ADVOCACY CENTRE for the ELDERLY

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Shafiq Qaadri, MPP
Standing Committee on Social Policy
Room 1405, Whitney Block
Queen's Park
Toronto, ON M7A 1A2

Dear Mr. Qaadri:

RE: Review of the *Personal Health Information Protection Act, 2004*

Thank you for the opportunity to provide input to the Standing Committee on Social Policy concerning the legislative review of the *Personal Health Information Protection Act, 2004 (PHIPA).*

After providing a brief introduction about ACE, we will raise and address several issues which need to be evaluated by the Standing Committee. We are pleased to contribute our views based on our extensive experience advocating for seniors in Ontario.

Introduction to ACE

ACE is a specialty community legal clinic that was established to provide a range of legal services to low income seniors in Ontario. The legal services include individual and group client advice and representation, public legal education, community development, and law reform activities. ACE has been operating since 1984 and it is the first and oldest legal clinic in Canada with a specific mandate and expertise in legal issues of the older population.

ACE receives, on average, over 2,500 client intake inquiries a year. These calls are primarily from the Greater Toronto Area but approximately twenty per cent are from outside this region, and may come from any part of the province, as well as from outside Ontario.

The individual client services are in areas of law that have a particular impact on older adults. These include, but are not limited to: capacity, substitute decision-making and health care consent; end-of-life care; supportive housing and retirement home tenancies; long-term care homes; patients' rights in hospitals; and elder abuse. Clients regularly seek our advice on issues relating to personal health information.

Lack of Understanding about *PHIPA*

Although an overarching purpose of *PHIPA* is to provide individuals with a right of access to personal health information about themselves, it is our common experience at ACE that *PHIPA* is not well understood by either health information custodians or the public, leading to a misunderstanding of the law. People are often not advised of their legal rights and face numerous barriers when they attempt to do anything connected to their records of personal health information.

The Standing Committee should review whether the law needs to be amended to require initial and ongoing training for health information custodians and whether new tools or methods should be developed to assist the public in understanding their rights. One easy way to disseminate information is for Community Care Access Corporations to be required to provide easy to understand brochures about *PHIPA* to residents upon admission to long-term care homes. The respective colleges and governing bodies of custodians should also be encouraged to better educate their members about *PHIPA*.

Fees

PHIPA permits health information custodians to charge a reasonable cost recovery fee for providing access to an individual's personal health record although it also specifically permits a custodian to waive all or part of the fee associated with an access request. In other words, the custodian has discretion to set a fee that it feels is appropriate to the disclosure being made, taking into account such factors as the amount of staff time needed to assemble the information, as well as photocopy charges or the cost of other expenses, and the costs to deliver the information. Whether the fee charged is reasonable or not is a question for the Information and Privacy Commissioner to consider.

Professional regulatory bodies may provide guidance to custodians as to what amount is considered reasonable. For example, the College of Physicians and Surgeons of Ontario refers physicians to the Ontario Medical Association's *Physician's Guide to Third Party and Other Uninsured Services* with respect to charging fees. The recommended minimum rate for making copies of the first five pages of a person's record of personal health information is $36.31 and $1.41 for each subsequent page. The fees are even higher when the records pertain to psychiatric care; it is suggested that physicians charge $48.57 for the first five pages and $1.95 for subsequent pages.

Due to the discretion given to custodians to charge fees, the amount being charged varies widely across the province. Clients of ACE, for example, have been asked to pay as much as $150 for a few pages. Such discrepancies prompted Ann Cavoukian, the

Information and Privacy Commissioner, to ask the government to address the issue of fees through regulation. The Ministry of Health and Long-Term Care published a proposed regulation concerning fees, as well as other matters, in the Ontario Gazette on March 11, 2006 and invited stakeholder input. To date, however, there is no regulation in place.

The Office of the Information and Privacy Commissioner has mediated several complaints regarding the excessive fees being charged to obtain copies of health records. Generally, the matters were resolved and the parties agreed to pay 20 cents per page for a copy of the record.

