



Psychiatric Patient Advocate Office

Bureau de l'intervention en faveur des patients des établissements psychiatriques

Submission to the Standing Committee on General Government
Regarding Bill 31
Personal Health Information Protection Act, 2003

January 28, 2004

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PROMOTING PATIENTS' RIGHTS



Our Logo

Our logo, with three divisions, places the patient at the centre, with the advocate and the patient's support network on either side. In our practice of advocacy, we at the Psychiatric Patient Advocate Office (PPAO) proceed from the patient's perspective, the heart of the matter. We believe that creating caring systems requires the effort of all those involved.

We chose the heart symbol as our logo because it best reflected our vision, values and principles:

- that consumers be actively involved in all decisions affecting their life, care and treatment;
- that consumers of mental health services be treated with dignity and respect;
- that consumers direct the advocacy process, using the advocate as a resource;
- that Patient Advocates respect each client's personal choices and provide advocacy from the client's point of view.



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January 28, 2004

Jean-Marc Lalonde, M.P.P.
Chair, Standing Committee on General Government
Room 1405, Whitney Block
Queen's Park, Toronto, ON, M7A 1A2

Dear Mr. Lalonde:

RE: Personal Health Information Protection Act, 2003

The Psychiatric Patient Advocate Office (PPAO) appreciates the opportunity to provide comments on the government's privacy legislation, the *Personal Health Information Protection Act, 2003 (PHIPA)*. We have noted that a number of our previous recommendations have been adopted in this new bill and are pleased that our comments relating to the rights of persons with mental illness have been recognized.

The PPAO is supportive of Bill 31 but also recognizes that there are weaknesses. I hope that our submissions will clarify the concerns that we have heard from our clients. For the past two decades the PPAO has worked to promote and protect the civil and legal rights of individuals with a mental illness. We know many of our clients face stigma and discrimination because of their illness and the stereotypes and misconceptions that the public holds with respect to mental illness. It is in light of this that we ask the Committee and the government to consider mental health information as a "special type" of information and that disclosure rules currently in the *Mental Health Act* be enshrined in PHIPA in order to provide maximum rights protection for our clients.

The PPAO is also concerned that PHIPA does not adequately address access by Patient Advocates to client personal health information. The bill, if enacted in its current form, would severely restrict our ability to provide a full range of advocacy services to some of the most vulnerable people in the mental health system. Our submission will highlight why the authority of the PPAO must be enshrined in this legislation.

We would encourage the government to move forward with this legislation. The PPAO would be pleased to work collaboratively with the government in drafting and reviewing the regulations, designing approved forms and educating stakeholders, including patients, families and health care providers. As a rights protection organization we want to ensure that any legislation with respect to personal health information does in fact provide the protection that our clients want and need. Should you have any questions please contact me at (416) 327-7007.

Sincerely,

Vahe Kehyayan
Director

Summary of Recommendations

The PPAO recommends the following:

Access by the PPAO

- The PPAO submits that those individuals, who are designated by the Minister of Health under section 9 of the *MHA*, are allowed to have access to patients' personal health information in any format without explicit consent either from the patient's clinical, any other record, or through discussion with staff. The authority could come through a specific appointment section, such as in the *MHA*, with appropriate complementary sections in the disclosure section. Alternately, the authority could be created through amendment to the *MHA* via Bill 31 with clear direction as to its relationship with *PHIPA*.

PPAO as a HIC

- The PPAO also submits that it be made clear under *PHIPA* whether it is the legislature's intent to categorize the PPAO as a HIC.

MHA Amendments

- The PPAO submits that section 35(2) refer readers back to *PHIPA* to reduce inadvertent disclosures that do not comply with that Act.

Disclosures without Consent

- The PPAO submits that all disclosures without consent contained in the draft legislation be carefully reviewed to ensure in all sections that permit disclosure without consent are absolutely necessary and are consistent in the area of mental health. Further, we submit that any such provisions are written as narrowly as possible to limit inappropriate disclosures. Finally, that such provisions where they remain necessary be accompanied by provisions requiring immediate written notification of the disclosure.

Access to PHI

- The PPAO submits that the present provisions under section 36 of the *MHA* be retained in the context of mental health facilities. Further, present provision for rights advice in section 38 of the *MHA* be retained.

Approved Forms

- The PPAO submits that *PHIPA* standardize the use of approved forms to standardize processes and applications for reviews, appeals, access to information, revocation of consent and complaints to the Commissioner.

Informed Consent

- The PPAO submits that the elements of consent under *PHIPA* be amended to replicate those in the HCCA, section 11 including subsection 11(2) and (3) with

necessary modifications to apply to PHI. Section 18(2) should be amended in the context of mental health information to ensure express consent is always obtained for its disclosure. The PPAO also supports the submissions of *CMHA*, Ontario Division regarding the expanded definition of informed consent, particularly their submission that “informed” include understanding that disclosure may be limited. Section 18(4) should be eliminated as “to know” will be changed to “informed consent”.

