PRIVACY AND CANADA'S HEALTH INFORMATION HIGHWAY

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FIPA is an advocacy group for the privacy rights of individuals, and we have identified the issue of HEALTH INFORMATION PRIVACY as the most significant privacy issue of our time.

This is because of the extreme sensitivity of this type of information on the one hand, and the phenomenal desire for access to this type of information by a wide variety of interests on the other.

Heading the list of interests that want access to and control of this information are our provincial governments and health bureaucrats across the country. Their objective is to create a seamless information system for the collection, use and disclosure of your personal health information and mine.

This has been named the Canadian Health Info-structure, and the proponents of this system fervently hope that individual privacy rights will not interfere with the flow of information in this system.

WHAT DO WE MEAN BY "PRIVACY RIGHTS"?

In your conference kits you will find a 'Declaration of Medical Privacy Rights' that codifies FIPA's concept of health privacy rights.

The essence of health privacy rights is, and traditionally has been, your right to control access to yourself and information about yourself. In practical terms, it has meant your right to give or withhold consent to the collection, use and disclosure of your information.

A key question to be addressed is: "Is privacy *a fundamental human right*?"

The Supreme Court has said it is.

Privacy, the Supreme Court has said, is at the heart of liberty in a modern state. "Grounded in individual moral and physical autonomy, it is fundamental to

Charter values of dignity and autonomy of the individual". [*R. v. Oslin* (1994), 109 D.L.R. (4th) 478.]

But provincial governments are in the process of developing, and indeed some have recently passed, health information laws that override the right of consent and thus severely limit our ability to control the fate of our most sensitive personal information.

If we accept the words of the Supreme Court and the concept that privacy is a fundamental human right, the bar is raised significantly for justifying any infringement of privacy. And the Court has stated that the bar is raised increasingly with the sensitivity of the information.

Unfortunately, it seems that provincial governments consider that the diminution of privacy rights is essential to the creation of the "Canadian Health Info-way".

I disagree. I think Canadians can have privacy rights AND the highest quality health care system.

And if we are truly talking about "Empowering the Public", as is stated in the official objectives of the Advisory Council on Health Info-structure, then we must uphold privacy rights.

THE VISION OF THE CANADIAN HEALTH INFO-WAY

For the record, I find little in the broad objectives of the Health Info-way and the Electronic Health Record to disagree with. I think such a system can be based on the consent principle.

But now let's consider the exact vision of the Health Info-way that is proposed to underpin this ideal.

In 1998 the report of the Canada Health Forum provided the basic outline of a comprehensive national health information "highway". This was further expanded in the final report of the Advisory Council on Health Info-structure and a report from the Canadian Institute for Health Information (CIHI) entitled the *Health Information Roadmap.*

What is readily apparent is that health information is now viewed as a commodity. The reports are detailed articulations of the vision of a nationally accessible complete personal "health" record. This record will span an individual's life and include all contact with health care providers receiving public funds.

But the extent of and uses for the record go far beyond direct patient care.

In addition, this record is to include information euphemistically referred to as "determinants" of health - demographic, financial, educational, occupational, recreational etc. For those proponents of this broader category it seems every aspect of ones life should be made available for both epidemiological and case-specific evaluation.

For researchers this is a cornucopia of data undreamed of a but few years before.

To those responsible for administering the health care system, it is a vision of unprecedented capacity to provide profiles of health utilization that will help manage scarce resources and prevent fraud.

What emerges is perhaps the dominant obstacle or problem for the entire enterprise: the question of who controls the information that goes into the system; who controls what comes out, and with whom it will be shared?

In other words, what about privacy?

In recognition of this, the reports called for a coordinated effort to develop integrated provincial and national legislation that would govern the flow of information.

These reports did not entirely ignore privacy. But there was a strong sense that it was viewed in a negative light, as an impediment or barrier to achieving the comprehensiveness that technology could provide.

On the other hand, there emerges from these texts an unspoken but clear message that, in a country that values its single-payer public health system as a near-sacred institution, and one that is struggling financially, the public should regard the sharing of personal health information as a civic duty and the resulting pool of information as a "public good".

HEALTH INFORMATION LEGISLATION IN CANADA

With regard to legislation, we are challenged to decide if privacy can exist with a series of overlapping "administrative" models or if we should adapt a "human rights" - based model.

