

(c) in the case of a person registered as a podiatrist under the *Podiatry Act*, professional misconduct;

(d) in the case of a person registered as a physical therapist under the *Physical Therapy Profession Act*, professional misconduct;

(e) in the case of a person registered as an optician under the *Opticians Act*, professional misconduct;

(f) in the case of a person registered under the *Health Disciplines Act*, professional misconduct.

(5) An authorized custodian may make prescribed health information in its custody or under its control accessible to authorized custodians via the Alberta EHR in accordance with the regulations.

(6) An authorized custodian, other than a regulated health professional, must, if the Minister requests in writing, make prescribed health information in its custody or under its control accessible to authorized custodians via the Alberta EHR in accordance with the regulations.

(7) For greater certainty, the making of prescribed health information accessible pursuant to this section does not

(a) constitute a disclosure of that information, or

(b) require the consent of the individual who is the subject of the information.

(c) by adding the following after the proposed section 56.3:

Duty to consider expressed wishes of individual who is the subject of prescribed health information
56.31 In deciding how much prescribed health information to make accessible via the Alberta EHR, a regulated health professional or an authorized custodian must consider as an important factor any expressed wishes of the individual who is the subject of the prescribed health information relating to access to that information, together with any other factors the regulated health professional or authorized custodian considers important.

(d) by striking out the proposed section 56.4(3)(a) and substituting the following:

(a) the regulated health professional or authorized custodian who originally made that information accessible via the Alberta EHR pursuant to section 56.3,

(e) by adding the following after the proposed section 56.4:

Maintaining record of Alberta EHR information
56.41(1) If an authorized custodian uses prescribed health information pursuant to section 56.4, the authorized custodian must keep an electronic log of the following information:

(a) a name or number that identifies the custodian who uses the information;

(b) the date and time that the information is used;

(c) a description of the information that is used.

(2) The information referred to in subsection (1) must be retained by the authorized custodian for a period of 10 years following the date of the use.

(3) An individual who is the subject of information referred to in subsection (1) may ask the authorized custodian or the information manager of the Alberta EHR for access to and a copy of the information, and Part 2 applies to the request.

(4) If, pursuant to subsection (3), an individual asks the information manager of the Alberta EHR for access to and a copy of the information referred to in

subsection (1), the information manager of the Alberta EHR must, in accordance with Part 2, provide that information in respect of all custodians who have used that individual's prescribed health information pursuant to section 56.4.

Multi-disciplinary data stewardship committee
56.42(1) The Minister shall establish a multi-disciplinary data stewardship committee whose function is to make recommendations to the Minister with respect to rules related to access, use, disclosure and retention of prescribed health information that is accessible via the Alberta EHR.

(2) At least 2 members of the multi-disciplinary data stewardship committee must be members of the public.

(3) Section 7(2) to (5) of the *Government Organization Act* apply with respect to the multi-disciplinary data stewardship committee.

(f) in the proposed section 56.5(d) by adding "a regulated health professional or" **after** "which";

C Section 22 is amended by adding the following after the proposed section 72.3:

Correction or amendment of health information by repository
72.4(1) Where a custodian has made a correction or amendment to health information pursuant to section 13, the custodian must notify a health information repository to which the custodian has disclosed the information that a correction or amendment has been made and advise the repository of the manner in which the health information must be corrected or amended.

(2) A health information repository that is notified pursuant to subsection (1) must, within 30 days,

(a) make the correction or amendment according to the advice of the custodian, and

(b) provide written notice that the correction or amendment has been made to the custodian, and the custodian shall then notify the individual who is the subject of the health information.

(3) An individual who is the subject of health information to which a correction or amendment is made pursuant to subsection (1) may ask the Commissioner to review a failure of a custodian to notify a health information repository of the correction or amendment or a failure of a health information repository to make the correction or amendment pursuant to subsection (2).