- Section 20(3) should be eliminated.
- Section 21 should clarify that there is no minimum age for capacity.
- That explicit consent be obtained in a consistent manner through the use of an approved form which clearly permits persons to limit disclosure and to create an expiry date.
- The PPAO submits that some thought be given to the notion of on-going consent. One concern that our office often hears from community organization is that consent only exists up until the point the consent is given – it is not clear that the consent can look forward to permit disclosure of on-going matters. This is problematic where organizations have regular communication with families or where hospitals have (consent-based) relationships with community organizations. As such, it would be of assistance for the legislation to address future consent with sufficient protections: informed consent would have to be very specific for “on-going” disclosures including the names to whom the information can be disclosed, it’s purposes, an expiry date and a straightforward mechanism to withdraw that consent and terminate the disclosures. Such disclosure clearly must meet the threshold for informed consent, if not a higher standard given the prospective nature.

Rights Advice and Rights Information

- The PPAO submits that section 22(1) should require independent rights advice for persons with mental illness. The provision of information for other persons should echo the language of section 17 of the *HCCA* and the guidelines incorporated by Colleges, requiring HICs to provide information on the consequences, the availability of review and assistance for the review. A person’s mental health status should never be a reason to choose not to provide that information and assistance. Section 22(2) should not limit the right of review to persons without substitute decision-makers. The provisions for appeal should be incorporated into *PHIPA* and not left to regulation.

Personal Representatives and Substitute Decision-Makers

- The PPAO submits that section 23(1)(3) be amended to place the personal representative at a level above substitute decision-makers under the *HCCA*.
- The PPAO also supports the recommendations of *CMHA* relating to substitute consent and provisions relating to prior capable wishes.

Fees

- The PPAO submits that there be an exemption from any fee where such a charge would prevent access or cause undue financial hardship. That where a HIC denies a waiver of the fees, the decision be reviewable by the Information and Privacy Commissioner. And that the regulations prescribe clear fees.

Disclosure without Consent

- The PPAO submits that *PHIPA* not permit such disclosures without the explicit consent of the individual. Alternately, section 37 be amended to only permit the disclosure of information regarding a person's status, location in the facility or their condition be limited to circumstances where such disclosures would not also disclose a diagnosis or mental health information [consistent with Manitoba privacy legislation]. Appropriate emergency provisions could be created to permit disclosures in limited circumstances.

Disclosure Regarding Harm

- The PPAO submits that disclosure for the purposes of the prevention of harm be more carefully outlined to provide guidance to HICs; that disclosure to prevent harm be limited to the information necessary to prevent that harm; that disclosure for the purposes of assessing custody not be made without consent; and that the person be notified of any disclosures made without consent.

Limitations and Appeals

- The PPAO submits that the limitations be harmonized at a minimum of one year for clarity; that the Commissioner have discretion on all matters to extend the time for review; and that prejudice be one factor considered in assessing whether to extend time but that it not be a determinative factor.
- The PPAO submits that an appeal right remains apart from the complaint process embodied in *PHIPA* and that damages be available for negligent behaviour resulting in harm.

Submissions respecting the *Personal Health Information Protection Act, 2003*

Psychiatric Patient Advocate Office
January 28, 2004

Introduction

The Psychiatric Patient Advocate Office (the “PPAO”) appreciates the opportunity to provide further comments on the government’s most recent privacy legislation, the *Personal Health Information Protection Act, 2003* (“*PHIPA*”). We have noted that a number of our previous recommendations have been adopted in this new bill and are pleased that our comments relating to the rights of persons with mental illness have been recognized.

While our submission will focus on areas of *PHIPA* that we feel are not adequate, we would like to acknowledge that the bill is a marked improvement from previous drafts. Specifically, the PPAO is pleased that *PHIPA* strengthens the privacy protections afforded to individuals through a broad definition of Personal Health Information (“PHI”), an obligation to obtain explicit consent for fundraising and marketing functions and an expanded oversight role for the Information and Privacy Commissioner. Further, *PHIPA* restricts access by the Minister of Health and Long-Term Care and balances that access with a number of safeguards. *PHIPA* as well incorporates whistle-blower protections and ensures public consultation for most regulations. In general, the legislation is based on the fundamental value that individuals own their information and consequently control its collection, use and disclosure.

However, as with any significant piece of legislation, *PHIPA* has certain limitations. It attempts to govern all PHI across a number of sectors. While consistent rules are necessary throughout the healthcare system, both institutionally and in the community, some PHI has a greater sensitivity attached to it due to its very nature. Mental health information is one of these special types of information that may require special rules.

