



65 Wellesley Street East, Suite 400
Toronto, Ontario M4Y 1G7
Tel (416) 340-7790/1-888-705-8889
Fax (416) 340-7248 www.halco.org

BY E-MAIL TO: healthprivacy.moh@ontario.ca

April 26, 2011

PHIPA Regulation Amendment – eHealth Ontario as a Health Information Network Provider
Health System Information Management and Investment Division
Ministry of Health and Long-term Care
1075 Bay Street, 13th Floor
Toronto, ON M5S 2B1

Dear Madam/Sir:

Re: comments on amendment to regulation 329/04 under PHIPA

Thank you for giving the HIV & AIDS Legal Clinic (Ontario) (a.k.a. HALCO) this opportunity to comment on the proposed amendment to regulation 329/04 made under the *Personal Health Information Protection Act, 2004* (PHIPA).

HALCO is a charitable, not-for-profit community-based legal clinic serving low-income people living with HIV/AIDS in Ontario. It is the only such legal clinic in the country, and has extensive, frontline experience in addressing the day-to-day legal issues faced by people living with HIV. HALCO provides legal advice and representation, and engages in law reform endeavors, public legal education initiatives, and community development work. Our client base is the over 27,000 people living with HIV/AIDS in Ontario (2006 figure: Report on HIV/AIDS in Ontario produced by Public Health and UofT, published by the Ontario Ministry of Health and Long Term Care– see <http://www.phs.utoronto.ca/ohemu/tech%20reports.html>).

The protection of privacy, especially the privacy of personal health information, is very important to our client base. People with HIV/AIDS (PHAs) are subjected to stigma and discrimination in every area of their lives because of their HIV status. They are terminated from employment, refused services (including medical/dental services) and evicted from housing. Even if they do not face these more extreme situations, they are very often subject to derision in their employment, housing, receipt of services or other areas of their lives like family and social interactions. The mechanisms by which a PHA may address these problems when they arise are seldom sufficient. To a great many PHAs, protection of the privacy of their health information is one of their highest priorities because if their HIV status is unknown they do not encounter these problems at all.

The stigma and discrimination faced by people with HIV was the subject of an attitudinal survey done by the polling organization EKOS in 2006. That study found that:

- 49% of those surveyed feel uncomfortable using a restaurant drinking glass once used by a person living with HIV/AIDS.
- 26% of those surveyed would be very or somewhat uncomfortable working in an office where someone is known to be infected with HIV/AIDS.
- 26% of those surveyed feel uncomfortable even wearing a sweater once worn by a person living with HIV/AIDS.
- 20% of those surveyed do not believe in supporting the rights of people living with HIV/AIDS.

(EKOS Research Associates Inc., HIV/AIDS Attitudinal Tracking Survey 2006: Final Report to Health Canada, March 31 2006, available on-line at http://www.phac-aspc.gc.ca/aids-sida/publication/por/2006/pdf/por06_e.pdf.)

On behalf of our client base, we have the following comments about the proposed amendment to regulation 329/04 (“the proposed amendment”):

1. It is not clear from the proposed amendment how the new e-health system will manage the “lock-box” provisions of PHIPA, or if any masking or opt-out or disclosure directive mechanism will be available to patients.
2. There is no provision in the proposed amendment for a patient’s access to his or her own record or for the correction of medical misinformation in a record.
3. It is not clear from the proposed amendment how or if patients may access the record referred to at section 6.2(2) paragraph 5 (record of accesses to information).
4. It is not clear from the proposed amendment how or if patients may access the record referred to at section 6.2(2) paragraph 7 i (record of results of assessment of vulnerability of information).
5. There is no provision in the proposed amendment for the alerting of patients whose health information is stolen, lost or accessed by unauthorized persons.

1. “Lockbox” provisions

Sections 20(3), 37(1), 38(1) and 50(1) together constitute the “lockbox” provisions in PHIPA. These provisions allow a patient to instruct his or her health care information custodian not to disclose some of his or her health information to other health information custodians. The proposed amendment does not state that eHealth Ontario will be required to operate in accordance with these provisions. There is no mention in the proposed amendment of any kind of masking or disclosure directives that might be available to patients in order to give effect to the lockbox provisions. This could be easily corrected by designating eHealth Ontario as a “health information custodian.” If eHealth Ontario is not to be designated as a “health information custodian,” provisions should be added to the regulation allowing for masking of information at the request of a patient or disclosure directives or some kind of opt-out procedure that would permit a patient to control how much information is disclosed to whom. If such provisions are added, it is important that the procedure be easy to implement and well-publicized. In addition, we strongly recommend that all Ontarians be given the opportunity to

opt out of the eHealth system entirely and that this opportunity be very well publicized and easy to implement.

