

**Response to the Final Report
of the
Select Special Health Information Act Review Committee**

from the
Information and Privacy Commissioner of Alberta

As the Commissioner responsible for the application and implementation of the Health Information Act, I feel it is incumbent on me to comment briefly on the Final Report of the Select Special Health Information Act Review Committee ("the Committee").

One must take into account that the task before the Committee was a daunting one: it had to review a complex piece of legislation dealing with an even more complex area (the entire health care system) in a very short time. This review was mandated by the *Health Information Act* ("the Act" or "HIA") and it simply had to be done within the required time. The Committee had to review a large number of detailed submissions. For background expertise, the Committee had to rely largely upon staff from Alberta Health and Wellness and my Office: it did not have its own research staff. I know the Committee availed themselves of this expertise fully. The learning curve for the Committee members would have been extremely steep.

Having said that, my response to the Final Report is as follows:

Who should be included in the Act – The Act specifically made the scope of the Act an item for review by the Committee. The Committee recommended maintaining the status quo for government departments and public bodies. The result of the recommendations is the scope of the Act would remain largely unchanged so far as governments and public bodies are concerned, with the exception that the Act should be expanded to apply to ambulance services. I agree with this: the public bodies which should be in the *Health Information Act* "arena" are in; others are covered by the *Freedom of Information and Protection of Privacy Act*. The two Acts have a good degree of harmony and information that needs to be shared between the various bodies, can be. The sharing is not always done in the most administratively convenient way, but the objective of both laws is privacy, not administrative convenience.

However, significant scope issues were not addressed, except to recommend a process for further review. The Committee recommended that a committee of the Legislature be established in early 2005 to complete a focused review and consider whether the issue of expanding the scope of the Act to include the privately funded health sector and health clinics of post-secondary educational institutions. The fact that the Act applies only to the publicly funded health sector (with the exception of pharmacies) is very problematic. The effect of this saw-off is jurisdictional chaos. Some health care providers are subject to 3 different privacy laws from 2 different jurisdictions, depending on what services

they are providing and, oddly, whether Alberta health care insurance is paying for the service. This unnecessarily complicates the already complicated lives of these health care providers.

Similarly, the issue of whether genetic information should be explicitly addressed by the Act was deferred.

Who gets health information without consent (Secondary Use) – The Committee considered a number of requests for creating additional categories for health information to be disclosed without consent. In my remarks to the Committee, I asked them to be jealous guardians of Albertans' health information and I am gratified to be able to say that the Committee did that for the most part. The Committee is to be commended for recommending against a number of disclosures without consent, for example, disclosure without consent to public bodies for common or integrated government programs. This may cause some administrative inconvenience but I think it was good judgment from a privacy point of view.

However, the Committee has recommended new disclosure provisions that involve law enforcement agencies. For example, the Committee recommended that custodians must disclose health information to the police when the custodian has reasonable grounds to suspect that an individual has been involved in some form of criminal activity and when the custodian has reasonable grounds to suspect that a prescription offence is being attempted or committed. The problem with this recommendation is that it puts the onus on the health care provider to make a call as to whether an individual has been involved in criminal activity. The Criminal Code covers a lot of ground: it is not reasonable to expect custodians to be more than passingly familiar with it. Furthermore, a health care provider's immediate and primary concern is the health of whatever patient presents to him or her. Health care providers should be free to keep this imperative. Health care providers have no interest in making hospitals havens for criminals. Their interest is in healing. This recommendation goes further than even the police services asked for. All the police asked for was to be able to get, on request, very limited information about a patient who is a suspect so as to enable the police to get a subpoena or warrant so the police can do their job. The request by the police services was reasonable and practical and I supported it at the time it was made. The Committee's recommendation pulls health care providers too far into law enforcement and places unreasonable expectations on them.

The Committee recommended that custodians should be allowed to disclose health information where there is reason to believe that an individual has committed fraud against the health care system. I do not have a problem with this since it is permissive (that is, a health care provider can disclose information if they think something is going wrong, but it does not require them to make an investigation on their own part).

General - I requested some changes to the Commissioner's powers to enhance privacy protection for Albertans, increase transparency and accountability and achieve consistency and efficiency in administering the concurrent provincial and federal privacy regimes. I commend the Committee for recommending my Office have explicit

authority to publish research approvals that have been granted by Research Ethics Boards in order to provide the public with more information about health research projects.

On the other hand, I asked for the explicit right to conduct and compel information for purposes of conducting audits. I requested explicit powers to enter into extra-provincial agreements and to consult and delegate extra-provincially to avoid duplication in administering the provincial and federal legislation that applies to the health sector. The recommendation is that consideration of these powers has been deferred to the 2005 committee. Neither of these are urgent issues. However, they are important to me to enable my Office to do its job.

Similarly, consideration of the need for more clear and transparent rules for the electronic health record has been left to that future committee. As the electronic health record evolves, the need for clarity and certainty will grow. This matter should not be left hanging for long.

Background - HIA was enacted on December 9, 1999 and has been in force for over three years, since April 25, 2001. Three other provinces have enacted specific health information legislation. Manitoba's legislation has been in force since 1997 and is currently undergoing its first legislative review. Saskatchewan's legislation came into force on September 1, 2003. Ontario's legislation is expected to come into force on November 1, 2004.

Since HIA was enacted, other legislative developments have occurred in the area of access and privacy that impact this review. The provincial access and privacy legislation for the public sector, the *Freedom of Information and Protection of Privacy Act* ("FOIP Act"), underwent its second legislative review. The provincial access and privacy legislation for the private sector, the *Personal Information Protection Act* ("PIPA"), came into force on January 1, 2004. The federal access and privacy legislation for the private sector, the *Personal Information Protection and Electronic Documents Act* ("PIPEDA"), came into force on January 1, 2004.

HIA created new rules to protect the privacy and confidentiality of the health information of Albertans. The Act allowed health information to be shared for the provision of health services and to manage the health system. HIA set out rules that require adequate safeguards as well as the collection, use and disclosure of health information in the most limited manner and with the highest degree of anonymity possible in the circumstances. The Act established new rights for individuals to access, correct and amend their own health information. HIA created remedies for individuals for contraventions of the Act and provided for independent review of custodian decisions and for resolution of complaints made under the Act.

The Act required that a special committee of the Legislative Assembly begin a comprehensive review within 3 years of coming into force and submit a report with recommendations within one year after beginning the review. The review had to consider the application of the Act to departments of the Government of Alberta, to local

public bodies under the FOIP Act and to any other entity that is not a custodian but has information about the health of an individual in its custody or control.

In addition to the scope issues that the Committee is statutorily required to address, it considered whether an appropriate balance was being achieved between the protection of individual privacy and the sharing and access to health information. The Committee also considered the impact of electronic health records and whether the Act and recommended amendments harmonized rules in accordance with the concurrent pan-Canadian health information privacy and confidentiality framework.

The Committee was an all party committee that was struck on April 2, 2004. The Consultation Guide that was circulated in June 2004 raised questions for consideration and provided focus for the review. The Committee received 72 written submissions and 15 oral submissions from stakeholders. Due to an impending election call the Committee tabled its Report within six months, on October 18, 2004.

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