It is from that perspective that we are bringing to you today the viewpoint of our clients and all persons who may have personal mental health information.

A. Access by Patient Advocates to Patient Records

Current Status

The PPAO has been providing advocacy in Ontario’s 10 provincial psychiatric facilities since 1983. That role has continued in the divested hospitals following divestment. During this period, the PPAO has endeavored to protect the civil and legal rights of in-patients through rights advice and advocacy services.

Advocacy takes many forms: assisting in self-advocacy, individual instructed and non-instructed advocacy, regional systemic advocacy, provincial systemic advocacy and education. In every case of individual advocacy, it is our preference to receive a client's instructions. Unfortunately, due to our clients' illnesses (e.g., dementia; dual diagnosis; severe Schizophrenia; acquired brain injury), their medication or other factors, they are sometimes unable to communicate their needs and to instruct Patient Advocates. In cases where such clients are unable to instruct Patient Advocates, we ensure that their basic quality of life and care concerns are met through non-instructed advocacy.

Our approach is to begin advocacy at the level of least contest: approaching the decision-maker closest to the issue. Such advocacy requires a great deal of communication with front-line staff and administration. Often issues are resolved very quickly with an inquiry by a Patient Advocate.

Current Authority

The authority to perform a Patient Advocate's duties presently comes from the *Mental Health Act* at section 9, which states:

9(1) Advisory officers. – The Minister may designate officers of the Ministry or appoint persons who shall advise and assist medical officers of health, local boards of health, hospitals and other bodies and person in all matters pertaining to mental health and who shall have such other duties as are assigned to them by this Act or the regulations.

(2) Powers. – Any such officer or person may at any time, and shall be permitted so to do by the authorities thereat, visit and inspect any psychiatric facility, and in so doing may interview patients, examine books, records and other documents relating to patients, examine the condition of the psychiatric facility and its equipment, and inquire into the adequacy of its staff, the range of services provided an any other matter he or she considers relevant to the maintenance of standards of patient care.

The Minister of Health and Long-Term Care designates Patient Advocates under section 9. Authority in divested hospitals is derived from a standard Memorandum of Understanding signed by the facilities, the Ministry of Health and Long-Term Care and the PPAO. The specific clause is found at Part IV, section 3:

Access to Patients and Records

For the purposes of instructed and non-instructed advocacy, and where permitted by law, the Tier 1 Receiving Hospital will provide the PPAO with reasonable access to patients and patient records at the former PPH site.

There has been a lack of clarity respecting the Patient Advocate's ability to access patient records for a period of time given the tension between section 9 of the *MHA*, which appears to provide authority for a Patient Advocate to access "books, records and other documents relating to patients" and section 35 which requires all disclosures to occur

according to the rules in that section. While the PPAO has largely been able to provide services despite the lack of clarity to this point, *PHIPA* will further complicate this process as that legislation and its disclosure rules appears to supercede any authority granted through section 9 of the *MHA*.

Access under *PHIPA*

PHIPA does not, presently, provide any non-formal access to patient records for Patient Advocates. While Patient Advocates could obtain formal consent by the person or their substitute decision-maker as would any other person wishing to access records, such a process would be impractical and unwieldy and would fail to ensure the protection of our most vulnerable clients – those who could not consent.

1. This process would be impractical because Patient Advocates would be unable to discuss client issues with staff on an *ad hoc* and would, therefore be unable to resolve matters quickly, without further escalation;
2. It would be unwieldy to regularly obtain updated consents for each client that Patient Advocates speak to and to have staff acknowledge the same by reviewing the record before each discussion;
3. Patient Advocates may not wish to alert staff immediately of an issue – they would want to review the information in the clinical record first in some situations;
4. It would fail to protect our most vulnerable clients, those who are unable to consent to release their own record or to instruct Patient Advocates. Patient Advocates must be able to protect these persons without the step of obtaining consent from a third party who is not their client.

PPAO Status as a Health Information Custodian (HIC)

The PPAO also requires clarification about whether or not, under *PHIPA*, our office is a HIC. Given that the PPAO operates under a Memorandum of Understanding with the Ministry, confirming its independence in its advocacy mandate but having administrative accountability, it is unclear whether the PPAO falls under the definition in section 3. We are continuing to review this matter and may provide additional comments to the Committee at a later time.

Recommendation: The PPAO submits that those individuals, who are designated by the Minister of Health under section 9 of the *MHA*, are allowed to have access to patients' personal health information in any format without explicit consent either from the patient's clinical, any other record, or through discussion with staff. The authority could come through a specific appointment section, such as in the *MHA*, with appropriate complementary sections in the disclosure section. Alternately, the authority could be created through amendment to the *MHA* via Bill 31 with clear direction as to its relationship with *PHIPA*.

The PPAO also submits that it be made clear under *PHIPA* whether it is the legislature's intent to categorize the PPAO as a HIC.

