Legislative Assembly of Ontario

Assemblée législative de l'Ontario

STANDING COMMITTEE ON SOCIAL POLICY

REVIEW OF THE PERSONAL HEALTH INFORMATION PROTECTION ACT, 2004

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Legislative Assembly of Ontario

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The Honourable Steve Peters, MPP
Speaker of the Legislative Assembly

Sir,

Your Standing Committee on Social Policy has the honour to present its Report and commends it to the House.

Shafiq Qaadri, MPP
Chair

Queen's Park
October 2008

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1st Session, 39th Parliament

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INTRODUCTION

The Review Process

Section 99(2) of the *Personal Health Information Protection Act, 2004 (PHIPA)* provides that sections 1-72 and 75-98 of the Act come into force on November 1, 2004. The statutory review provision in *PHIPA* is section 75 which reads as follows:

> **75.** A committee of the Legislative Assembly shall,
>
> (a) begin a comprehensive review of this Act not later than the third anniversary of the day on which this section comes into force; and
>
> (b) within one year after beginning this review, make recommendations to the Assembly concerning amendments to this Act.[1]

The provincial election in October 2007 delayed the fulfillment of the review requirements. In accordance with section 75(a) and with a motion passed in the Legislative Assembly of Ontario on June 3, 2008, the Standing Committee on Social Policy held public hearings at Queen's Park on August 28, 2008.[2] Notice of the hearings was posted on the Ontario Parliamentary Channel and the Legislative Assembly website.

The Standing Committee issued an invitation to the Information and Privacy Commissioner/Ontario (IPC) to appear before the Committee. The Committee also notified 28 organizations that public hearings were taking place, and invited them to make submissions. All groups and individuals who contacted the Committee Clerk by 5:00 p.m. on Friday, August 8, 2008, were scheduled as witnesses at the public hearings.

In addition to hearing from 15 witnesses, the Committee also received 18 written submissions. All of the oral and written submissions are listed at the end of the document.

The Committee extends its appreciation to staff of the Ministry of Health and Long-Term Care for their attendance at the hearings and to all those who made submissions. The Committee also acknowledges the assistance provided during the hearings and report writing by the Ministry of Health and Long-Term Care,

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[1] *Personal Health Information Protection Act*, S.O. 2004, c. 3, Sch. A. E-laws Internet site at http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_04p03_e.htm.

[2] Committee *Hansard* may be accessed at http://www.ontla.on.ca/web/committee-proceedings/committee_transcripts_details.do?locale=en&Date=2008-08-28&ParlCommID=8875&BillID=&Business=Review+of+the+Personal+Health+Information+Protection+Act%2C+2004.

the Clerk of the Committee, and staff of the Legislative Library's Research and Information Services.

This Report

This report emphasizes priority recommendations that require further action. The context of these recommendations is *PHIPA*'s status as the only provincial health information privacy legislation that has been declared substantially similar to the federal *Personal Information Protection and Electronic Documents Act* (*PIPEDA*).[3]

A notice published by Industry Canada in the *Canada Gazette* regarding the criteria for attaining "substantially similar" status provided that provincial legislation must incorporate the ten principles set out in Schedule 1 to *PIPEDA*, which is the *Model Code for the Protection of Personal Information* developed by the Canadian Standards Association. For example, section 4.3.4 of the *Code* provides that the express consent of individuals must be required for the collection, use, and disclosure of sensitive information, including medical records.[4]

The importance of *PHIP*A maintaining this designation is that harmonizing federal and provincial requirements in regard to personal health information makes privacy law easier for individuals to understand and for organizations to implement.[5]

LOCKBOX

The term "lockbox" is not specifically defined in the legislation. The rule in *PHIPA* that enables a patient to expressly withdraw or withhold consent to the collection, use or disclosure of personal health information for the purpose of providing or assisting in the provision of health care to that patient has been referred to as the "lock box." Sections 20(2), 37(1)(a), 38(1)(a) and 50(1)(e) of *PHIPA* provide patients with the opportunity to place limits on the collection, use and disclosure of their personal health information. The Committee heard that the lockbox is working well, is integral, and should be maintained in its current form.

