

**Verbal Submission to the Standing Committee of the Alberta Legislative
Assembly on Health
Regarding: Bill 52, Health Information Amendment Act, 2008
From the Sheldon Chumir Foundation for Ethics in Leadership
Presentation to the Committee: February 4, 2009**

Introduction

On behalf of the Sheldon Chumir Ethics Foundation for Ethics in Leadership, I would like to thank you for the offer to provide comments on proposed Bill 52.

The observations I will forward in this presentation were made after consultation with ethics and privacy experts and after review from a legal perspective.

First I would like to outline our proposed recommendations for changes in the amendments, and then I would like to discuss various scenarios that could highlight the reasons for making these amendments.

Before I move into our recommendations, we would like to acknowledge that there could be considerable patient benefit in the creation of an electronic health record. However, we also wish to note that advances in technology do not eliminate the possibility of system failures and that when technology fails, it often does so spectacularly and with significant impacts to people's privacy and even personal security.

With such important implications to consider, we encourage committee members to take very seriously the various recommendations we and others make that are intended to avoid significant harm to the public.

Base Recommendation # 1:

Our base recommendation refers to including Informed Consent for Inclusion of Personal Information into the electronic health record and Alberta Netcare.

Recommendation # 2:

Create Limits on Disclosure of Information and the ability to Mask Information

Recommendation # 3:

Define Health Information Repositories more clearly

Recommendation # 4:

Strengthen consent for disclosure of information, including research consent

Recommendation # 5:

Retain the Need for Privacy Impact Assessments when providing health information to the Minister

Recommendation # 6:

Return Bill 52 to Government of Alberta legal counsel for identification of all possible conflicts with the Charter of Rights and Freedoms and removal of those provisions that do offend the Charter.

Base Recommendation:

Our base recommendation refers to including Informed Consent for Inclusion of Personal Information into the electronic health record and Alberta Netcare.

Recommendation 1. We recommend that the Bill be amended to:

- a) include an obligation for health services custodians and health information repositories to seek informed consent from patients to include their personal and health information in the electronic health record,
- b) place a reasonable limit on the length of time an electronic health record can be used without review of that initial consent,
- c) allow for the patient to withdraw any consent earlier given to inclusion of their data in the electronic health record, and
- d) if consent is so withdrawn, then we suggest that there is reasonable monitoring systems in place to ensure that personal and health information is in fact removed (eliminated, archived, or deleted) from the electronic health record.

Rationale:

The obligation to consider patients wishes to provide informed consent is the most basic ethical criterion to consider when collecting, using, disclosing, or sharing information. Informed consent helps to ensure that all parties are informed about where that information is used, reduces the possibility of abuse of information, and reduces the possibility of information being used in ways that it was not intended. It gives direction, not only to the person giving consent, but to the entire system that might use the information regarding what is acceptable and not acceptable as a use or means for use of information.

Reference:

See. p. 17: Proposed 56.3.2.a “does not...require the consent of the individual...”

Recommendation # 2 – Create Limits on Disclosure of Information and the ability to Mask Information

Recommendation 2. We recommend that amendments include an obligation for health services custodians and health information repositories to address patient requests to have any part of their personal and health information in the electronic health record be masked or hidden from view.

Rationale:

There appears to be no provision in the amendments to address an individual's request to mask information. This is a fundamental breach of Albertans' rights to privacy. Without provisions for masking information, the opening of all health information could have potentially harmful impacts on individuals through custodians' authorized or unauthorized use of information. Completely unmasked information could have harmful impacts.

1) Consider a domestic abuse situation where the abusive person has access through their work or office to the health and personal information on the victim of their abuse. If the victim cannot mask information, not only his or her privacy may be violated, but their very physical or emotional security may be put at risk because the abuser will have an easier time tracking them down. It is possible that further violence may actually be facilitated by the electronic health record simply because the information was not masked.

2) These risks are probably greater for Albertans in small communities, than for people in large communities, because it takes less information to pick out a person in a small community than it does in a larger one. For example, age and gender alone are not normally identifiable; however when this is combined with ethnicity and place of residence in the context of a small village, then this information becomes identifiable. Let's extend this example further whereby a rural person applies for a job and as a matter of course, the person requires an HIV test for additional health benefits. If the HIV test results are entered into the system (even negative results) and then this is then disclosed into the small community without

the knowledge of the original reason for testing, then this person could risk social or economic discrimination or harm for merely taking the test. Thus, rural Albertans may be disproportionately at risk for the harm.

Reference:

Refers generally to the act with provisions that would allow for masking of information missing.

Recommendation # 3 – Define Health Information Repositories more clearly

Recommendation 3. We recommend that the definition of the role and responsibilities for a health information repository be clearer and include limits on the activities of a health information repository, including:

- a) a well defined description of the role of the health information repositories,
- b) a narrowing of the possible types of organizations that might be eligible to be a designated a repository to those organizations with a health services or health research mandate, and
- c) an appropriate eligibility review process, such as a Privacy Impact Assessment, be required by a proposed health information repository to ensure the proposed repository has eligibility and a full complement of processes to protect individual privacy. In particular, this would ensure that the proposed repository agency, company or entity has qualified individuals to handle health information, has appropriate levels of safeguards in place to protect individual privacy, and is clearly compelled to protect individual privacy over agency, company and entity interests.