(4) Sections 74 to 82 apply with all necessary modifications to a request to the Commissioner for a review under subsection (3).

(5) For greater clarity, the duties and responsibilities of a custodian as outlined in sections 74 to 82 also apply to a health information repository for the purposes of this section.

Consultation with Commissioner
72.5 The Minister must consult with the Commissioner in the preparation of the regulations under this Part.

D Section 24 is amended by striking out the proposed subsection (6.1).

Appendix A: Minority Report

Laurie Blakeman, MLA
Edmonton–Centre (AL)

The important issue that I believe has not been adequately considered and addressed in the committee's review of Bill 52 regards access to private personal health information through Alberta Netcare. Under current legislation the only way to protect one's personal health information is through global masking. I believe that masking will not be enough to protect the health information of Albertans. This is an important issue for individuals who have certain health conditions: if their health information were known in the community, there could be adverse professional, personal, and societal reactions.

While custodians must follow a protocol – in other words, select an option from a menu – to unmask information, personal information can be revealed by any custodian for almost any reason. With a process as simple as that, an individual's personal health information, which they did not want to be disclosed, is now open to any custodian who wants it. This creates a false sense of security among Albertans. The only evidence that is left for the individual is the audit trail of who accessed their record, but by that point their information has been made available. The protection that a global mask offers for an individual's privacy is clearly not sufficient and is, in fact, inadvertently misleading. It erodes public confidence in the confidentiality of Alberta's health information system.

The only viable option for ensuring that the health information of Albertans remains private is to create a lockbox provision. A provision such as this would address many of the concerns that have been raised regarding the privacy of electronic health records. A lockbox provision will give Albertans an assurance that, if needed, their personal health information will be handled with the desired amount of privacy and respect.

Examples of other jurisdictions in Canada which have lockbox (or stronger masking) provisions in their health information legislation are Manitoba, Ontario, Saskatchewan, British Columbia, and Newfoundland. The best example of the lockbox provision is in Ontario's *Personal Health Information Protection Act*. Through this legislation an individual has the right to instruct their health care provider not to use or disclose their personal health information. The pertinent sections read as follows. (I have bolded certain parts for emphasis.)

> 37 (1) A health information custodian may use personal health information about an individual,
>
> (a) for the purpose for which the information was collected or created and for all the functions reasonably necessary for carrying out that purpose, **but not if the information was collected with the consent of the individual or under clause 36(1)(b) and the individual expressly instructs otherwise;**
>
> 38 (1) A health information custodian may disclose personal health information about an individual,
>
> (a) to a health information custodian described in paragraph 1, 2, 3 or 4 of the definition of "health information custodian" in subsection 3(1), if the disclosure is reasonably necessary for the provision of health care and it is not reasonably possible to obtain the individual's consent in a timely manner, **but not if the individual has expressly instructed the custodian not to make the disclosure;**

> 50 (1) A health information custodian may disclose personal health information about an individual collected in Ontario to a person outside Ontario only if,
>
> (e) the disclosure is reasonably necessary for the provision of health care to the individual, **but not if the individual has expressly instructed the custodian not to make the disclosure**;

Because of the reasons outlined above, I urge the Legislature to include a lockbox provision in the *Health Information Act,* which would allow Albertans to create lockboxes around their health information through express instruction. Global masking insufficiently addresses the privacy concerns of various segments of the public and could have a negative impact on the lives of many Albertans. As such, a lockbox provision should be included in Bill 52. This provision will build greater confidence in the *Health Information* Act as the personal health information of concerned Albertans would be handled with due privacy and respect.

Appendix B: Minority Report

Rachel Notley, MLA
Edmonton-Strathcona (NDP)

1. Introduction

There are two general areas relating to Bill 52 that in the opinion of the NDP opposition caucus are not adequately addressed in the majority report of the Standing Committee on Health. Firstly, the Bill changes the definitions of custodian and health service in order to include an unlimited number of privately funded health care providers. Secondly, the Bill creates new entities (health information repositories) and gives them authority to receive personally identifying health information but excludes them from the vast majority of privacy protection rules included throughout the rest of the Act.