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[3] On December 14, 2005, an order of the Governor in Council was published in *the Canada Gazette* declaring *PHIPA* to be "substantially similar" to Part I of *PIPEDA*. The order exempted health information custodians and their agents, as defined in *PHIPA*, from the application of *PIPEDA* in respect of the collection, use and disclosure of personal information that occurs within the Province of Ontario. *Canada Gazette*, Vol. 139, No. 25 – December 14, 2005. Internet site at http://canadagazette.gc.ca/partII/2005/20051214/html/sor399-e.html.

[4] Schedule 1 of *PIPEDA* incorporating the Principles set out in the National Standard of Canada entitled *Model Code for the Protection of Personal Information*, CAN/CSA-Q830-96, may be accessed at http://laws.justice.gc.ca/en/showdoc/cs/P-8.6/sc:1//en?noCookie/.

[5] Government of Canada, Canada Gazette, *Health Information Custodians in the Province of Ontario Exemption Order*, Regulatory Impact Analysis Statement, Vol. 139, No. 6, February 5, 2005. Internet site at http://canadagazette.gc.ca/partI/2005/20050205/html/regle4-e.html.

Recommendation 1

There should be no change to the lockbox provisions in PHIPA.

SHARING OF PERSONAL HEALTH INFORMATION WITH FAMILIES AND FRIENDS PROVIDING CARE

Currently, *PHIPA* allows the disclosure of personal health information with the implied consent of the patient, but only to health information custodians who form part of the "circle of care" (discussed on p 7).[6]

Family members of patients with mental health issues told the Committee that they had great difficulty obtaining information about their family member from health information custodians. This was the case even when the patient was being discharged into their care. In one instance, a mother was unable to find out whether her child had been admitted to hospital or released.[7] The witness told the Committee that "I am good enough to pay bills and support him, but I'm not good enough to have any information or relate any information to the treating teams or doctors or hospitals."[8] Some witnesses requested amendments to section 38(3) of the Act to permit the sharing of personal health information with family and friends without the consent of the patient.

In its deliberations, the Committee considered the importance of maintaining *PHIPA*'s designation as "substantially similar" legislation to *PIPEDA*. As indicated above, s. 4.3.4 of Schedule 1 to *PIPEDA* requires organizations to obtain express consent for the collection, use and disclosure of sensitive information, including medical records.

The Committee proposes to address the issue of access to personal health information by friends and family without altering the requirement that the express consent of the patient be obtained in order for such information to be shared.

Recommendation 2

Consideration should be given to a PHIPA amendment requiring health care institutions to ask patients or residents whether they consent to the disclosure of their personal health information to family members or friends who care for them.

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[6] The term "health information custodian" is defined in *PHIPA*. Health information custodians include health care practitioners, service providers under the *Long-Term Care Act, 1994*, and others outlined in s. 3(1) of *PHIPA* and s. 3 of O. Reg. 329/04 under the Act.

[7] See the submission on behalf of the Schizophrenic Society of Ontario, East York Chapter, 28 August 2008.

[8] Ibid.

BREACH NOTIFICATION

Some witnesses asked the Committee to recommend an amendment to the breach notification requirement in s. 12(2) of *PHIPA*. Currently, s. 12(2) provides as follows:

> **12.** (2) Subject to subsection (3) and subject to the exceptions and additional requirements, if any, that are prescribed, a health information custodian that has custody or control of personal health information about an individual shall notify the individual at the first reasonable opportunity if the information is stolen, lost, or accessed by unauthorized persons.

Ontario's IPC asked for an amendment permitting the Commissioner to authorize health information custodians to relax this requirement in certain circumstances. According to the IPC, in some situations the minimal risk posed to personal privacy outweighs the potential impact of a notification.

In contrast, the Ministry of Health and Long-Term Care told the Committee that the provision should not be amended. Generally speaking, according to the Ministry, breach notification provisions are increasingly common in legislation. They promote transparent information practices. They also reinforce the confidence of patients in the operation of the health system. Finally, the issuance of a breach notification is a powerful educational tool for the organization required to do so.