ACE is of the opinion that a regulation should be passed as soon as possible in order to provide clarity and consistency. We agree with the outcome of those complaints resolved by the Office of the Information and Privacy Commissioner that custodians are permitted to charge individuals a maximum fee of approximately 20 cents per page. Alternately, if the information is stored on an electronic medium such as a DVD and the individual seeking the information is agreeable to receiving the information in this format, there should be a nominal flat fee in the range of $5 to $10. We do not feel it is appropriate to allow custodians to levy fees for reviewing or finding records unless there are extraordinary circumstances. If custodians maintain their records properly and follow good recordkeeping principles, the information should be easy to find and reproduce.

Since cost should not be a barrier to access to information, we believe that the regulation should specifically state that no fees shall be charged for low-income individuals, including those whose only income source is the Ontario Disability Support Program or a government pension.

Circle of Care

The "circle of care" is a phrase that does not appear in *PHIPA* but it is frequently used by custodians. It describes custodians and their authorized agents who are permitted to rely on an individual's implied consent when collecting, using or disclosing personal health information for the purpose of directing health care.

Custodians are broadly interpreting the phrase to include any custodian that they believe may potentially be useful in the care of one of their patients. For example, it is the norm, not the exception, for Community Care Access Corporations to unlawfully disclose information and hospital custodians to collect information in the context of patient discharge planning. Once a patient is designated by a physician as requiring long-term care, the local Community Care Access Centre is mandated by law to assist the patient (or the patient's substitute decision-maker, if he or she is incapable of consenting to admission to long-term care) to be placed in a long-term care home. Depending on the person's facility choices, placement might occur relatively quickly or it may take several months or years. Although the information about placement does not relate to health care (it merely consists of the names of the three long-term care homes where the person would like to live), this information, as well as the estimated wait time, is almost always

disclosed to hospital custodians. Once hospital staff becomes aware of a potential delay, they routinely exert pressure on the patient to move to a home with a shorter waiting list although it may not be in his or her best interests – they want the patient to leave as quickly as possible because they do not want him or her to take up an acute hospital bed. It needs to be emphasized that one of the reasons why Community Care Access Centres, and not hospitals, are lawfully required to handle discharge planning to long-term care is because they are advocating for the patient whereas the hospital is acting in its own interests. ACE believes custodians should be made aware of the fact that the patient and the Community Care Access Centre have completed the placement application; however we do not believe hospital custodians need to know the homes or the length of the waiting lists to which the patient is seeking admission pending placement.

In light of the ambiguity and the ensuing misapplication of this phrase, ACE is of the opinion that the legislation should be amended to include a precise definition of the circle of care.

Access Requests

Once a person makes a request to access his or her information, the custodian must respond within thirty days of receiving the request. The custodian may extend the time period up to an additional thirty days if they notify the person of the extension within the initial thirty day period.

The response times for access requests in *PHIPA* represents a significant change from the now repealed provisions in the *Long-Term Care Act, 1994* which required facilities to respond to a person's request for access within seven days. As previously pointed out in this submission, it should be easy to find and produce records if the custodian abides by good recordkeeping principles. Thus, custodians should not be permitted such lengthy timeframes to produce information.

Another problem faced by our clients relates to the comprehensiveness of records of personal health information. If a patient in a hospital or a resident of a long-term care home requests access to their information, they might not necessarily receive the entire record. For instance, a person may only be given the notes created by the physicians and nurses but not those from the occupational therapist, social worker of pharmacist. Moreover, there are frequently additional difficulties if custodians use electronic records. A person may only receive the paper chart and not be aware that electronic records exist. The onus, consequently, is on the person requesting the information to ask the right questions to ensure the records are complete.