B. Amendments to the Mental Health Act

The *Mental Health Act* enshrines patients' rights in the law and outlines the various checks and balances in the mental health system that serve to protect and promote these rights. Some of the checks and balances include: the provision of rights advice, application to the Consent and Capacity Board for review of a finding and the right to retain and instruct counsel. These mechanisms have served patients in the mental health system well and many of these measures must be codified in *PHIPA*.

Disclosure

PHIPA revokes the present provisions of section 35 under the *MHA*, which currently provides very stringent rules for disclosing information in a clinical record, and replaces them with very broad language as to the collection, use and disclosure of PHI. While this section is intended to be read in the context of *PHIPA* and its limiting provisions surrounding disclosure, such a broad apparent authority in the *MHA* will undoubtedly lead to inappropriate disclosure of information for persons with mental illness in hospital. Clear language is necessary to refer mental health workers and HICs to the complementary provisions of *PHIPA* to guard against inadvertent misuse. A simple mechanism could be to amend sub-section 35(2) of the *MHA* to include the phrase "in accordance with the *PHIPA* to maximize rights protections for those who are in psychiatric facilities". This would create greater awareness for health practitioners that they must refer to both the *MHA* and *PHIPA* when considering disclosure and the threshold set out in the law.

Recommendation: The PPAO submits that section 35(2) refer readers back to *PHIPA* to reduce inadvertent disclosures that do not comply with that Act.

Disclosure without Consent

In a number of situations throughout the amendments to the *MHA* and in the new provisions of *PHIPA*, there are situations in which disclosure can be made without consent. One example is section 35(4.1), which allows the Officer in charge to disclose PHI to the chief executive officer of a health facility that is currently involved in the direct health care of an individual. While we appreciate that there are circumstances in which consent is impossible or waiting to obtain consent would be unsafe, such disclosures must be accompanied by immediate notification of the individual. Written notification should include the purpose of the disclosure, the date of the disclosure and to whom it is disclosed.

Recommendation: The PPAO submits that all disclosures without consent contained in the draft legislation be carefully reviewed to ensure in all sections that permit disclosure without consent are absolutely necessary and are consistent in the area of mental health. Further, we submit that any such provisions are written as narrowly as possible to limit inappropriate disclosures. Finally, if such provisions remain necessary, we submit that

they be accompanied by provisions requiring immediate written notification of the disclosure.

Access to Information

PHIPA will repeal the provisions of section 36 of the *MHA* and replace the section with access to one's own PHI provisions under *PHIPA*. The PPAO believes that Section 36 of the *MHA* should not be repealed but should remain and be exempt from *PHIPA*.

Section 36 of the *MHA*, in its present form provides significantly increased protections to persons in mental health facilities. Under the *MHA*, the facility must provide access to a record within 7 days as opposed to the 30 days with indefinite extensions found in *PHIPA*. The *MHA* places the burden of withholding a portion of the record on the Consent and Capacity Board; that is, if the facility wishes to withhold the record, it must apply for permission to do so. *PHIPA* places the burden of the application on the individual. Instead of providing clear and responsive access to one's own record, *PHIPA* significantly erodes the protection of our clients.

Recommendation: The PPAO submits that the present provisions under section 36 of the *MHA* be retained in the context of mental health facilities. Further, present provision for rights advice in section 38 of the *MHA* be retained.

Approved Forms

There are currently a number of approved forms attached to the *MHA*. The usage of these forms has standardized processes such as the release of information, application to review the clinical record and several rights-based circumstances. The approved forms have made it much easier for people to pursue their rights and entitlements as the process is standardized and known by all parties involved.

Recommendation: The PPAO submits that *PHIPA* standardize the use of approved forms to standardize processes and applications for reviews, appeals, access to information, revocation of consent and complaints to the Commissioner.

C. PHIPA

Capacity to Consent to the Collection, Use or Disclosure of PHI

Section 18 of *PHIPA* outlines the elements required for consent under that Act. The elements are not the same as those created for the purposes of informed consent under the *Health Care Consent Act* (section 11) in two fundamental ways: (1) the requirement that consent be "informed" under the *HCCA* is replaced with "knowledgeable" under *PHIPA* and (2) the requirement that the consent be "voluntary" is removed.

At the very least, the inconsistency between the two pieces of legislation will lead to confusion as to the elements of consent. More concerning, the different elements from *PHIPA* will lead to a reduced standard in the context of records. For example, case law has interpreted the word "informed" to create an obligation on the health care practitioner to provide all requisite information to the individual. The failure to do so may vitiate

consent. By using the term “knowledgeable” in place of “informed” it is unclear whether the obligation to obtain information would remain with the practitioner. Similarly, the exclusion of “voluntary” from the elements may lead to situations in which individuals are pressured into consenting.

