

# Assessing the State of Health Privacy

## Privacy Trends: Complying with New Demands

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Good afternoon.

Alberta is one of 3 provinces that has, in force, legislation that deals with health information. The *Health Information Act* came into force in 2001. Being responsible for this legislation has made it necessary for me to develop some understanding and awareness of the health information landscape. I propose to share that with you as you finish your lunch.

HIA applies to “custodians”. Custodians include:

- hospitals and nursing homes outside of those operated by regional health authorities;
- provincial health boards;
- Regional health authorities;
- The Alberta Cancer Board;
- A health service provider who is paid under the *Alberta Health Care Insurance Act* to provide health services;
- Licensed pharmacies;
- Pharmacists;
- The Minister of Health and Wellness;
- Any one else named in the Regulations.

HIA gives individuals the right to access any record a custodian has about them, subject to some exceptions (section 7), for example if the disclosure would harm the applicant. It also allows individuals to request corrections to their information (section 13).

HIA establishes different kinds of information: diagnostic, registration and health services provider information, for example, and then sets out rules

respecting the way in which these can be collected, used and disclosed. For example, a custodian can disclose “registration information” for the purpose of collecting a fine or a debt owed by the individual (section 36), but could not release diagnostic information for that purpose.

HIA allows non-identifying information to be used for any purpose. “Non-identifying information” is information from which “the identity of the individual cannot be readily ascertained”. A custodian can perform data-matching on the information that they hold internally, but personal information from two or more databases may not be matched without consent (sections 68 –72).

HIA contains a list of the disclosures that may be made of personal health information without asking for the consent of the individual (section 35). Some of the more notable of these are:

- to another custodian for the purposes of providing health services, determining eligibility for services, conducting professional discipline proceeding, conducting research, for internal management, among others;
- to persons responsible for caring for the individual;
- to family members or those in a “close personal relationship” with the person;
- to auditors;
- for court proceedings;
- for complying with warrants;
- to police in situations where they are investigating “life threatening injury” to the person, unless the person specifically says not to disclose;
- to another custodian for detecting fraud or abuse of the system;
- to any person in order to avert an “imminent danger” to any one; and
- to descendants of the person, in order to provide health services (i.e. genetic history).

Note that the section says “may”, not “must”. This means that the final decision as to whether or not to disclose rests with the custodian. This feature of HIA has attracted the most controversy.

What is the state of health privacy in Canada? Is it a war zone, a game show, a tower of Babel, the Brave New World or is it just a mess?

There is no other kind of information that attracts the same number of demands from the same number of diverse interests.

What are these interests and what are their demands?

Well, in the beginning there was the patient and the doctor. The patient wanted to get well and the doctor wanted to make the patient well and earn a living. But medical science advanced: more diseases are identified, more research is done, more drugs are invented, more drug interactions are identified, more treatments are developed, and health care is more expensive. Then too, the personal computer became powerful and inexpensive. And here is where we are:

- An electronic patient record would enable health care providers to keep accurate legible records of patients that can be matched against benchmarks for treatment. Reduce mis-diagnoses, reduce adverse drug interactions, and indicate the widest variety of available treatments. Specialized “micro” databases are reproducing like bunnies. I have seen stand-alone databases for emergency rooms, intensive care units, maternity units, cancer facilities and extended care facilities.
- An electronic health record would ensure that any Canadian could be fully treated anywhere in Canada, anytime of the day or night because her records would be available 7/24, as they say. One emergency room physician told me she practices what amounts to veterinary medicine: she attends patients who cannot tell her what is wrong with them or what their history is.
- Researchers have powerful electronic tools for manipulating huge volumes of data. They want health information so they can find the determinants of cancer, AIDS, Alzheimer’s, CF. Researcher’s, who sometimes think they are doing God’s work, are not all very sympathetic towards arguments of privacy, control or consent. “I’m going to cure cancer and you are worried about me seeing your health record?”
- System administrators are trying to run increasingly expensive health care systems with increasingly tight money. How much taxes are we willing to pay to support health care, especially when there do not seem to be any limits to the resources needed. The administrators want to know why an appendectomy is cheaper in Moncton. They want to know why there are more health care numbers in Ontario than

- there are people. They want to know which health care providers are bilking the system and for how much.
- The public health people want to track and isolate diseases. Where have the cases of West Nile virus been reported in the past 12 hours?
  - The health surveillance people want to know how Caitlin, who presented in emergency last night, managed to step on that rusty nail? Was she playing in an alleyway? Were there no playgrounds in her neighbourhood? Was she unsupervised? Single parent family? Income level?
  - Statistics Canada wants to know the state of health of Canadians. So does the Canadian Institute for Health Information and Canada Health Infoway.
  - Law enforcement authorities want to know if that bruise could have been a result of a blow struck in anger or if those burns would be consistent with a bomb exploding prematurely or if that unconscious guy has a blood alcohol content of 0.08, or how many knife wounds are in emergency tonight.
  - The people who run screening programs claim they need as close to 100% participation to make the program effective, especially from the people who might not volunteer or consent. These are, demographically, often the ones who are most at risk.