2. Privately Funded Health Care Providers and Health Services

The proposed language in Bill 52 would significantly open the door for privately funded health care providers to get access to patients' electronic health care records. This is ill advised for at least three reasons.

2.1 Public Funding of Health Care

Firstly, the language does not support the need to maintain a full range of publicly funded health care in our province. Government continually maintains that while they may promote private delivery, they will not increase private funding of health care delivery. Therefore, there is no clear rationale for including this change.

Health care information which is critical to the management of a patient's care should already be in the electronic health record through the input of publicly funded providers. An exception to this notion is pharmaceutical information, which is already addressed in current legislation. There may also be merit to including dental information. That exception can be added to the legislation.

It is not necessary to give the government unfettered authority to include privately funded providers unless it anticipates that list will increase. In the short time that the Bill has been before the committee, the government has delisted chiropractic services and gender reassignment treatment, thus requiring those services to be exempted as well. While allowing the government authority to include the ever-expanding list of privately funded health care providers and health care services does not initiate these moves to privatization, they certainly facilitate them. Following through with the amendments on this issue will be yet another vehicle on the road to privatization of our health care system and thus should be rejected.

2.2 Increased Risk of Privacy Breach

Secondly, the change to include privately funded health providers and health services creates greater risk of privacy breaches as more and more private-sector and extraprovincial entities gain access to the personally identifying health information of Albertans. The Auditor General has already noted concerns regarding the security of government computer records.

Moreover, in the last three years we have seen several incidents where small private-sector registry offices were vulnerable to criminal influence, creating serious risks that the public's privacy was breached.

By inviting privately funded health care providers into the health information arena, the practical ability to control how that information is used and protected is reduced.

2.3 Employer or Adjudicator Access to Private Health Information

Thirdly, this legislation fails to contemplate or plan for the very real risk that individuals' employers may gain access to their records through medical staff employed by an employer or insurance company who may have conflicting duties as employee and health care provider.

This problem already exists for the roughly 100,000 employees employed in health care. A recent decision of the Privacy Commissioner (Investigation Report H2009-IR-003 & F2009-IR-OO1) concluded that an employee's privacy was breached when an occupational health and safety nurse accessed the employee's electronic health record to gain medical information on which an internal job competition decision was based. While the decision reached in that case was a good one, the reasoning within the Commissioner's decision highlights the current confusion around assessing the dual role of health service provider and employee, and it is not clear that the Commissioner would have made the same decision had the employer's management objectives involved planning a return to work, assessing sick time usage, assessing the employer's legal duty to accommodate or dealing with a workplace injury and an employee's entitlement to WCB payments.

In these cases, employers who employ health service providers to engage in the dual role of human resources management and health care provision may well now have complete access to an employee's medical history for the above-noted purposes. The sector that has already been subject to this arrangement includes one of the more sophisticated employers in the province (from a labour relations point of view) and the most highly unionized employee population. As a result, there have been at least some internal checks and balances in place that either limit or challenge the circumstances in which privacy can be breached.

The same cannot be said of the roughly 1 million Albertans who would now be added to the group of employees who are at risk of having their health records accessed by health service providers working with their employer, an insurance company or the WCB.

As previously noted, the 2004 select standing committee recommended against including the WCB or Alberta Blue Cross under the Health Information Act. Now, through the unclear role of health service providers within each of these bodies, it is very likely that a certain portion of this recommendation is being ignored with little or no discussion as to why.

3. Health Information Repositories

Section 22 of Bill 52 creates health information repositories. These entities are in theory designed to consolidate health information for the purposes of health care research. This is a worthwhile objective. Unfortunately, while the objective is worth while, the vehicle for achieving it, established through Bill 52, is flawed.

