

Consumers' Association of Canada (Alberta)

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Mr. Broyce Jacobs, Chair, and Committee Members
The Select Special Health Information Act Review Committee
Box 801 Legislature Annex, 9718-107 Street
Edmonton, Alberta, T5K 1E4

July 30th, 2004

Dear Mr. Jacobs and Committee Members,

The Alberta Chapter of Consumers' Association of Canada was pleased to see the formation of the Health Information Act Review Committee this spring. We have been anticipating an opportunity to provide input to the Committee's deliberations and consultations.

Our organization and its affiliates have a long history of scrutiny and analysis of the impact of the increasing electronic collection, use, and disclosure of the personal information and medical records of ordinary Canadians. We have tracked and participated in provincial and national discussions on such issues for the last 15 years. These include development of the CSA Privacy Code, PIPEDA, the National Privacy Working Group on Health Information, and a CAC/PIAC study of citizen expectations on secondary uses of health information.

We believe our on-the-ground experience and insights through calls and letters from consumers who have experienced this new environment, and our knowledge of the practical realities and larger social context in which new applications and legislation are coming forward, would have great value to Committee members. We believe that a deliberate effort to inform, educate and engage the public in a thoughtful dialogue regarding the risks and benefits and management of electronic records would provide important insights for your Committee.

Therefore, we were taken aback by the poorly constructed consultation document we received early in July, the short deadline for input during the summer, the lack of details regarding the pan-Canadian framework discussions and intent, and the lack of evidence of planning for any significant public dialogue or consultations.

The people who will have the fabric of their daily lives most affected by this Legislation, and the struggling community based organizations representing their interests do not have the financial or human resources to meet these deadlines. The timelines also preclude any opportunity for investigation of the issues raised by inter-relationship of the proposed changes (and gaps) in the consultation document and/or meaningful public dialogue. There will probably be little general public response as most Albertans are woefully unaware of the issues due to lack of past disclosure, and would have great difficulty decoding the consultation document.

We had anticipated that we would see an announcement of some kind of extensive consultation and hearings - similar to those held when the *Freedom of Information and Privacy Act* came into being, particularly since such consultations had been neglected when the *Health Information Act* passed - and was later amended. We also expected to see more disclosure of current practices and issues and some risk/benefit/cost studies. Instead, a decision to have Committee staff summarize input raises concerns that important considerations will be completely missed.

We therefore urge your Committee to reconsider and extend its timelines. We also urge the Committee to secure funds and plan a deliberative dialogue with Albertans through a number of strategic initiatives. One such initiative could be funding and working with organizations such as the Consumers' Association and Alberta Civil Liberties Foundation to develop case studies to elucidate the issues and trade-offs, sponsor forums, and conduct public consultations. Another

could be sponsoring a Citizens' Lay Consensus Panel Conference on the implications and management of a state mandated central database of electronic health-related records of all citizens for treatment, administration, payment, research, and possible other purposes. Dr. Edna Einsiedel at the University of Calgary has experience with this model of consultation. Since the Committee has identified this legislation may create a precedent nationally, we would urge the Committee to invite national citizen groups to participate. Examples include as the Public Interest Advocacy Centre, the Canadian Civil Liberties Association, the National Privacy Coalition, related National Human Rights groups, the Canadian Taxpayers Association, and Democracy Watch.

We are also requesting an opportunity to make a formal presentation to your Committee on September 14th at the earliest. We would anticipate providing more detailed background material and examples, and responding to your questions. Some of the issues we would address include:

- The need to revisit and revise the stated purposes and language of the *Act* to more accurately reflect its nature and enabling applications which have removed traditional citizen safeguards related to the privacy and confidentiality of medical records.
- The inappropriate protection (and inclusion) of *health provider* information in the HIA which restricts public access to the business information of providers, thus compromising care, provider accountability, and informed choice.
- Disturbing reports about how the HIA is being used by some providers to increase the expense and hassle of accessing of one's own medical records and information on treatment decisions - leading to less patient control and participation in decisions, less medical record accuracy, and less provider/payer accountability.
- Implications of extending the HIA (and expanding circle of information sharing without knowledge or consent) outside public health plan funding.
- Implications of proposed disclosures of personal and health information to private insurance companies for payment purposes without one's knowledge or consent.
- Implications of expanding circles of care, consolidation of records, increased reliance on private payers, lack of patient knowledge or consent for sharing information, the new research environment, and secondary uses of health and personal information.
- Implications of the current broad definitions of "health information" in the HIA which include a person's physical or mental health, the treatment they are receiving and have received, drugs they have been provided with, authorized healthcare aids or products received, and the amount of health care benefits paid or payable.
- Implications of rapid function creep in collection, use, and disclosure of medical records through scope, practices, interpretations, and amendments in past 10 years.
- The larger societal context in which these changes are occurring, including the increasing reliance on (unreliable) predictive testing and diagnosis to determine public and private benefits, and the limited ability of governments and citizens to control access to consolidated and centralized health records by third parties.
- The high costs and the lack of demonstrated risk/benefit/cost evaluations of initiatives undertaken and enabled under the HIA to date.
- The missed opportunities for using computerization and more limited electronic records and systems to work to the genuine benefit of patients and citizens!

To date, most of the early promised benefits for patients and citizens from the use of information technology in the field of healthcare and health records have not been fulfilled - here or in other provinces. Instead, patient and citizen rights have been dramatically eroded. Far too many well-intended people promoting these initiatives have been willing to trade off historic ethical codes and human rights in the name of efficiency as unanticipated problems have arisen. Yet, there is no evidence they have taken into account the very real, but often less visible, human, social, economic, and democratic costs of these trade-offs. Nor have they demonstrated compelling reasons to justify the loss of so many privacy rights and expectations, and the enormous sums of public dollars diverted to these initiatives.

In closing, we acknowledge your genuine interest in trying to do the right thing for Albertans, but wish to alert you to the fact that your Committee's decisions will have far reaching consequences for you and all Albertans. Your decisions could adversely affect your access to healthcare and health plan coverage, freedom of treatment choice, access to credit, mortgages, and insurance products, future employment options, the accountability of public and private healthcare providers and insurers and access to redress and remedies. For example, some studies suggest that that increased surveillance of citizens without compelling and agreed upon societal reasons, contribute to stress and ill health. Therefore, we urge you not to make decisions with only a limited understanding of the practical realities and issues at stake.

Your committee has a unique opportunity to provide genuine leadership in Canada by embarking on a review of other international jurisdictions, particularly Australia, and undertaking and facilitating informed public dialogue on these important issues. We urge you to do so, and would be pleased to assist you in this regard. With some sober second thought we believe it is possible to find the right path to maximize the benefits of computerization and minimize the harm.

We look forward to an opportunity to meet with you in order to discuss these important issues.

In the meantime, our association has a number of letters on file (in PDF format) relating to our past input on the development of an integrated health information system and Legislation in Alberta from 1997 to 2003. If Committee members would like copies of these documents, please contact our office manager, Mr. Scott Kidd at 426-3270 or e-mail cacab@ecn.ab.ca.

Yours truly,

Larry Phillips, President, and Members of the Board
Consumers' Association of Canada (Alberta)

CC Hon. Gary Mar, Minister of Health and Wellness
Hon. Dave Hancock, Alberta Minister of Justice and Attorney General
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Public Interest Advocacy Centre, Attn: John Lawford
National Privacy Coalition, Attn: Ms. Valerie Steeves,
Canadian Civil Liberties Association, Attn: Attn: Jeremy Patrick-Justice
Canadian Taxpayers Association, Attn: Mr. John Carpay
Democracy Watch: Attn: Duff Conacher
Consumers' Association of Canada - provincial affiliates (via e-mail)
Alberta Civil Liberties Association, Attn: Mr. Stephen Jenuth
Alberta Civil Liberties Foundation, Attn: Ms. Linda McKay-Panos
Dr. Edna Einsiedel, Faculty of Communications and Culture, University of Calgary
Canadian Mental Health Association, Alberta Division: Attn: Mr. Ron LaJeunesse
Hon. Anne McLellan, Deputy Prime Minister, Canada
Hon. Ujjil Dusanjih, Minister of Health, Canada
Ms. Jennifer Stoddard, Privacy Commissioner of Canada