Then we have the “Tower of Babel” that is our regulatory system.

- “Health” is a matter of provincial jurisdiction, which the Federal Government has entered via the Canada Health Act. As a result, there are 14 jurisdictions with regulatory power in the area of health information (10 provinces, 3 territories, Ottawa).
- Most have legislated access to information and protection of privacy.
- Ottawa has PIPEDA, the implications of which for health information are not clear to me. The last thing I heard was that the Federal Privacy Commissioner seemed to indicate that when he was reviewing research proposals, he would be looking for patient consent.
- Alberta, Saskatchewan and Manitoba have specific health information statutes (Saskatchewan’s is not in force).
- Ontario has a private sector privacy bill that would cover health information.
- BC’s FOIP Act covers health professions and they are discussing a bill that would cover the private sector.

- There are 32 health care professions (docs to dieticians) covered by the Alberta Health Professions Act. Each self-governing profession could have by-laws dealing with health information, doctor-patient confidentiality and so on. Multiply that by, let's say, 13 jurisdictions.
- Alberta has 6 recognized Research Ethics Boards. Let's pretend that is an average (Ontario has more, PEI less) per jurisdiction. That is 78 REB's, each having jurisdiction over health information. We'll include entities like the Medical Research Council of Canada in that number. Interestingly, you may have noticed that last week Health Canada has announced its intention to become involved in setting uniform standards for research involving human subjects.

Is anyone keeping count of these jurisdictions?

Finally, we have, thanks to cheap technology and very useable software, databases proliferating everywhere. Heaven knows what is in them and heaven knows how they are being linked. In Alberta, I am supposed to get privacy impact assessments when a database is either created or linked. We have under a hundred PIAs and I suspect there are a lot more databases than that. I understand that Canada Health Infoway Inc is going to do an inventory of these.

You may be surprised if I now tell you that these things do not give me cause for despair (although I am often left shaking my head in wonder). Here is what I take from the situation:

- Health information is tremendously valuable to a large number of people.
- There is a very high degree of concern over how it is to be used.
- There is massive tension between the needs of the system and society versus the rights of the patient or individual. Everyone is wrestling with this and, might I add, not just in the area of health information.
- We are on the cusp.

Let me give you some anecdotal examples of what I mean by this "cusp". A respected lawyer said to me: "Taking something from me without my consent is theft. My health information is my property." A dean of a health care faculty told me: "We could do so much valuable research if we had ready access to health information. Privacy is an obstacle." When the

Health Information Act of Alberta was first proposed, it was roundly criticized for the lack of consent to the collection, use and disclosure of personal health information. Now, two years later, many health care professions are calling for the repeal of section 59 which calls for the consent of the patient before health information is disclosed by electronic means (i.e. put in a database such as an electronic patient record or electronic health record). Why? Are they evil? Not at all. They found out that it takes around 15 minutes per patient to obtain minimally informed consent. They found that databases like the Pharmaceutical information Network are impaired by the inability to get a high percentage of consent. They found that administering a consent database is costly and cumbersome.

Are these issues unique to health information? No. Consider security and law enforcement since September 11: surveillance cameras proliferate; databases abound; law enforcement agencies have power to intercept communications and inspect databases that they never had before. Why? Because we have decided, rightly or wrongly, that the security of society is more important than the privacy of the individual.

And where do I stand as a Privacy Commissioner? Torn, to be honest. I very much regret the loss of individual control over personal information and health information in particular. But I cannot ignore the bigger picture, the undeniable benefits which flow from the use of health information. I am torn as to what to do. Demand consent? That's the best I can come up with at the moment (and I am open to suggestions):

- Bargain for informing the public of what is being done with health information.
- Give offices such as mine the power to investigate and address complaints about the misuse of health information.
- Allow really concerned patients to "opt out".

One thing is for sure: we, all of us in this room and then some, are going to have to take a lot responsibility for the information we are entrusted with. That means respecting the patients; not building databases that are not clearly needed, not linking them without compelling reason, not sharing information with anyone who asks, and limiting our collection of information to what is necessary for the task.

Thank you for your attention.