The Committee accepts the submissions of the Ministry of Health and Long-Term care on this issue. Minimal risk is in the eye of the beholder. In other words, because of its sensitivity, health information custodians should be required to notify an individual if their personal health information has been stolen, lost or accessed by unauthorized persons.

Recommendation 3

There should be no amendment to the breach notification requirement in section 12(2) of the Personal Health Information Protection Act, 2004.

THE INSURANCE SECTOR AND PHIPA

The Committee heard evidence from the Ontario Psychological Association (OPA) about the personal health information practices of some insurance companies. According to the OPA, psychologists are often asked for information that appears to exceed what is required to determine eligibility for insurance coverage. The OPA asked that insurers be classified as health information

custodians under *PHIPA* in order to control their collection, use and disclosure of personal health information.

In its deliberations, the Committee has considered the regulation of insurance companies by the federal private-sector privacy legislation, *PIPEDA*. The Committee examined the federal Privacy Commissioner's 2007 *Annual Report to Parliament* in which the Commissioner indicated that 35 of the 350 complaints the Office had received under *PIPEDA* concerned the insurance sector.[9] In September 2008 the Federal Court of Appeal held that the relationship between an insured and an insurer was commercial in nature, and therefore within *PIPEDA*'s scope.[10]

Recommendation 4

Insurance companies should remain outside the scope of the Act.

FEES

Section 54(11) of *PHIPA* provides that the fee charged by a health information custodian for making a record or part of a personal health information record available to an individual shall not exceed the amount outlined in regulations under the Act; nor shall it exceed the amount required for reasonable cost recovery. Currently, there are no regulations concerning fees under the Act.

The Committee heard evidence from some witnesses regarding fees charged by health information custodians for copies of health records. The Ministry of Health and Long-Term Care reported that in 2006, a proposed fee schedule was published in the *Ontario Gazette*. The Ministry conducted a sixty-day consultation in which opinions expressing a variety of views were received.

Some health profession regulatory bodies, such as the College of Physicians and Surgeons of Ontario, have established recommended minimum fees which may be charged. The Advocacy Centre for the Elderly told the Committee that some clients had been asked to pay as much as $150 for a few pages of their record. The IPC told the Committee that it had responded to numerous complaints and inquiries from members of the public regarding the fees charged by health information custodians. The IPC asked the Committee to consider a regulation prescribing the fee that may be charged by a health information custodian for copies of a record.

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[9] Canada, Office of the Privacy Commissioner, *Annual Report to Parliament, 2007* (Ottawa: Minister of Public Works and Government Services, 2008), p. 69. Internet site at http://www.privcom.gc.ca/information/ar/200708/2007_pipeda_e.pdf.

[10] *Wyndowe* v. *Rousseau*, 2008 FCA 39, paragraphs 34-36. Internet site at http://decisions.fca-caf.gc.ca/en/2008/2008fca39/2008fca39.pdf.

Recommendation 5

There should be a regulation setting fees that may be charged by health information custodians for the disclosure of personal health information. The regulation should also prescribe fees that may be charged by health information custodians for making a record available to an individual as well as for providing copies of all or part of a personal health record. "Reasonable" cost recovery should not be left to the discretion of health information custodians and their agents.

RELEASE OF PERSONAL HEALTH INFORMATION BY POLICE

The Committee heard that in response to requests by employers for police record checks, information regarding contact between individuals and police under section 17 of the *Mental Health Act* is sometimes released. This information may have been disclosed under s. 41(1.1) of the *Police Services Act* and O. Reg. 265/98 under that Act. When a prospective employer or organization seeking volunteers has access to this kind of information, certain unfair and incorrect assumptions may be made about the suitability of a candidate for a particular position.

On November 28, 2007, the Ontario Human Rights Commission (OHRC) released a draft paper for public consultation entitled *Policy on Mental Health Discrimination and Police Record Checks*.[11] The purpose of the public consultation is the development of a draft policy for organizations requesting police reference checks.