The health information legislation that has been passed in Canada or is currently on the table is based on the administrative, not the human rights model. Its primary purpose is to facilitate management and administration of the health care system. In fact, several drafters of the legislation have stated that a main goal was to legitimize the information flows and information-sharing practices that currently exist.

While some of the pieces of legislation are better than others, they can all, to greater or lesser degrees be characterized as “access” legislation. They are all in place to provide a set of rules for the flow of personal health information to health care practitioners, researchers and administrators. Individual consent is acknowledged as a guiding principle, but in many instances the legislation allows for a broad range of secondary uses of information without specific consent.

ALBERTA’S HEALTH INFORMATION ACT

Let’s take the example of Alberta’s recently-passed *Health Information Act.*

When introduced as a bill in 1997, it was called the *Health Information Protection Act*, but the word “protection” was dropped somewhere along the way to enactment.

As Alberta’s Information and Privacy Commissioner observed, it is “...not a privacy act: it is an information act which provides for disclosure of information under controlled conditions.”

(Alberta privacy advocates were dismayed when the same Commissioner who made that statement dropped his opposition to the act, apparently in exchange for having it added to his jurisdiction.)

FIPA was one of a consortium of four groups that united to oppose the act. One of our partners was the Alberta Medical Association, which objected that the act:

- does not meet the standard of the Canadian Medical Association’s Health Information Privacy Code, which the AMA endorses;
- fundamentally changes the doctor/patient relationship;
- compromises physicians’ ability to safeguard patient records in their offices; and
- redefines patient consent for therapeutic reasons to encompass a broad range of activities not directly related to the medical care of the patient.

Under this act, the Minister of Health, a provincial health board, a regional authority, and other so-called “custodians” of health information may demand the personal health information of any individual, and may in turn disclose this information to others.

Let me give you a real-time example of the effect this is having in Alberta.

The Alberta branch of the Canadian Mental Health Association (CMHA) provides mental health services under contract to the Alberta government.

The Alberta Mental Health Board has demanded access to all the personal files of patients who are served by the CMHA, for what they call a “program review”. They have also demanded all the staff records. I am told that they have taken the position that, under the Health Information Act, the CMHA’s records are THEIR records.

The CMHA is going to refuse to turn over the records, and the Mental Health Board has stated it will cut their funding on March 31 if they do.

The last word has not been spoken on Alberta’s legislation. We have high hopes that a challenge will be filed under the Charter of Rights and Freedoms, and that such a challenge will be successful in striking down some parts of this legislation

HARMONIZING DOWNWARD

There currently exists a federal/provincial Advisory Committee on Health Info-structure which has a privacy working group. I understand that this group is attempting to come up with a piece of model legislation that will harmonize coverage across the provinces. This is considered essential to building the Health Info-way.

Unfortunately, I believe there is no way that this will result in anything but a proposal for the lowest common denominator of privacy protection.

Looking at Alberta’s example, it is inconceivable that any province will accept being bargained into a higher standard of privacy protection.

However, I was cheered to hear that Allan Rock, until recently the federal Minister of Health, had refused to accept their latest draft as an acceptable standard of protection. Perhaps this and other pressures may compel the Privacy Working Group and even the Alberta government to reconsider their approach.

WHERE DO WE GO FROM HERE?

My organization believes there are tremendous benefits to be gained by the creation of a national health information system. However, for it to be successful and fly with the Canadian public, we think that a few things are necessary :

- There must be widespread acceptance of individuals’ right to control their personal health information. We must ensure that information may be collected, used and shared only with consent.
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- There must be recognition that the needs of researchers and administrators, while important, should not override the right to refuse to provide information or consent to secondary uses.
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- The code developed by the CMA should be promoted as a valuable guide to all those required to protect patient privacy and ultimately deliver better health care.

The CMA Code remains the best attempt to date to provide a framework from which to view privacy of health information.

Now is the time to ensure that we have strong legal protections in place to deal with health information. There can be no substitute for giving control to the individual patient except in the direst of medical emergencies. This can be best achieved by clarifying our right to privacy in law.

If people are confident that the information they provide is being handled in a responsible manner, the likelihood of their consenting to the use of some or all of their information for beneficial secondary purposes will only increase.

At the end of the day we are likely to develop technological solutions that can enhance privacy and provide researchers and administrators with information that is still far beyond what is currently available.

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