Implied consent to disclose information is inappropriate as it relates to mental health records or information, even where such information is being disclosed to another health practitioner for the purposes of providing health care. The increased sensitivity of such information and the continuing stigma encountered by our clients dictates that such disclosures only be made on the express consent of the individual or their substitute decision-maker.

The PPAO submits that section 20(3), a provision allowing a disclosing HIC to advise a receiving HIC that full disclosure was not provided due to limited consent is inappropriate in the mental health context. One of the recurring themes in criticism of privacy legislation in the past has been that health care practitioners will share information about patients without consent. While this provision improves on such open disclosures, a real concern exists that persons with a mental health history will be required to share that information with unrelated health care practitioners: which may result in actual or perceived reduction in service. For example, clients have advised our office that their complaints of physical symptoms are not taken as seriously by health practitioners when the practitioners are aware of a mental health history. Inquests have also raised this issue. As such, persons with a mental health history are perhaps justified in not sharing that information with health care practitioners they are seeing for unrelated purposes. Allowing the disclosing HIC to advise of the undisclosed information will undermine that ability. Information belongs to the individual and he or she must be permitted to disclose it as wished. If non-disclosure places them at risk, that is a risk that the individual may assume with appropriate informed consent. If non-disclosure of significant information is an issue, it may become part of the determination of capacity.

Recommendation: The PPAO submits that the elements of consent under *PHIPA* be amended to replicate those in the *HCCA*, section 11 including subsection 11(2) and (3) with necessary modifications to apply to PHI. Section 18(2) should be amended in the context of mental health information to ensure express consent is always obtained for its disclosure. The PPAO also supports the submissions of *CMHA*, Ontario Division regarding the expanded definition of informed consent, particularly their submission that “informed” include understanding that disclosure may be limited. Section 18(4) should be eliminated as “to know” will be changed to “informed consent”.

Section 20(3) should be eliminated.

Section 21 should clarify that there is no minimum age for capacity.

That explicit consent be obtained in a consistent manner through the use of an approved form which clearly permits persons to limit disclosure and to create an expiry date.

Finally, the PPAO submits that some thought be given to the notion of on-going consent. One concern that our office often hears from community organizations is that consent only exists up until the point the consent is given – it is not clear that the consent can look forward to permit disclosure of on-going matters. This is problematic where organizations have regular communication with families or where hospitals have (consent-based) relationships with community organizations. As such, it would be of assistance for the legislation to address future consent with sufficient protections: informed consent would have to be very specific for “on-going” disclosures including the names to whom the information can be disclosed, its purposes, an expiry date and a straightforward mechanism to withdraw that consent and terminate the disclosures. Such disclosure clearly must meet the threshold for informed consent, if not a higher standard given the prospective nature.

Ability and Right to Appeal

The *Health Care Consent Act* and the *Mental Health Act* enshrine a person’s right to review findings that impact on their legal rights. Being informed of and being able to review health care practitioner’s findings are fundamental safeguards built into the legislation. The companion sections in *PHIPA* erode these protections. In section 22(2), a person found incapable of consenting to the collection, use or disclosure of their PHI is only permitted a right of review if they do not already have a substitute decision-maker under the *HCCA*. The limit on the rights of review is a significant departure from the premise that a person may challenge a legal finding made by a health care provider to an independent body.

Further limiting a person’s ability to appeal are the provisions in section 22(1), which require a HIC to provide information about the consequences of the finding only where it is “reasonable in the circumstances”. To limit information provision to a “reasonableness” standard will no doubt ensure that many persons with mental illness are never provided with this information. While the legislature may be envisioning reasonableness to mean that a physician need not review the information with a person who is unconscious, such a broad term is likely to include a number of persons, particularly those with mental illness, whose mental health practitioners believe could not understand the information.

Additionally, information relating to the consequences of the finding is not sufficient to ensure that the incapable person learns of the right of review. In section 17 of the *HCCA*, a health care practitioner is required to provide information in accordance with the guidelines established by the appropriate governing college (there is no release of the duty where “reasonable”). The College of Physicians and Surgeons’ guideline requires that a physician advise an incapable person of the consequences and, if the person disagrees, about the availability of review by the Consent and Capacity Board. The physician has the further obligation of assisting the person to apply.

Such should be the minimal standard for informing a person following a finding of incapacity. The *Mental Health Act* sets a much higher standard where findings are made affecting legal rights. Due to the potential vulnerability of persons with mental illness,

the *MHA* requires that findings of incapacity to disclose or review ones own clinical record be followed by rights advice from an independent rights adviser. The rights adviser provides information regarding the consequences of the finding and the ability to review the decision. If the person so directs, the rights adviser would also assist the person in applying to the CCB, applying for legal aid and in obtaining a lawyer. Such protections must be granted to persons with mental illness in *PHIPA*.

