

**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 Leadership¹**

Submitted: January 28, 2009

Presentation to the Committee: February 4, 2009

Introduction

The Sheldon Chumir Foundation for Ethics in Leadership was invited to make a submission to the Standing Committee on Health on Bill 52. We are pleased to have been able to accept this offer to provide comments on this proposed legislation.

We acknowledge that there could be considerable patient benefit in the creation of an electronic health record. However, we also wish to be on record as noting that advances in technology do not eliminate the possibility of system failures. Not only can more technologically sophisticated systems for holding and managing data fail, when they fail they often do so spectacularly. Whereas a single paper record might become lost or be stored carelessly, when a lap-top computer, CD or flash drive holding vast numbers of electronic records is, for example, left carelessly on a city bus, literally thousands, even millions, of people can be impacted by such a mistake.

When data storage and handling fails, it is not only individuals' privacy that may be compromised. Such failures can also have considerable negative impacts on other liberties and even on 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.

We have reviewed the proposed amendments and have concerns about potential abuses to the protection of privacy, erosion of the lack of individual rights to protect one's own personal information, and the opening of disclosure of personal information to agencies, companies and entities without assurances from these entities that appropriate privacy safeguards are in place.

Concern # 1 – Consent for Inclusion of Personal Information into the electronic health record and Alberta Netcare.

Our most serious concern relates to Bill 52 amendments which appear to remove the obligation to consider patients wishes to provide informed consent and their wishes to limit the collection, access, and disclosure of information via an electronic health record.

¹ For information about the Foundation see Appendix 1 to this Submission.

The amendments seem clear: entry of health information into the electronic health record collection “does not require consent.”

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 ensure that personal and health information is in fact removed (eliminated, archived, or deleted) from the electronic health record.

Concern # 2 –Limits on Disclosure of Information and Masking Information

Related to the removal of the obligation to consider patients wishes to limit the access, use, and disclosure of information via an electronic health record, 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.

We could easily envision a wide range of scenarios, whereby unmasked information could have harmful impacts. For example, 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.

It has come to our attention that these risks are probably greater for rural Albertans, than for people in the cities, because it takes less identifying information to pick out a person in a small community than it does in a larger one. Accordingly, rural Albertans may be disproportionately at risk for the harm posed by Bill 52.

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.

Concern # 3 – Health Information Repositories

The amendments add new agencies, companies, or entities to the Alberta health network as health information repositories, however little direction is given on the role, function, and limits of these entities. Furthermore, the types of companies or entities that may be so designated are not well defined and could include companies with interests outside of health related services. The designation of a proposed repository does not appear to require an appropriate degree of review or scrutiny of the proposed repository's processes to protect privacy.

Recommendation 3. We recommend that the definition of the role and responsibilities for a health information repository be reviewed and that amendments be made as a result of that review, at a minimum, to 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.

Concern # 4 – Consent for disclosure of information, including research consent

Related to the inclusion of new health information repositories, it appears that the electronic health records will be disclosed to these new repositories for research and other purposes. However, it does not appear that in all research activities the agencies, companies, or entities would require research consent from the patient

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 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.

Concern # 5 – Removal of Need for Privacy Impact Assessments when providing health information to the Minister

With respect to the disclosure for health systems purposes, Bill 52 compels custodians to make patient information accessible for the electronic health record or Netcare and makes it an offence not to comply with the Minister regarding such matters. Yet it appears that a Privacy Impact Assessment (PIA) is not required prior to complying with such a request.

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 to the Minister or Department. Retention of a PIA process would help to protect individuals and their health information from requests that may place an individual's liberties or security at risk.

Concern # 6 – Exposing the health information system to a Charter challenge

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. For example, 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.

Through such violations of privacy other constitutionally protected rights may also be put at risk by Bill 52. For example, 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 right to privacy is protected by section 7 of the Canadian Charter of Rights and Freedoms, as is the right to security of the person. According to experts with which we have consulted, Bill 52 creates the "ripest environment for a constitutional challenge in the country."

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.