The Bill adds section 72.3, which simply says that the new entity's purpose and function will be established through regulation. Yet through Section 72.2, this entity will have the legislative authority to collect personally identifying health information of individuals. While this invasive authority is set out in the Act, the rules around the rights of individuals who are the subject of that

information, the rules around use of the information and around the disclosure of the information are all left to regulation.

Finally, by virtue of its definition the health information repository is not subject to the many privacy protections contained throughout the remainder of the Health Information Act.

3.1 Committee Acceptance of Opposition Amendments

We acknowledge that two amendments put forward by the opposition parties were adopted by the committee in an effort to address concerns regarding the health information repository. Unfortunately, while they represent small improvements to the problem, neither amendment on its own provides the guarantee of privacy protection that Albertans deserve.

The amendment put forward by the Official Opposition is designed to assist individuals who might want to correct incorrect information in the possession of the health information repository. The amendment obliges the health information repository to report that it has corrected inaccurate information when advised of it by a custodian under the Act or, alternatively, to report that it has not corrected it. The difficulty with this approach, however, is that the health information repository is treated differently from other custodians in that the individual must rely on the assurances of the health information repository but is unable to check the information held by the repository directly.

The NDP opposition proposed an amendment designed to put a small check on the authority of the government to develop the regulations without legislative oversight. The amendment added to section 72.3 the obligation of the Minister to consult with the Privacy Commissioner in the course of developing regulations. While this consultation is an improvement, it does not negate the ability of the government to ultimately overrule concerns of the Privacy Commissioner should it so choose.

3.2 Other Amendments

The NDP opposition also proposed to add a clause that would have more clearly set out the purpose and the function of the health information repository in the legislation. This amendment was rejected. It is regrettable that the authority for the health information repository to assert maximum incursion into an individual's privacy is included in the legislation while counterbalancing limits on the entity must be left to regulation which may or may not achieve this objective.

Finally, while failing to treat the health information repository as a custodian under the Act, the majority on the committee has adopted a course which limits the ability of the office of the Privacy Commissioner to perform its traditional oversight role. While the Health Information Act allows for a generalized oversight, the specific duties and obligations which the Commissioner would otherwise enforce arise from the status of custodian. All other holders of personally identifying health information are custodians under the Act. However, under Bill 52 the health information repository is not.

The NDP opposition proposed an amendment which would have amended the definition of custodian to include health information repositories. While it is acknowledged that this change might have had consequences beyond those sought to be addressed through this amendment, our view is that this speaks less to the need to address the problem than it does to the haste with which this Bill was moved through the committee and the Legislature.

4.0 Summary

The capacity of the system to provide health service providers with an individual's personal information is evolving every day. The technology to mask information at the request of an individual is underdeveloped. The law around the dual role of health service provider and employee of employer or insurance company is also still a work in progress. The purpose, function and policing of the health information repository remain undetermined. As a result, the consequences to an individual's privacy are uncertain. The wise course would be to err on the side of ensuring the protection of Albertans' privacy with respect to their health records. The changes included in Bill 52 allowing for addition of privately funded health service providers and health services and the creation of a new, unregulated information-holding entity do not reflect this course.

Appendix C: List of Submitters and Presenters

At the invitation of the Standing Committee on Health, 12 stakeholders made oral presentations at the January 21, January 30, and February 4, 2009, meetings of the Committee, which took place in Edmonton, Alberta.

The Standing Committee on Health invited written submissions on Bill 52 from the public. The Committee received written submissions from 48 individuals and groups.