In 2006, the Information and Privacy Commissioner/Ontario received two complaints about the mental health record disclosure practices of an Ontario police service. In its decision concerning these complaints, the IPC noted that some police services in Ontario have adopted a risk-based approach to this issue. In other words, before releasing police records in response to a request, the police service assesses the risk posed by an individual.

In this regard the Committee is aware of the practices adopted by the London Police Service, where mental health information is released as part of a police record only if the safety of others was at risk during the police contact.

Although personal health information has acquired protected status under *PHIPA*, this information becomes vulnerable once it enters a police record and falls outside the legislation.

[11] The OHRC draft policy may be accessed at http://www.ohrc.on.ca/en/resources/Policies/mhdraft.

Recommendation 6

In order to protect the integrity of PHIPA, best practices should be established with respect to the disclosure of personal health information by police services. The Ministry of Health and Long-Term Care should work with stakeholders, including police services, to prevent unnecessary and detrimental disclosures of personal health information gathered during a Mental Health Act intervention by police services. If there is no indication that the person poses a safety risk to others, mental health information should not be disclosed as part of a police record check.

CIRCLE OF CARE

The Committee heard that health information custodians are not clear about the persons to whom they may disclose personal health information. The phrase "circle of care" is sometimes used to describe health providers who are working together to make care decisions for a patient. As noted earlier in this report, section 20(2) of *PHIPA* provides that certain health information custodians may assume the implied consent of the individual to disclose personal health information to another custodian within the circle of care. While some witnesses suggested that this "circle of care" was too broad, others said that there was a lack of consistency in the disclosure practices of health care facilities. As a result, in some cases family practitioners have been unable to obtain personal health information about their patient.

The Committee is aware that the concept embodied by the phrase "circle of care" is dealt with slightly differently in the legislation of other jurisdictions.

Recommendation 7

The Ministry of Health and Long-Term Care should examine the use of the term "circle of care" in other jurisdictions to see whether experiences elsewhere have some application here, and consider whether the term should be defined in PHIPA.

TIME FRAME TO RESPOND TO A REQUEST FOR A RECORD

Currently, s. 54(2) of *PHIPA* gives health information custodians up to 30 days to respond to a request for access to a record of personal health information. The Committee heard from witnesses who asked that the time frame to respond to a request be reduced to seven days.

The Committee is of the opinion that 30 days is too long to respond to a request for access to a personal health record.

Recommendation 8

The Ministry of Health and Long-Term Care should consider introducing an amendment to section 54(2) to give health information custodians ten working days to respond to a request for access to a personal health record.

E-HEALTH

The term "E-health" describes the application of information and communications technologies in the health sector. It encompasses electronic patient administration systems in the hospital setting and home care (for example, e-health can be a component of home dialysis systems). General practitioners and pharmacists may use e-health to manage patients, facilitate electronic prescribing, and maintain medical records.

The Ministry of Health and Long-Term Care told the Committee that the regulation-making power over e-health in s. 73(1)(h) of the Act was drafted at a time when some current applications of e-health were unforeseen. The Act currently provides as follows:

> **73.** (1) Subject to section 74, the Lieutenant Governor in Council may make regulations,
>
> . . .
>
> (h) specifying requirements, or a process for setting requirements, for the purposes of subsection 10(3) with which a health information custodian is required to comply when using electronic means to collect, use, modify, disclose, retain or dispose of personal health information, including standards for transactions, data elements for transactions, code sets for data elements and procedures for the transmission and authentication of electronic signatures.

Section 10(3) in turn provides as follows:

> **10.** (3) A health information custodian that uses electronic means to collect, use, modify, disclose, retain or dispose of personal health information shall comply with the prescribed requirements, if any.

The Ministry asked the Committee to consider proposing an amendment to this provision which would allow regulations to be made that reflect current and future e-health applications.