Summary

We have been pleased to have been invited to provide a submission to the committee. We acknowledge that adoption of Bill 52 might possibly bring some benefits

to Albertans. However, we have grave reservations 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. This includes retention of an individual's basic right to provide informed consent and withdraw their consent if they so choose. We suggest provisions to address requests to mask specific parts of data files. We recommend that greater clarity, definition and limitations be placed upon the Health Information Repositories. Furthermore, we suggest that greater protections be put into place to ensure minimal disclosure of information. This includes retention of the need for Privacy Impact Assessments and reviews for disclosures of information, even those to the Minister and Department. We also suggest that consultations with legal counsel and privacy experts occur to avoid possible conflicts with the Charter of Rights and Freedoms.

Finally, on a procedural point, we respectfully suggest that greater time and warning of deadlines be given for public input into the amendments and the legislative process. The limited amount of time given from receipt of the request to make a submission to the deadline for written submissions created difficulty in providing an appropriate response.

WHO WE ARE, AND WHAT WE DO

**A backgrounder prepared by Janet Keeping, President,
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1.0 Introduction: What is the Sheldon Chumir Foundation for Ethics in Leadership?

The Sheldon Chumir Foundation for Ethics in Leadership is a non-profit organization and a registered charity. The Foundation was created by Sheldon Chumir to carry out programs aimed at *the betterment of society through the encouragement of leadership which is motivated by high ethical purpose*. Although from time to time the Foundation provides financial support to other organizations, it is not primarily a granting body.

The Foundation was created in 1992, the year of Mr. Chumir's death. It began active operation in 1999 with the appointment of Dr. Marsha Hanen as first President.

The Foundation is governed by a Board of Directors of five people from a number of different walks of life, including business, the judiciary and academia. The Board has decided that it is time to expand its membership and this document has been prepared to give prospective board members an introduction to what the Foundation is and what it does.

To date, Foundation activities have been funded largely by the income generated by Mr. Chumir's estate. Gifts from individuals and estates, and grants from other organizations, supplement these monies and are always welcome.

2.0 Geographical reach of the Foundation

The Foundation is based in Calgary where Mr. Chumir was born, grew up and – after studying in Britain and working in central Canada for a few years – spent most of his life. We see ourselves as an integral part of the Calgary scene, but carry out programs and strive to have strong relationships in other Alberta centres, especially in Edmonton.

The Foundation also has a network of individuals and organizations across Canada with which it works. These range from the British Columbia Civil Liberties Association in Vancouver and the Canadian Civil Liberties Association in Toronto, to the

Centre for Values and Ethics at Carleton University in Ottawa to the School of Journalism at University of King's College in Halifax.

The Foundation is beginning to explore opportunities to carry out programming in Europe, possibly on ethical questions connected with resource development.

3.0 Vision, Mission and Focus

The Foundation's Vision is *an active, involved citizenry in a society characterized by principled and trustworthy leadership.*

Our Mission is *to promote action which exemplifies ethical principle.*

Our Focus: The Foundation's activities are open to the public, private and voluntary sectors and seek to:

Support open dissemination of ideas and tolerant discussion by providing a forum for dialogue on the ethical dimensions of the issues of the day;

Develop informed dialogue on how to foster principled, fair, community-minded values and behaviour;

Recognize and support role models who exemplify an ethical approach to successful leadership; and

Serve as a center for ideas and resources for the promotion of its objectives.

4.0 Priority areas of interest

The mandate of the Foundation could, given its general language, extend over an extremely broad range of areas. To make a difference, we have to concentrate our efforts. The following are our current priorities:

- Ethical issues connected with identity, diversity and "otherness";
- Recognition, enhancement and protection of human rights and civil liberties;
- Public sector governance, rule of law and renewal of our democratic institutions;
- Business ethics; and
- Ethical leadership on major resource development projects, for example, of the Alberta tar sands.

5.0 Current programming

This section of the Backgrounder will describe some of the activities the Foundation is currently engaged in and will be broken down according to the priority areas identified above. In addition to the work mentioned below, the Foundation also puts out a quarterly newsletter – the *Chumir Ethics Forum*.

5.1 Ethical issues connected with identity, diversity and “otherness”

The Foundation anticipates that over the next few years activities aimed at exploring the ethical dimensions of identity, diversity and “otherness” will occupy a considerable portion of our time. While much of what we were already doing could be seen as fitting within this area (for example, our work on Alberta human rights law and policy, see below), we formally launched a Project on these topics this year, in October 2008, with a symposium on “Identity and Polarization: Implications for our Ability to Live Well Together”. Immediately following this 1½ day gathering, we spent an additional day with the symposium speakers exploring where they thought we should concentrate our efforts in future work. Speakers at the Symposium included Kwame Anthony Appiah, Morton Weinfeld, Janice Stein and Daniel Weinstock.