Recommendations: The PPAO submits that section 22(1) should require independent rights advice for persons with mental illness. The provision of information for other persons should echo the language of section 17 of the *HCCA* and the guidelines incorporated by Colleges, requiring HICs to provide information on the consequences, the availability of review and assistance for the review. A person's mental health status should never be a reason to choose not to provide that information and assistance. Section 22(2) should not limit the right of review to persons without substitute decision-makers. The provisions for appeal should be incorporated into *PHIPA* and not left to regulation.

Personal Representatives and Substitute Consent

In section 23(1)(3), the personal representative of a person appointed by the Consent and Capacity Board is at the same level of decision-making as substitute decision-makers under the *HCCA*. For example, if the person has a substitute decision-maker for treatment decisions, that person would have equal authority to make decisions about PHI as a personal representative appointed by the CCB expressly for that purpose. The section should provide clarity as to the representative's authority.

Recommendation: The PPAO submits that section 23(1)(3) be amended to place the personal representative at a level above substitute decision-makers under the *HCCA*.

The PPAO also supports the recommendations of *CMHA* relating to substitute consent and provisions relating to prior capable wishes.

Access to Records

Section 34(2) permits HICs to charge fees for the disclosure of PHI equal to reasonable cost recovery or the prescribed amount. Such fees can be prohibitive for low-income persons. Cost should not prevent access to PHI.

Recommendation: The PPAO submits that there be an exemption from any fee where such a charge would prevent access or cause undue financial hardship. That where a HIC denies a waiver of the fees, the decision be reviewable by the Information and Privacy Commissioner. And that the regulations prescribe clear fees.

Disclosures of Information without Consent

PHI relating to mental illness is perhaps one of the most sensitive of the various types of information. Rules around disclosing that information cannot be dealt with in the same manner as general health information, yet *PHIPA* makes no distinctions. The continuing discrimination against persons with mental illness makes disclosure of information

without consent a serious matter. A person who has been admitted to the psychiatric unit in crisis is much less likely to want that information shared than a person admitted to cardiac care.

Consequently, section 37 is not appropriate in the mental health context. The provision allowing a facility to contact a relative or friend if the person him or herself is unable to consent where they are “injured, incapacitated or ill” is far too broad a statement. Many persons with mental illness entering hospital may be in crisis and unable to immediately communicate their wishes regarding contact. That same person may feel very strongly that he or she does not wish to have family involved due to embarrassment or other factors.

Further, the ability to share information with those inquiring relating to whether or not the person is a patient, their general health status and location in the hospital is inappropriate. If the facility is a psychiatric hospital, informing someone that the person is a patient also discloses that the person is likely to have a mental illness. The person’s general status could mean disclosing that the person is acutely ill and in four point restraints. Location in a facility, when it is a general hospital could mean stating the person is being held on the psychiatric ward. Many persons with mental illness would not want this information shared, particularly if the inquirer were an employer, probation officer or a separated spouse involved in a custody dispute.

Recommendations: The PPAO submits that *PHIPA* not permit such disclosures without the explicit consent of the individual. Alternately, section 37 be amended to only permit the disclosure of information regarding a person’s status, location in the facility or their condition be limited to circumstances where such disclosures would not also disclose a diagnosis or mental health information [consistent with Manitoba privacy legislation]. Appropriate emergency provisions could be created to permit disclosures in limited circumstances.

Disclosures Related to Risk

Section 39 attempts to codify risk disclosures from both Canadian and United States common law. The language falls far short of the rules created by *Jones v. Smith* (SCC, 1999), which permits only necessary disclosure in very narrow circumstances. The case looks at whether public safety outweighs confidentiality (in the case solicitor/ client privilege was at issue) by considering three primary factors: (1) Is there a clear risk to an identifiable person or group of persons? (2) Is there a risk of serious bodily harm or death? (3) Is the danger imminent? If after considering all appropriate factors it is determined that the threat to public safety outweighs the need to preserve confidentiality, then the confidentiality must be set aside but the disclosure should be limited so that it includes only the information necessary to protect public safety.

Disclosures under subsection 39(2) to those charged with determining detention, either in the criminal or mental health context, are inappropriate. There are methods to obtain assessments where appropriate with necessary safeguards. To simply permit disclosure for this purpose without any checks and balances is inappropriate and may lead to

“gating”, or the means of transferring someone from jail at the end of a criminal sentence to mental health custody, without due process.

Neither disclosure, where permitted, presently requires that the individual be notified either before or after the fact.

Recommendations: The PPAO submits that disclosure for the purposes of the prevention of harm be more carefully outlined to provide guidance to HICs; that disclosure to prevent harm be limited to the information necessary to prevent that harm; that disclosure for the purposes of assessing custody not be made without consent; and that the person be notified of any disclosures made without consent.