2. Access and correction

Sections 51-54 of PHIPA prescribe a process for patients to access their health records from health information custodians. The proposed amendment does not mention whether or how a patient may access their electronic health record. This could be easily corrected by designating eHealth Ontario as a “health information custodian.” The existing process would then apply to records maintained by eHealth Ontario. If eHealth Ontario is not to be designated as a “health information custodian,” provisions should be added to the regulation requiring eHealth to provide patients with access to their own electronic health record. A patient’s electronic health record will likely be composed of several records from several sources, including all health care providers and all laboratory test results. A patient may discover that one of his or her health care providers is under the impression that he or she has a certain diagnosis of which he or she was not aware. Access to the entire electronic health record would give that patient the opportunity to see the source of this information. Provisions for the correction of information would give the patient an opportunity to correct the record. Correction is particularly problematic under the proposed amendment, as it is not clear that a health information custodian would be required to correct the eHealth record if a patient had engaged s.55 of PHIPA and successfully corrected his or her health record with that particular health information custodian.

3. Record of accesses to information

Section 6(2) paragraph 5 of the proposed amendment provides as follows:

[eHealth Ontario] shall take steps that are reasonable in the circumstances to keep an electronic record of all accesses to all or part of the personal health information contained in the electronic health record, and shall ensure that record identifies the person who accessed the information and the date, time and location of the access.

It is not stated how or if patients may access this record of accesses to their health information. It is vital that patients have some access to this information. With paper records and PHIPA, a patient could have reasonable confidence that his/her information was only accessed by his/her circle of care and those third parties s/he has specifically authorized to access the information. A consolidated electronic record may be accessed by a much greater number of people, possibly without the consent of the patient. If this happens the patient should be entitled to know about it in order to address it. If patients are granted the right to information regarding accesses to their personal health information, they are more likely to have confidence in the security of that information (assuming the accesses that they learn about are all authorized by consent or PHIPA).

4. Record of results of assessment of vulnerability of information

Section 6(2) paragraph 7 i of the proposed amendment provides as follows:

[eHealth Ontario] shall make available to each health information custodian that provides personal health information to it for the purposes of creating or maintaining one or more electronic health records a written copy of the results of the assessment carried out under paragraph 6 for each record created or maintained for that custodian...

Section 6(2) paragraph 7 ii provides for a summary of the results of this assessment to be made available to the public. There is no provision allowing for a patient to access the full version of

the assessment with respect to his or her own health records. Giving individual patients access to the full version of this assessment would raise patient's confidence in the security of their electronic health information. We strongly recommend that a provision be added which allows patients to access the full version of the assessment with respect to their own health records.

5. Alert re: information that is lost, stolen, or accessed by unauthorized persons

There is no provision in the amendment for e-Health alerting patients whose health information is stolen, lost or accessed by unauthorized persons. Subsection 12(2) of PHIPA requires that a health information custodian that has custody or control of personal health information about an individual shall notify a patient at the first reasonable opportunity if his or her information is stolen, lost, or accessed by unauthorized persons. This clearly obligates health information custodians to notify their patients of such adverse events respecting the information over which they have custody. It does not necessarily obligate a health information custodian to notify a patient when the health information custodian is notified by eHealth about such an adverse event. This issue could be easily corrected by designating eHealth Ontario as a "health information custodian." The existing process would then apply to records maintained by eHealth Ontario. If eHealth Ontario is not to be designated as a "health information custodian," provisions should be added to the regulation requiring eHealth to notify patients if their personal health information is stolen, lost, or accessed by unauthorized persons. Alternatively, provisions should be added in order to make a health information custodian's obligation more clear where they are notified by e-Health that personal health information has been stolen, lost, or accessed by unauthorized persons.

Yours truly,
HIV & AIDS LEGAL CLINIC (ONTARIO)
per:

Renée Lang
Barrister & Solicitor