While we are still in the process of assessing the outcomes of those discussions and integrating them with our own views as to what is most important in this arena, it looks like we will be focusing especially on 1) the appropriate role of religion in Canadian public life (including the overlap of diversity, religion and gender and the impact of large-scale immigration from cultures which do not recognize a secular sphere), 2) diversity and poverty (both the divisiveness of large differences in wealth and the racialization of poverty in Canada), 3) the impact of increasing diversity on the strength of our democratic institutions, such as respect for freedom of expression, and 4) issues connected with citizenship.

One of the points of overlap with our work on human rights and civil liberties protection (see below) is our programming on “offensive speech”. Since January of this year (2008) we have held a series of events, and provided commentary in the media, on the ethics and law of offensive speech. These public events have been held in both Alberta and Nova Scotia, have involved speakers from across the country and generated considerable discussion in the blogosphere and other media.

5.2 Recognition, enhancement and protection of human rights and civil liberties

We are eager to work on civil liberties issues – especially on freedom of expression – whenever good opportunities arise, but our biggest piece of recent work in this area has addressed the need for significant reform of Alberta’s law, policy and administrative practice in the area of human rights, in particular, of anti-discrimination measures. A project on these issues was launched in December of 2005 and a report to the Alberta government containing recommendations for reform was submitted to the

Minister responsible for the Alberta Human Rights Commission in September of this year (2008).

This project probably illustrates better than any other the variety of activities in which we engage. In the course of the project the Foundation conducted research in-house and commissioned reports by independent experts. We held events for the public at large, including a policy workshop in Edmonton using speakers from Alberta as well as several other Canadian jurisdictions and a more community-oriented event in Calgary involving a theatre company which enacted discriminatory scenarios and invited audience participation in discussion of them. We offered professional development seminars in several locations around the province on “How the Alberta Human Rights Commission Works and How It Could Work Better”, which were partially financed by the Alberta Law Foundation. When our draft recommendations had been formulated we held a series of consultations with interested members of the public in eight different Alberta communities, from Fort McMurray in the north to Lethbridge in the south of the province. We also cooperated with Human Rights Commission staff on the review of a set of guidelines for the hospitality industry and prepared advisory materials for university and college students on how they can protect their rights to be free from discrimination.

5.3 Public sector governance, rule of law and renewal of our democratic institutions

Like many Canadian organizations, the Chumir Foundation is concerned about the health of Canadian democratic institutions, including – with voter turnout levels at record lows across the country, but especially low in Alberta – our electoral system. Although we do not yet have a full-scale project laid out on democratic renewal, we will be working consistently in this area and will coordinate activities with other organizations, especially in Alberta. For example, the Foundation’s Research Associate, Dan Shapiro, sits on Public Interest Alberta’s Democracy Task Force.

This is not a new area for the Foundation. For the last two years we have been running a series of public events (in Calgary, Edmonton and Lethbridge) on women in electoral politics. And from its inception, the Foundation has been involved in efforts to strengthen democratic institutions, such as the concept of citizenship (see below).

We are regularly called upon to speak on public sector governance issues, such as, allegations of corruption, or freedom of information and other transparency issues. For some concrete examples, our President, Janet Keeping, spoke recently in Ottawa at the annual conference of the Canadian Access and Privacy Association on “Combating Corruption Through Public Information Systems: The Primacy of the Rule of Law”. In March 2009 she will be speaking at the First Global Conference on Ethics in Public Life in Salzburg, Austria. The title of her paper will be “Ethics at the Alberta Energy and Utilities Board: Appearance or Reality?”

Growing out of her more than 10 years of work on governance reform in the former Soviet Union, Janet Keeping is especially interested in issues concerning the rule of law, both in Canada and abroad.

5.4 Business ethics

Although business ethics has not constituted a large portion of our work, it has always figured in the Foundation's programming. Currently, the Chumir Foundation is part of an extensive network of Canadians interested in business ethics. Run out of York University's Schulich School of Business, the Canadian Business Ethics Research Network (CBERN) brings together academic researchers and industry practitioners together with organizations such as the Chumir Foundation, which are focused largely on public engagement, so as to increase the productivity of all and give business ethics issues greater public profile.

