



# Psychiatric Patient Advocate Office

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

May 10, 2006

Ms. Carol Appathurai  
Ministry of Health and Long-Term Care  
Strategic Policy Branch  
8<sup>th</sup> Floor Hepburn Block  
Toronto, Ontario  
M7A 1R3

Dear Ms. Appathurai:

Thank you for the opportunity to provide comment respecting the amendment to Regulation 329/04 under the *Personal Health Information Protection Act, 2004*.

The Psychiatric Patient Advocate Office (PPAO) was established in 1983 as an arms-length program of the Ministry of Health and Long-Term Care to protect the legal rights and entitlements of patients in the current and divested provincial psychiatric hospitals. The PPAO has a mandate to speak to issues affecting the legal rights and entitlements of consumers of mental health services. In 2005 the PPAO provided approximately 21,000 first rights advice visits in the current and divested provincial psychiatric hospitals, in Schedule 1 facilities and to individuals being considered for the issuance or renewal of a Community Treatment Order and their Substitute-Decision Maker, if any. The PPAO also responded to more than 3,500 individual instructed and non-instructed advocacy issues and worked to resolve more than 75 systemic issues. Service was provided in 42 languages during 2005.

The proposed amendments to Regulation 329/04, although described as “minor housekeeping amendments,” have implications for the individuals who approach our office for service as well as individuals who access care from a health information custodian whether a hospital, the family physician, or dentist. The legislation and its regulations impact every citizen of Ontario. Some of the amendments and our proposed recommendations are significant from a rights protection perspective and we believe they would further strengthen the legislation and provide additional protection to vulnerable populations.

...2

## Destruction of Record – Section 1

The proposed amendment to section 1 of the Regulation is viewed by the PPAO as a positive step as it sets requirements for the destruction of a record so that the reconstruction of the record is not reasonably foreseeable in the circumstances. Setting out this requirement in the Regulation places a high obligation on health information custodians for the complete destruction of the record.

However, the phrase “reconstruction of the record is not reasonably foreseeable in the circumstances” may be arbitrarily applied and does not provide sufficient direction as to the true meaning of “destruction”. Most people would assume that “destruction” means that information no longer exists in any recorded form. Perhaps it could be defined by the type of information being destroyed such as paper or computer records. Further, it does not appear that non-compliance with this section carries any penalty for the health information custodian who fails to comply. This section would be strengthened if this section made reference to both compliance and enforcement provisions.

## Fundraising Purposes – Section 10

Section 10 allows a health information 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. However, the onus should not be on the individual to know and advise the health information custodian but rather there should be a positive obligation on the part of the health information custodian to specifically ask the patient if this information can be shared, with whom and for what period of time. The health information custodian should have this discussion with the client either on admission or as soon as practical but they must be required to have an explicit conversation with each client.

Clients must also be advised that if they choose not to disclose this information it will not impact on their ability to access service or the quality of service they receive from the health information custodian. For those clients who choose to allow the health information custodian to disclose their personal health information, there should also be a requirement that they be told that they can withdraw their consent at any time, without penalty or retaliation. This section would be strengthened if it required the health information custodian to record the client’s decision and perhaps this could be done on a standard regulated form attached to the *Personal Health Information Protection Act*.

The contact information which may be provided for the purposes of fund-raising should not include information regarding the patient’s substitute decision-maker without the patient’s explicit consent. The substitute decision-maker’s (SDM) involvement is restricted to a specific decision-making capacity. The patient and the SDM may be at odds as to the SDM’s involvement. The regulations should

reflect the limited role of the SDM by eliminating the SDM's contact information from this section.

### Use of Health Numbers – Section 11

The proposed amendment to section 11 of the Regulation permits a person who conducts health research to collect and use health numbers to the extent that the individual has provided a valid consent for the collection and use of the number for that purpose. Given the ability to link personal health information to the person via their health number there must be stringent guidelines put in place to ensure that the personal health information and rights of patients are protected. Clients must be afforded the opportunity to make an informed decision without fear of reprisal or coercion, be advised that they can withdraw consent at any time and that the service they receive from the health care provider will not be impacted by a refusal to grant access to their personal health information.

### Amount of Fees – Section 9

Although the proposed fee structure clearly defines the fees that can be charged for accessing a record of personal health information and it is better than having the Regulation remain silent on this issue, it will still serve as a barrier to access. Many mental health consumers in Ontario have an income below the poverty level and may only be in receipt of government assistance. The Regulation should specifically state that no fees should be charged for those whose only income is the Personal Needs Allowance, Ontario Disability Support Program or any other form of government pension, or regular or disability benefits.

We are concerned that the new fee schedule prescribes fees for the review of the record by the health information custodian to determine if the record contains information to which access may be refused as well as for supervision of an individual's examination of their own record. This piling on of access fees will act as a barrier to access and discourage people from accessing their own health information, which rightly belongs to them. It is our opinion that a client should not be charged for having the health information custodian assess their file or supervise them while reading their record. These two functions must be considered as an obligation and responsibility of the custodian and as part of the total provision of health services for which they already receive public funding. We would recommend that these two provisions be struck entirely from the regulation given the potential for them to become a barrier to access.

There should be no charge for access to a record of personal health information by the patient and/or his/her legal counsel for the purposes of preparation for a hearing before the Consent and Capacity Board or the Ontario Review Board. A fee should not be charged for supervision while the record is reviewed or for photocopies for use at the hearing. There should be no charge to have a custodian review the file to assess if some information should be withheld. In each of these cases any fee may disadvantage individuals to the extent that they

are denied access to justice as this financial encumbrance may prevent them from being adequately prepared to appear before the Board. A fee structure for many mental health clients would be an insurmountable barrier.

### Disclosure and Monetary Incentives

The PPAO is concerned that if a health care custodian is to receive any monetary incentive for disclosing the personal health information of a client, the regulation specifically set out guidelines for the notification of clients, the requirement that consent be obtained, a requirement that clients be advised that they can withdraw consent and that they understand why the information is being provided for monetary compensation. Since others may gain financially from the disclosure of information that belongs to the recipient of health care services, that person has the right to be advised of this situation. For example, if a hospital is to be compensated for completing a questionnaire regarding the client's needs, assessment, treatment or discharge plan then they should be required, by law, to advise the client that they are both reporting this information to another party and that they are being compensated for their efforts and the disclosure of the information.

Should you have any questions or require additional information please contact me at (416) 327-7004. Again, thank you for the opportunity to comment on this very important regulation.

Sincerely,



David Simpson  
Director (A)

c.c. John McKinley  
Assistant Deputy Minister