The Committee also heard from various witnesses with respect to the evolving importance of e-health. The Committee wishes to underscore the importance of accelerating e-health initiatives. In its deliberations, the Committee examined Newfoundland's *Personal Health Information Protection Act* (not yet proclaimed), which provides comprehensive regulation-making powers concerning e-health matters. The Newfoundland statute provides as follows:

> **90.** (1) The Lieutenant Governor in Council may make regulations,
>
> . . .
>
> (i) respecting the creation, retention, disposition and reproduction of records of personal health information in electronic form, including integrated records of personal health information . . .
>
> . . .
>
> (2) For the purpose of paragraphs [(1)(i)], the regulations that may be made may include provisions respecting
>
> (a) the technology or process that shall be used to make or send an electronic record;
>
> (b) the format of an electronic record, including the making and verification of an electronic signature;
>
> (c) the place where an electronic record may be made or sent;
>
> (d) the time and circumstances when an electronic document is to be considered to be

sent or received where it is considered to have been sent or received; and

(e) the procedure for responding to a request for access to or disclosure of a record of personal health information by a person outside the province.[12]

Recommendation 9

Section 73(1)(h) should be amended to allow the development of a more comprehensive range of regulations related to e-health with a view to accelerating e-health initiatives.

PUBLIC EDUCATION

The Committee heard about a public opinion survey conducted by Ekos, a market research consulting firm, in June/July 2007. While 88% of Canadian survey respondents supported the development of an e-health record, 45% worried that personal information in their e-record might be accessed for the wrong reasons.

In light of the importance attached to the privacy of e-health records, the Committee believes that there should be renewed efforts to educate Ontarians about the control they have under *PHIPA* with respect to the collection, use and disclosure of their personal health information.

Section 66(b) of *PHIPA* currently provides that the IPC may conduct public education programs and provide information concerning the Act and the Commissioner's role and activities.

Recommendation 10

The Ministry of Health and Long-Term Care should educate Ontarians about the control they have over the collection, use and disclosure of their personal health information under PHIPA. Further, the IPC should emphasize this issue in its public education campaigns.

[12] *Personal Health Information Act*, S.N.L. 2008, c. P-70.1. Internet site at http://www.canlii.org/nl/laws/sta/p-7.01/20080818/whole.html.

LIST OF WITNESSES AND SUBMISSIONS

Organization/Individual	Date of Appearance
Advocacy Centre for the Elderly	Written submission
ARCH Disability Law Centre	28 August 2008
Association of Local Public Health Agencies	Written submission
Atherley, Gordon	Written submission
Canada Health Infoway	Written submission
Canadian Health Information Technology Trade Association	Written submission
Canadian Institute for Health Information	Written submission
Canadian Medical Protective Association	28 August 2008
Canadian Mental Health Association	Written submission
Central East Prehospital Care Program	Written submission
College of Medical Radiation Technologists of Ontario	Written submission
College of Physicians and Surgeons of Ontario	Written submission
Community and Legal Aid Services Programme	28 August 2008
Community Counselling Centre of Nipissing	Written submission
Council of Academic Hospitals of Ontario	28 August 2008
Family Council	Written submission
Friends and Family of Schizophrenia	28 August 2008
HIV AIDS Legal Clinic	28 August 2008
Information and Privacy Commissioner/Ontario	28 August 2008
Ministry of Health and Long-Term Care	28 August 2008
North York General Hospital	Written submission
Ontario College of Social Workers and Social Service Workers	Written submission
Ontario Hospital Association	28 August 2008
Ontario Medical Association	Written submission
Ontario Peer Development Initiative	Written submission
Ontario Psychological Association	28 August 2008
Psychiatric Patient Advocate Office	28 August 2008
Schizophrenia Society – London Chapter	28 August 2008
Schizophrenia Society of Ontario	Written submission
Schizophrenia Society of Ontario – East York Chapter	28 August 2008
Sound Times Support Services	28 August 2008
The SIMS Partnership	Written submission
Toronto Centre Local Health Integration Network	Written submission
Toronto Public Health	Written submission
Worden, Jo-Ellen	28 August 2008