Review of Access by Privacy Commissioner

The limitation periods for complaint to the Privacy Commissioner are different depending on the subject matter. Where a person is alleging that there has been a contravention of the Act, there is a one-year limitation. However, where an individual has been denied access to his or her record, there is a six-month limitation. For complaints regarding contravention, there is the possibility for an extension of time whereas the Commissioner has no such discretion regarding complaints about access refusal.

Recommendation: The PPAO submits that the limitations be harmonized at a minimum of one year for clarity; that the Commissioner have discretion on all matters to extend the time for review; and that prejudice be one factor considered in assessing whether to extend time but that it not be a determinative factor.

Civil Actions

Section 63 appears to allow a person to commence a proceeding in the Superior Court of Justice if the Commissioner has issued an order. Individuals should not be obligated to proceed through the complaint process as a condition precedent to initiating a claim. Further, the section notes that a court may only award damages if harm was caused to the plaintiff as the result of a violation of the Act that the defendants engaged in “willfully or recklessly”. Damages should also flow where there has been negligence.

Recommendations: The PPAO submits that an appeal right remains apart from the complaint process embodied in *PHIPA* and that damages be available for negligent behaviour resulting in harm.

Conclusion

In conclusion, the PPAO is pleased with a number of the changes that have been made in this new version of the *PHIPA*. However, as a rights protection organization we are also concerned with a number of items in this proposed legislation.

Bill 31 must address access to personal health information for those designated by the Minister, and charged with the responsibility of providing rights protection and advocacy services to individuals in Ontario's mental health system. Patient Advocates working for

the PPAO require reasonable access to fulfill their rights protection mandate. The current requirements for consent would make this task nearly impossible. Thus, advocacy with the most vulnerable people in mental health facilities, those unable to instruct or provide consent, including persons with dementia, a dual diagnosis or an acquired brain injury, would be limited. If consent were required before Patient Advocates could address quality of care and life issues. In some cases, if the Substitute Decision-Maker had to provide the consent, they might be reluctant to do so for fear of reprisal for their loved one, out of fear that service might be terminated or the person discharged or simply because they did not wish to have the Patient Advocate involved. This may occur if the SDM and the person had conflicting ideas or wishes. In this way the Patient Advocate could be prevented by the SDM from fulfilling their mandate and protecting the rights of the individual. This could be contrary to the wishes of the individual themselves. The services offered by the Patient Advocate serve as an important check and balance in the mental health system and in the promotion and protection of patients' rights.

As a rights protection organization we believe that this Bill can be strengthened to provide maximum rights protection to individuals in mental health facilities. Mental health information should be treated differently than other types of health information, given the misunderstanding of mental illness, the stigma attached to it and the discrimination that those with mental illness face in the broader society. We would encourage the government to revisit the proposed complementary amendments to the *Mental Health Act* taking this into consideration.

The PPAO recommends broad-based education targeting health information custodians, health care workers, government, our clients and the general public to further promote compliance with *PHIPA*. Education programs will help everyone understand their rights and responsibilities, as well as complaint and enforcement mechanisms detailed in this legislation.

In conclusion, Ontario has a strong and proud history of protecting vulnerable people and ensuring a balance between individual rights and those of the state. Bill 31, is an attempt to extend rights protection by setting clear rules for the disclosure of personal health information. Incorporating the recommendations in our submission will make the proposed legislation much stronger, more effectively protecting the personal health information of all Ontarians.

Appendix 1

1.	Vision, Mission, Mandate and Values	15
2.	Guiding Principles of Advocacy	17
3.	Glossary of Terms	18
4.	Best Interest vs. Client Instruction	19

Vision, Mission and Mandate

Mission

The PPAO provides independent and confidential advocacy services and rights advice to consumers of and those seeking access to psychiatric services. We work to empower our clients to make informed decisions about their care, treatment, and legal rights. We use information, education, negotiation, and referral to conduct instructed, non-instructed, and systemic advocacy. We conduct public education on these issues. We promote self-advocacy and self-determination.

Vision

The vision of the Psychiatric Patient Advocate Office (PPAO) is that persons with mental illness in Ontario be treated with dignity and respect, that their legislated rights and entitlements be upheld at all times, and that they be actively involved in decisions affecting their life, care, and treatment.

Mandate

- To advance the legal and civil rights of psychiatric patients by means of both individual case work and systemic advocacy;
- To inform the patient, family, hospital staff, and the community about patients' legal and civil rights;
- To assist, facilitate (self advocacy), and help resolve the complaints made by psychiatric patients by providing an avenue for resolution through negotiation according to the patient's instructions;
- To investigate alleged incidents and to assess institutional and systemic responses to these instances;
- To refer patients, when necessary, to outside community advocacy resources such as community organizations, lawyers, or physicians who may offer a second opinion.

