Ontario Health Information Privacy Legislation

A Briefing Paper

By Alex Drossos

Importance of Health Information Privacy

Canadians value the privacy of their health information.[1,2] In fact we have known this since 1980 when Justice Krever released his *Report on the Confidentiality of Health Information*. In Ontario, only twenty-two years later, we are now really getting serious about this issue. Recent studies of Canadians show that the public's attitudes to the privacy of their health information are highly dependent on the context, i.e. how the information is to be used. Effectively this research demonstrates that individuals do not want others to access their personal health information unless it is influencing the health or well-being of another and even then the information should only be used in the strictest of confidence.[3]

Some provinces already have adopted legislation guiding the collection, use and disclosure of personal health information (e.g. Alberta, Saskatchewan, and Manitoba[4]), but Ontario is taking longer to get it right[5]. At the federal level, numerous industrialized countries have legislation, including the European Union, Australia and perhaps most prevalently for Canadians, the HIPAA (*Health Information Privacy and Accountability Act*) legislation in the United States.[6,7]

Most Canadians, and indeed Ontarians, believe that their health information is protected by law today.[8] Most often it is protected by codes of ethics of colleges representing health professionals, but those codes are not legally binding. Furthermore, once in the hands of the private sector there is little regulation and accountability for the collection, use and disclosure of personal health information.

At the federal level there has been action to protect personal information, in general, through legislated standards. The Canadian government adopted the *Personal Information Protection and Electronic Documents Act* (PIPEDA) in April of 2000.[9] This piece of legislation takes effect in stages. The first stage took effect on January 1, 2001 for all federal and international uses of personal information, not including personal health information. On January 1, 2004 it will take effect for all provincial uses of personal information (including health information), unless the given province has adopted 'substantially similar' privacy legislation.[10] The PIPEDA is based on the ten principles of the Canadian Standards Association Model Code for the Protection of Personal Information.

These principles include: accountability; identifying purposes; consent; limiting collection; limiting use, disclosure, and retention; accuracy; safeguards; openness; individual access; and challenging compliance. These principles are important because all provincial legislation that will be deemed 'substantially similar' must also follow them.

Background and Research Questions

In Ontario, the 'saga' began in 1997, when the draft *Personal Health Information Protection Act* was released for discussion purposes only, to get the policy process started.[11] One year later, a revised version (a new statute in fact) entitled the *Personal Health Information Privacy Act, 2000* (PHIPA) was tabled in the Ontario legislature, but died on the Order Paper before reaching the third reading.[12]

Three iterations and five years later the current draft, the *Privacy of Personal Information Act, 2002* (PPIA) is pushing forward, but it too is experiencing obstacles. Given the context of Government Bill adoption and a current majority government, why has this process taken so long? Based on the way in which the policy process has unfolded, what has caused the need for numerous iterations and drafts before reaching consensus? Has this been a result of stakeholder input, or institutional arrangements,[13] or both? It is these questions, as well as where the process is expected to go next, that we seek to explain herein. This briefing paper does not seek to explain the impact of the health information privacy legislation on organizations and other users of the health information.

Policy Analysis Summary

The traditional model of the policy process, in its simplified form, consists of four components:[14]

1. Problem Definition and Agenda Setting
2. Policy Formulation and Adoption
3. Policy Implementation
4. Adoption

The process that has unfolded for Ontario health information privacy legislation is cycling through the first and second components (save the adoption piece) – numerous times. It seems that the problem is not being clearly defined in the first place or otherwise the policy that is being formulated isn't consistent with the original definition. Whatever the reason, the current

progressive conservative government in Ontario is feeling the 'heat' as a result. With an election only months away, and a Premier whose popularity is less than that of his predecessor, Mike Harris (who was in power when this process began), one wonders whether or not the legislation will even be adopted in time for the likely spring election.