Foundation staff also participate in local business ethics-related activity. For example, Heather MacIntosh (currently on leave, working in Bolivia) has been an active member of the leading corporate social responsibility (CSR) networking group in Calgary.

As an on-going contribution to business ethics education, the Foundation funds the "ethics event" at the annual Inter-Collegiate Business Competition at Queen's University.

5.5 Ethical leadership on major resource development projects, for example, of the Alberta tar sands

To date, the Chumir Foundation has not been involved in resource development issues to any significant extent. But one of Canada's major public policy dilemmas surrounds the development of the Alberta tar sands. Given the Foundation's base in Calgary, the host of ethical issues surrounding the tar sands and the manifest lack of leadership on those issues, it is proving impossible to remain aloof from questions about development of the tar sands. The Foundation will be addressing the overarching issue of what would ethical leadership on the tar sands look like? Our activities in this context will be undertaken in conjunction with partners (as is the Foundation's usual practice), including possibly other CBERN members.

6.0 Past activities – some examples

The Foundation's first major undertakings were bi-annual symposia: in 2000 on "Beyond Cynicism, Towards Ethics in Leadership", in 2002 on "Community Values in an Age of Globalization" and in 2004 on "Canadian Values in the World Community". On the basis of each of these events, a book was published by the Foundation. Speakers

at these events included Alan Borovoy, Maureen Maloney and Bob Rae; Lloyd Axworthy, Bronwyn Drainie, Naomi Klein and Stephen Lewis; Andrew Cohen, Madelaine Drohan, Ahmad Kamal and Jennifer Welsh.

Early on, two fellowship programs, of four-month duration each, were established, one devoted to ethics and public policy, the other to media ethics issues. Although these programs have been discontinued, one fellowship gave rise to an especially valuable piece of work – an examination of why homelessness remains an unsolved problem in Canada. This was published as “Shelter, Homelessness in a growth economy: Canada’s 21st century paradox”. Its author Gordon Laird, a Calgary-based journalist, continues to speak all over Canada on the report’s conclusions that homelessness is a crisis created by policy changes taken in the 1990s and that we spend far more money in Canada not housing people than were we to provide permanent accommodation for the homeless. Gordon is likely to work with the Foundation again, this time on the poverty issues to be addressed by our project on diversity.

One question that Foundation activity focused on during the early years was, what does citizenship look like in a healthy democracy? Renewal of our democratic institutions has always been part of the Chumir Foundation’s focus.

The Foundation has established three essay prizes or scholarships, one each at the University of Alberta, the University of Calgary and Mount Royal College in Calgary. It has also worked for several years now with local junior and senior high-schools, for example, on debating competitions and workshops aimed at ethical issues of especial interest to young people.

7.0 International aspects and applications

The Foundation has conducted some activities outside North America, but these have been few in number and limited in scale. We would like to expand the international dimensions of our work in at least two ways. First, we intend to ensure that international comparisons with Canadian practices are integrated into our programming wherever appropriate. This is already being done, for example, in connection with our work on diversity issues: how are issues of the integration or assimilation of immigrants being addressed in Europe, as compared to Canada? Who stands to learn what from whom in this context?

Second, we would like to carry out more programming abroad. To that end, we are beginning to explore possibilities for working with international NGOs, possibly for example, Transparency International, on governance issues in Eastern Europe. This is a region where our current President, Janet Keeping, has considerable experience.

We will also continue to participate in study tours, and other such efforts, to expose leaders from the developing world to better governance practices. For example, over the last eighteen months the Foundation set up meetings and seminars for two

groups of officials from China with Albertans – largely provincial government officials – working in areas of interest to the Chinese, such as access to information policy and law. Our Canadian partners in these cases were Transparency International and York University’s Centre for Practical Ethics. In the past the Foundation has been involved in similar projects with government officials from Tanzania.

8.0 Current staffing

As of January 2009, the Foundation has five permanent employees. We also run an Intern program which means that every year we have either one or two additional people working with us. We are contemplating opening a smaller, satellite office in Toronto.

9.0 Conclusion

The Sheldon Chumir Foundation for Ethics in Leadership is an organization that seeks to dispel cynicism by illustrating how society can advance through action motivated by high ethical principle.