Rationale:

The lack of clarity of the role of health information repository may open the role up for use and mishandling of information for purposes other than is intended. We do not see who could act as a health information repository and such recent scandals as Enron and Madoff, give us reminders that we should be careful who we give information and resources to handle on our behalf. A better defined role, function, and limits of these entities would give some protection. It could ensure companies with interests outside of health related services or that have conflicts with health service delivery are prevented in becoming a health information repository. It could also provide a degree of review or scrutiny of the proposed entity's processes to protect privacy.

Reference:

See: p. 20, Part 6.1, 72.1-3

Recommendation # 4 – Strengthen consent for disclosure of information, including research consent

Recommendation 4. We recommend that amendments include greater obligation on repositories to protect individual health information for research purposes, this includes obligations on custodians and health information repositories to:

- a) obtain patient consent for research or evaluation on ongoing and active health concerns and other issues,
- b) include in of the types of research requiring consent, at a minimum, program evaluation and policy development, and
- c) make health records anonymous for all archival research prior to the commencement of any use or disclosure of information for those research purposes.

Rationale:

It does not appear that in all research activities the agencies, companies, or entities would require research consent from the patient. This may open up the disclosure of information for purposes other than research, but perhaps under the pretext that research or other health services may be occurring. We could envision that data mining and searching of records could occur with the result that needless disclosures of information be made. Such disclosures place people's privacy and security at risk. We suggest limits to ensure all disclosures have a purpose, and identifying disclosures only occur when all other means have been exhausted.

Reference:

See: 31(1) A custodian may disclose non-identifying information for any purpose.

35(1) A custodian may disclose individually identifying information ... information without the consent of the individual ... (a.1)... for health system planning, management and health policy development...

Recommendation # 5 – Retain the Need for Privacy Impact Assessments when providing health information to the Minister

Recommendation 5. We recommend that amendments include a requirement to retain the need for a Privacy Impact Assessment when individual information is being requested for disclosure by the Minister or Department.

Rationale:

Retention of a PIA process would help to protect individuals and their health information from requests which 1) may place an individual's liberties or security at risk and 2) simultaneously protect the minister and department from potential public and legal consequences. For example, without such a provision, we could envision scenarios whereby it may be tempting to request or to forward to the minister or department more detailed information about high profile cases that may already have some information circulating publicly. If such actions occurred and further public information noted inconsistencies and inaccuracies between public knowledge and the disclosures of information from the minister or department, then these could potentially place the minister or department at risk of significant embarrassment. Or, in the case where information was available to the medias, and if the case went as far as becoming open to court and civil challenges, not only could this exposure be publicly embarrassing, but also this and the court challenge would then occur in a very public manner.

A requirement for a Privacy Impact Assessment (PIA) to complying with request departmental or ministerial requests would immediately place a barrier for disclosure thereby reducing the risk of embarrassment or possible litigation.

Reference:

See: p. 11, section 46 (b), 5 repealed

Recommendation # 6 – Return Bill 52 to Government of Alberta legal counsel for identification of all possible conflicts with the Charter of Rights and Freedoms and have it returned with changes to mitigate against any challenges.

Recommendation 6. We recommend that Bill 52 be returned to Government of Alberta legal counsel for identification of all possible conflicts with the Charter of Rights and Freedoms. We further recommend that Bill 52 be amended so as to fully comply with the Charter’s guarantees of privacy and security of the person and any other rights that are revealed as relevant by that legal review.

Rationale:

Upon consultation with lawyers and privacy experts on the subject, our conclusion is that the amendments proposed by Bill 52 imperil Albertans’ rights to privacy in many ways. According to experts with which we have consulted, Bill 52 creates the “ripest environment for a constitutional challenge in the country.”

This is based upon far too many scenarios whereby

- 1) the need for informed consent to include information in the health record is omitted or
- 2) far too many disclosures of information are possibly created, this includes the possibility of requesting that portions of a health record be masked is omitted from the amendments and the system proposed by Bill 52 creates many risks of disclosure for purposes other than health services.

One of the best examples of possible problems may arise if an abused woman’s health records fall into the wrong hands (say, the abusive spouse with whom she is embroiled in a custody dispute), her physical or psychological security may be seriously compromised.

The Charter applies to this proposed legislation as it applies to all legislation. The right to privacy and security of the person more generally (the right to privacy is

included in security of the person – see the Supreme Court of Canada decision in the Morgentaler case) are contained in section 7 of the Charter. Those rights may well be violated by Bill 52 because the forced inclusion of health information in the electronic system is not carried out “in accordance with the principles of fundamental justice”. For example, there is no need for the informed consent of the patients whose health information is at stake.

Reference:

Refers generally to the act; missing parts to create masked information.

Summary

We have been pleased to have been invited to provide a submission to the committee and acknowledge that adoption of Bill 52 might possibly bring some benefits to Albertans. However, we have serious concerns about aspects of the Bill and recommend that precautions are carefully considered and included in the amendments to ensure that measures are in place to protect both privacy and security of the person.

The most basic of these is:

- 1) the individual’s basic right to provide informed consent, the right to withdraw their consent if they so choose,
- 2) right to mask specific parts of data files.

We further recommend that

- 3) greater clarity, definition and limitations be placed upon the Health Information Repositories.
- 4) greater protections be put into place to ensure minimal disclosure of information, including making data anonymous before use in evaluation and policy research,

- 5) there be retention of the need for Privacy Impact Assessments and reviews for disclosures of information, even those to the Minister and Department.

Finally, we also suggest that:

- 6) consultations with legal counsel and privacy experts occur so that Bill 52 can be amended so as to avoid conflicts with the Charter of Rights and Freedoms.