We now return to the first bill that was tabled in cabinet in 2000, Bill 159. The Ontario government learned a lesson or two from its first attempt at putting through health information privacy legislation in this province with the PHIPA, 2000. After considerable opposition from numerous stakeholders in both the public and private sector it decided to take a different approach. (The views of the stakeholders are considered below.) The Information and Privacy Commissioner (IPC) of Ontario herself, Ann Cavoukian, publicly described Bill 159 as "seriously flawed".[15] Her federal counterpart, George Radwanski, went a step further to say it was so utterly flawed it should be scrapped altogether so the process can begin anew.[16]

As a result of the failure of the PHIPA, 2000, Ontario's then Premier, Mike Harris, announced that the next round of draft legislature would combine both the health information and general personal information components (formerly the *Ontario Privacy Act*) that were both already under development. This would be much like the format of the federal PIPEDA.[17] Ann Cavoukian and the office of the IPC agreed with this approach.[18] In order to take the limelight away from the Health minister who was under much scrutiny as a result of Bill 159, the new draft legislation, soon to be known as PPIA, 2002, would be created under the direction of the Ministry of Consumer Business and Services (MCBS).[19] The Ministry of Health and Long-Term Care would act in a supporting role for the health information components of the legislation.

Much of the change that resulted since the "death" of the PHIPA was due to the large amount of stakeholder submissions. Over three hundred submissions were made and due to the overwhelming response the submission period was extended and stakeholder group meetings were even held through part of the feedback process. The values of some of the major stakeholder groups were mostly as one would predict. As already noted, the office of the IPC applauded the government's work thus far, noted some major flaws, and favoured merging the health information privacy legislation with the private sector information privacy legislation.[20] The physician groups (including the Ontario Medical Association and the College of Physicians and Surgeons of Ontario) were highly in favour of the proposed privacy legislation. They indicated that physicians have always valued the privacy of their patients' health information and have always followed codes of ethics to protect this information. They too noted areas of concern, and contrary to the IPC were

opposed to merging the health information component with the private sector information component. Their reasoning was that health information is so important that it must receive special treatment to ensure the protection of the patient.[21,22]

The three nursing groups that submitted included the Registered Nurses Association of Ontario, the College of Nurses of Ontario, and the Ontario Nurses' Association. They all presented similar positions. As with the physician groups, they valued the protection of health information and were pleased to see the efforts of the Ontario Government to establish legislation in this area. None of the groups put forth a strong position on the subject however.[23,24,25] Finally, groups whose interests were in the use of health information for research purposes clearly noted that they could not allow the new legislation to impede their research efforts, which ultimately assist the Ontario public by finding new treatments and therapies and evaluating the efficacy of current ones.[26,27,28] Therefore, one clear reason that this policy process has taken as long as it has is a result of the diffuse interests of all of these (and other) stakeholder groups.[29]

Merging the health information and private sector personal information components resulted in very complex wording in the draft PPIA legislation, with the two components being tightly interwoven. Ms. Cavoukian indicated that the PPIA draft contains complex drafting, inconsistencies, redundancies, and duplication. She calls it 'complex and confusing'.[30] Mr. Radwanski recognized the improvements over the previous version, the PHIPA, but also noted there were still numerous problems.[31] The media has not helped the cause either. As a result of exploiting the breeches of privacy of two prominent Canadians at the University Health Network earlier this year[32,33] the media has ensured that the public is aware of the current problems with the lack of laws to protect personal health information, as well as the long, drawn out process that has occurred to create legislation.

Many drafts later (and fixes to the above-mentioned problems), the results are promising and the end point appears to be in sight. Having said that, just recently when the new draft legislation was tabled in cabinet it was once again passed on to a committee for review, creating further delays.[34] With PIPEDA taking effect on January 1, 2004 one would fully expect that Ontario will have equivalent legislation in place before then. With a provincial election not far away one can only begin to predict whether Ontario's privacy legislation will be in effect by early in the new year, or just in time before PIPEDA will take effect. We'll leave that prediction to the political powers that be. Either way, the process for making this Bill become a Law will long be remembered as one of the most interesting, convoluted, and lengthy in recent history.

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