Substitute decision-makers who are authorized to make decisions about treatment, long-term care admission or personal assistance services pursuant to the *Health Care Consent Act* are often given erroneous information about their ability to access the individual's record. They may be informed that they are not allowed to access the individual's personal health information although they need this information in order to make properly informed decisions. Alternatively, they may be told that they can access

the information (see the chart), but not have copies, or vice versa, that they cannot view the chart, only ask for copies. ACE surmises that some custodians believe that the information can only be disclosed if individuals not only have a substitute decision-maker under the *Health Care Consent Act* but have also been found to be incapable to consent to the release of information under *PHIPA*. Accordingly, ACE recommends that *PHIPA* be amended to explicitly state that substitute decision-makers can access and obtain copies of records of personal health information if it is ancillary to their decision-making authority under the *Health Care Consent Act* even if the individual is capable of consenting to the collection, use or disclosure of information.

Complaints to the Ministry of Health and Long-Term Care

The issue of complaints to the Ministry of Health and Long-Term Care about long-term care facilities is currently not covered by *PHIPA*. Complaints made by residents or their substitute decision-makers are investigated by compliance advisors but they are provided scant information respecting the process or details about the outcome of the investigation. It is a little known fact for both individuals and staff at long-term care homes that complainants may request copies of the compliance advisor's investigatory report by making a freedom of information request pursuant to the *Freedom of Information and Protection of Privacy Act*.

ACE believes that the compliance advisor's report should be automatically made available to the complainant, especially where the complaint pertains to health care issues (e.g., inappropriate medical care or feeding). It should only be in exceptional circumstances that the report is not provided and, if necessary, information relating to third parties redacted. Therefore, ACE recommends that changes be made to *PHIPA* because the information is directly relevant to the complainant's health care and a lack of information undermines confidence in the long-term care home system.

Rights Advice versus Rights Information

Rights advice is the process where an individual is informed of their rights by a rights adviser when their legal status has changed. The rights adviser cannot be a person involved in the direct clinical care of the person to whom the rights advice is given. There are currently eight mandatory rights advice situations, most of which only affect patients in psychiatric facilities. The rights adviser has the responsibility to explain the significance of the legal situation to the individual and, if requested to do so, assist that person to apply for a hearing to challenge the finding before the Consent and Capacity Board, obtain a lawyer, and apply for financial assistance from Legal Aid Ontario. Rights advice is viewed as a legal protection for individuals.

Currently, the law does not provide for mandatory rights advice to individuals found incapable of consenting to the collection, use or disclosure of personal health information if they are not a patient in a psychiatric facility. For persons deemed to be incapable outside a psychiatric facility, they are not afforded rights advice but rights information – custodians have an obligation to provide information to the incapable

person about the consequences of the determination of incapacity, including any prescribed information, but only if it is "reasonable in the circumstances." To date, there are no regulations about the information that must be provided by custodians.

Unfortunately, in ACE's opinion, many custodians fail to provide rights information. As a result, individuals are unaware of their statutory rights and the procedures necessary to exercise these rights. We encourage the Committee to evaluate the benefits of amending the legislation to require mandatory rights advice for all individuals, regardless of location, who are found incapable of consenting to the collection, use or disclosure of personal health information. At a minimum, the phrase "reasonable in the circumstances" should be removed as it is extremely subjective.

Applications to the Consent and Capacity Board

If a custodian determines an individual is incapable of consenting to the collection, use or disclosure of personal health information, *PHIPA* says he or she may apply to the Consent and Capacity Board for a review of the finding. However, this right is not extended to individuals who already have been found treatment incapable and have a substitute decision-maker under the *Health Care Consent Act* where a decision about the collection, use or disclosure of information on behalf of the patient is necessary for, or ancillary to, a decision that a substitute decision-maker is authorized to make under that legislation.

ACE believes that all individuals should be able to challenge a finding of incapacity to the Board, not just those who do not have a substitute decision-maker. As the issues respecting treatment and information are separate and distinct, every individual should have a right of review.

Where a custodian is of the opinion that a substitute decision-maker has not complied with the factors to be considered for giving, withholding or withdrawing consent, he or she may apply to the Board for a determination as to whether the substitute decision-maker is acting in compliance with the legislation.