Stakeholder Oral Presentations

	Name	Organization
1	Susan Cress	AIDS Calgary Awareness Association*
2	Sandy Slator and Linda Mickelson	Alberta Cancer Foundation
3	Greg Eberhart	Alberta College of Pharmacists
4	Dr. Christopher Doig and Mike Gormley	Alberta Medical Association
5	Tom Shand	Canadian Mental Health Association
6	Dr. Trevor Theman and Dr. John Pasternak	College of Physicians and Surgeons of Alberta
7	Wendy Armstrong	Consumers' Association of Canada (Alberta)
8	Dr. John Cowell and Charlene McBrien-Morrison	Health Quality Council of Alberta
9	Debra Jakubec	HIV Edmonton
10	Frank Work, QC, and LeRoy Brower	Office of the Information and Privacy Commissioner
11	Dr. Kelly Ernst	Sheldon Chumir Foundation for Ethics in Leadership
12	Dr. Tom Marrie	University of Alberta, Faculty of Medicine & Dentistry

Written Submissions

	Name	Organization
1	Jack Grant and Ken Kobly	Alberta Chambers of Commerce
2	Kathy Hilsenteger	Alberta Federation of Regulated Health

* HIV Edmonton and AIDS Calgary Awareness Association made a joint presentation to the Committee.

	Name	Organization
		Professions
3	Dr. Jordan Stuart Cohen	Alberta Medical Association, Section of Child and Adolescent Psychiatry
4	Dr. E. Sandra Corbett	Alberta Psychiatric Association
5	Heather Welwood	Alberta School Boards Association
6	Sharon Polsky	Canadian Association of Professional Access and Privacy Administrators
7	Elaine Ashfield	Canadian Blood Services
8	Geoffrey M. Pradella	Calgary Chamber of Commerce
9	Dr. Robert Ouellet	Canadian Medical Association
10	Dr. John E. Gray	Canadian Medical Protective Association
11	Dr. Alice Leung	CASA – Child, Adolescent and Family Mental Health
12	Alayne Sinclair	City of Edmonton
13	Mayor Stephen Mandel	City of Edmonton
14	Margaret Hadley and Mary-Anne Robinson	College and Association of Registered Nurses of Alberta
15	Dr. Trevor W. Theman	College of Physicians and Surgeons
16	Larry Phillips	Consumers' Association of Canada (Alberta)
17	Beth Kidd, Dr. Katharina Kovacs Burns, Mary E. Chibuk, Lorraine Penton, Jeanne Keith-Ferris, and Gail Attara	Creating Synergy Coalition
18	Jeanne Keith-Ferris	Gastroparesis & Dysmotilities Association
19	Tracey M. Bailey, Karin Kellogg and Gergely Hegedus	Health Law Institute
20	Anonymous (1)	Private Citizen
21	Anonymous (2)	Private Citizen
22	Anonymous (3)	Private Citizen
23	Laverne Asselstine	Private Citizen

	Name	Organization
24	Rose Balcom	Private Citizen
25	Dr. Nancy Brager	Private Citizen
26	David and Ruth Doull	Private Citizens
27	Alicia Ellis	Private Citizen
28	Dr. Tom Enders and Dr. Alan Segal	Private Citizens
29	Faith Fernalld	Private Citizen
30	Susan Gilchrist	Private Citizen
31	Glenn G. Griener	Private Citizen
32	Pamela Head	Private Citizen
33	Anita Jonsson	Private Citizen
34	Pat Kimura	Private Citizen
35	Dr. Suzanne Kresta	Private Citizen
36	Dr. Ved Madan	Private Citizen
37	Sheila McKay	Private Citizen
38	Vicki Miller	Private Citizen
39	John and Verna Milligan	Private Citizens
40	Adam Norris	Private Citizen
41	G. Lorraine Ouellette	Private Citizen
42	Johanna Sandkuhl	Private Citizen
43	Ljubica and Vlasta Stubicar	Private Citizens
44	John and Joyce Trynchuk	Private Citizens
45	Dave Waddington	Private Citizen
46	Jean H. Young	Private Citizen
47	Noel Somerville	Public Interest Alberta, Seniors Task Force
48	Chief Arthur Noskey	Treaty 8 First Nations of Alberta