Values

In providing services to its clients, the PPAO is guided by the following values:

People:

- We believe in the autonomy of all people and in each person's right to make informed choices. We value all people as members of our communities and recognize that we may need a variety of formal and informal supports and services in our lives.

Education:

- We believe education is a powerful tool to effect social change and that this is a part of advocacy.

Community:

- We believe that with sufficient community options and supports, most mental health consumers are able to remain in their home community if this is their choice.

Process:

- We believe that the advocate's first responsibility is to act upon the client's expressed wishes and personal choices, and to promote the safety, quality of life and care of clients who cannot instruct an advocate.

Independence:

- We believe that we must be maximally free from actual, potential, or perceived conflicts of interest in order to serve our clients more effectively.

Consumer Participation:

- We believe that it is essential for consumers, to the extent that they want to and are able to, participate and have the sense of ownership in the policy development of the PPAO.

Guiding Principles of Advocacy

Advocacy is Client Directed

Unless the client is incapable of instructing an advocate, advocacy is client directed. That is, the actions of the advocate are guided by the instructions of the client. The advocate serves the client on a voluntary and consensual basis. The advocate does not substitute for the client's instructions his or her own personal or professional view of what course of action is in the "best interests" of the client. Central to advocacy is the determination of the client's wishes and the servicing of those wishes, unless the client's instructions are illegal or impossible to carry out.

Advocacy is Independent

Advocacy should be, and be seen to be, independent. In order to avoid any potential or perceived problems with conflict of interest, advocates should be independent both from the psychiatric facilities where and service providers from whom their clients receive care and treatment.

Advocacy is Accessible

For advocates to be able to assist vulnerable clients, they must be readily accessible to them. They must also be assured of the opportunity to communicate with their clients without interference from others.

Advocacy Uses Avenues of Least Contest

Advocates seek to resolve issues at the level of least contest by beginning with the decision-maker closest to the client's problem before escalation to higher authorities. They seek all avenues to promote patients' rights and freedoms including conciliation, mediation and reasoned discussion.

Glossary of terms

Advocacy

Advocacy is a process that ensures that the rights of vulnerable people are protected, that their self-defined needs are met, and that they are supported to make decisions that affect their lives. It is also a vital component of patient protection, assuring that the vulnerable person's legal and human rights are respected, and that their self-determination, independence and autonomy are maintained. The PPAO differentiates between the concepts of "protection" and "advocacy". "Protection" refers to interventions offered to people with disabilities on the assumption that they are unable to understand their options, express their views or make and take responsibility for choices about their lives, care and treatment. "Advocacy", on the other hand, emphasized a person's capacity for autonomy and ability to make such choices, particularly if offered assistance in understanding the options available, and in communicating personal preferences to others. In the case where a vulnerable person cannot instruct an advocate and is at risk of abuse or neglect, an advocate's intervention may be seen as "protection." Hence, this dimension of "protection" is included within the concept of "advocacy."

Self-Advocacy

Advocacy that is undertaken directly by the individual to achieve a specific goal. This form of advocacy may be enhanced through contact with an advocate who can provide information; resources, and an outline of options and expected outcomes of an individual's actions.

Instructed Advocacy

Advocacy that is undertaken directly by an advocate based on a client instruction. The process is guided by the principles of self-determination, client empowerment and self-advocacy. The advocate outlines options and the client determines the path to issue resolution. The advocate assumes the competency of the client to instruct unless the contrary is indicated.

Non-Instructed Advocacy

In keeping with the principles of self-determination, client empowerment and self-advocacy, non-instructed advocacy is conducted on behalf of an individual who for some reason is unable to instruct an advocate at the given time. Issues may concern the quality of life of an institutionalized person or those where a failure to take action will compromise the health, estate, personal security or dignity of the client.

Systemic Advocacy

Systemic advocacy focuses on issues that affect a broad segment of a particular population. These initiatives may, for example, comprise strategic efforts to change administrative structures and service delivery within the context of psychiatric institutions. This can include law and policy reforms that provide the basis for services provided in the mental health care system. The goal of systemic advocacy is to promote changes that support the legal rights social and therapeutic entitlements of clients; and to address power inequities inherent in institutional settings.

Best Interest vs. Client Instruction

Best Interest v. Client Instruction:

Fundamental to the practice of advocacy is the notion that a client's instructions dictate the actions done on his or her behalf. Reinforcing an individual's right to self-determination, the advocacy relationship must respect the client's ability to make choices that reflect his or her own values. An advocate is neither a gatekeeper nor a decision-maker: his or her own beliefs must not dictate the path taken.

An advocate joins with the voice of the client, strengthening and supporting the position taken. The development of a true advocacy relationship ensures that the ultimate decisions made with respect to a client's care, treatment and quality of life reflect the client's position.