Regrettably, there is no opportunity for the incapable person to make such an application to the Board. ACE believes the legislation should be amended to permit the incapable person or any other individual acting on behalf of the incapable person to apply to the Board.

Fundraising

PHIPA permits a custodian to assume an individual's implied consent to use and disclose the individual's name and specified contact information for the purpose of fundraising activities unless the individual has expressly withheld or withdrawn the consent.

ACE has had several clients who have complained to us that hospitals have provided their information to fundraisers despite the fact that the subject was never broached with them. It appears as if the concept of implied consent is being applied very loosely so as to vitiate proper consent. We believe that the onus should not be on the individual to know and advise the custodian that he or she does not want information shared with fundraisers. Instead, there should be a positive obligation on the custodian to specifically ask the individual if his or her information may be shared, whom it may be shared with and for what time period. Moreover, if the individual chooses to disclose their information to a fundraiser, he or she should be advised that consent may be withdrawn at any time.

Deceased Individuals

It has been ACE's experience that the statutory provisions pertaining to deceased individuals are not well understood.

PHIPA stipulates that where an individual has died, the estate trustee or the "person who assumed responsibility" for the administration of the estate if the estate does not have an estate trustee, may consent to the collection, use or disclosure of personal health information on behalf of the individual. Custodians, particularly those at long-term care facilities, are often unsure as to who is a "person who has assumed responsibility." ACE is of the opinion that this phrase should be statutorily defined so that if a person is able to provide some proof as to their role, they will be considered a person who has assumed responsibility.

The statute also permits custodians to disclose information about an individual who is or is reasonably suspected to be deceased for the purposes of identifying the individual or informing any person whom it is reasonable to inform in the circumstances. However, our clients have advised us that they are not receiving information to which they are entitled. This is of particular concern in those circumstances where there are potential liability issues with respect to the actions of the custodians.

Prosecution for Offences

A person or corporation can potentially be liable for a multitude of offences pursuant to *PHIPA*. The maximum fine for a conviction is $50,000 for a person and $250,000 for a corporation. However, the relevant provisions set a high threshold for conviction; actions must be either wilful and/or the legislation must be knowingly contravened.

The Attorney General of Ontario is responsible for authorizing and prosecuting offences but there is no separate enforcement official with a budget directed specifically at enforcement of *PHIPA* violations. To date, there have been no prosecutions under the legislation.

While ACE is supportive of the strict penalties contained in the legislation for offences, it is concerned about the high threshold for conviction. It is reasonable to hypothesize that

custodians would be more likely to adhere to the legislation if there was a higher likelihood that they could be found guilty of an offence for contravening the statute. Thus, the Committee may wish to consider revising the sections respecting offences and prosecutions.

Limitation Periods

Depending on the nature of the complaint being made to the Information and Privacy Commissioner about violations of *PHIPA*, there are different limitation periods. Where a person is alleging that there has been a contravention of the statute, there is a one-year limitation period while a person alleging the denial of access to his or her record is subject to a six-month limitation period. For complaints respecting contravention of the legislation, there is the possibility for an extension of time although the Information and Privacy Commissioner has no discretion regarding complaints about access refusal.

ACE believes that the different limitation periods are unduly confusing and the timelines are restrictive. We recommend that the limitation periods be amended in order to achieve consistency with the general limitation period of two years for most civil actions found in the *Limitations Act*, *2002*.

Conclusion

Generally speaking, *PHIPA* sets out a positive framework for collecting, using and disclosing personal health information but the most significant obstacle is its repeated misapplication. Education about the statute is paramount to ensure that the rights of individuals are protected. Health information custodians must be reminded of the purposes of the legislation.

Thank you again for the opportunity to participate in this review. We urge the Standing Committee to use our comments, and those found in submissions from other stakeholders, to meaningfully provide individuals with rights respecting their personal health information.

Yours truly,

ADVOCACY CENTRE FOR THE ELDERLY

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