

**RECOMMENDATIONS CONCERNING  
THE *PERSONAL HEALTH INFORMATION PROTECTION ACT*  
FROM THE SCHIZOPHRENIA SOCIETY OF ONTARIO**

**Submitted to the Standing Committee on Social Policy  
of the Legislature of Ontario on August 27, 2008**



A REASON TO HOPE · THE MEANS TO COPE  
SCHIZOPHRENIA SOCIETY OF ONTARIO

SOCIÉTÉ ONTARIENNE DE LA SCHIZOPHRÉNIE  
UNE SOURCE D'ESPOIR · DE SOUTIEN ET D'ENTRAIDE

# RECOMMENDATIONS CONCERNING THE PERSONAL HEALTH INFORMATION PROTECTION ACT FROM THE SCHIZOPHRENIA SOCIETY OF ONTARIO

## Introduction

The Schizophrenia Society of Ontario (SSO) was initiated in 1979 by family members of persons with schizophrenia. Today, the Schizophrenia Society of Ontario has over 1,000 members and 8 regional offices throughout the province. Our organization's mandate is to improve the quality of life of those affected by schizophrenia and psychosis through education, support programs, public policy and research. SSO is unique in Ontario in its focus on the family and on fostering community support networks for people affected by schizophrenia.

Although our primary focus is on the families of people with schizophrenia, we are also naturally concerned with the best interests of those who live with this disease and other forms of serious mental illness. Consequently, the SSO strives to incorporate the welfare and perspectives of individuals with schizophrenia as well as their families in all aspects of our advocacy work. Our organization believes that a strong support network is an important part of the recovery process, and envisions a health care system which is inclusive of families.

The four recommendations we have provided aim to promote the continued protection of individuals' privacy rights, and at the same time foster a more sensible, balanced, and responsible approach to privacy access and protection. For the edification of the Standing Committee on Social Policy, these proposals are presented in two categories: recommendations for outright amendments and additions to the *Personal Health Information Protection Act*, and recommendations that pertain to the matter of public and professional awareness.

## Background

Schizophrenia is a chronic brain disease characterized by symptoms such as hallucinations, delusions, and thought disorder. Schizophrenia affects people of all ages, educational and income levels, and cultures. In fact, 1 in 100 Ontarians will develop schizophrenia during the course of their lives.

Individuals with mental illness are commonly referred to as mental health service consumer-survivors, consumer-survivors, or simply consumers. In this submission, we will use the term 'consumer'. Historically, consumers have been poorly served by the mental health system, sometimes suffering great indignity and neglect, loss of personal autonomy, and general lack of consideration for their human rights. Consequently, it is important now more than ever that their right to confidentiality of personal health information be respected and strongly protected by the *Personal Health Information Protection Act* (PHIPA).

However, families also have rights and preferences which should be considered in the review of the *Act*. Families of persons with schizophrenia are indirectly affected by the disease, especially when they are acting in a caregiving capacity. The complexity of the mental health care system compels many families to act as informal case managers or system navigators for their family members. In order to take on this role, they require the minimum amount of

health information necessary to assist their family members in accessing treatment, taking the prescribed medications, attending their medical or counseling appointments, and generally supporting them in their recovery process.

Yet many families have voiced a concern over the inability to obtain even limited information about their family members' state of mental health, let alone sufficient information to allow them to assist and support their treatment and recovery. Though the SSO does support privacy legislation which protects the personal health information of consumers, we believe that a culture of over-cautiousness has developed among many health professionals where the release of such information is concerned, to the point where many reportedly refuse to make disclosure even when it is clinically appropriate and legally valid to do so.

### **Recommendations Concerning Amendments and/or Additions to the Act**

#### **1. Amend Section 38(3) of PHIPA to impose a duty to inquire such that:**

**Health care facilities shall ask individuals who are patients or residents within them, when they receive inquiries from external parties, whether they may disclose personal health information [as currently listed in s. 38(3)] before actually disclosing or refusing to disclose it to the external parties at hand, with the caveats that:**

- (a) the duty to inquire be suspended upon receipt of consent to disclose in instances where subsequent inquiries are received by approved external parties;**
- (b) the individual be permitted to withdraw consent at any time, in which case the duty to inquire shall again be in effect; and**
- (c) the individual may qualify at any time the specific types of information that can be given to particular parties without triggering the duty to inquire, so long as consent to disclose is not revoked entirely.**

Section 38(3) of the *Personal Health Information Protection Act* presently allows facilities providing health care to reveal to any party who inquires such information as whether an individual is a patient or resident therein, what their general health status is, and where they are located within the facility, only if the individual in question was offered at the first available opportunity an opportunity to object to these disclosures. This does not mean that there is a duty on the part of the facility to make such an inquiry with the individual, but rather, that the information is only disclosed upon knowing that the individual has been given the opportunity to object.

In practice, many families call health care facilities to inquire about their family members, only to be told that no information whatsoever about them may be revealed. There is no certainty that the institution has asked for consent to reveal the information and that the individual did, indeed, object. In order to ensure that consumers have full control over who has access to their health information, the *Act* must make it the responsibility of institutions to ask for consent when a request for health information is made. The current wording of section 38(3) does not require that health care facilities take this step. Consequently, a

health care facility could perpetually refuse to disclose the requested information without ever inquiring with the individual about whether they consent to its release.

In addition to amending section 38(3) of the *Act* to require hospitals to ask the consumer whether or not they may release basic health information, it is recommended that the amendment include three further specifications. The first one should indicate that once permission is acquired for disclosure to particular parties, permission need not be sought each time they subsequently make an inquiry. The second stipulation should ensure that the individual still be permitted at all times to withdraw consent, and that the withdrawal of consent revive the practice of seeking permission for information sharing each time an inquiry is received. The third would allow the individual to specify at any time the types of information that may be released to individual(s) making inquiries.

We believe this amendment would both provide individual consumers with more control over their personal health information and ensure that health care facilities have an accountability to ensure that a request for consent is made.

**2. Amend Section 40(1) of PHIPA to impose a duty that:**

**Health information custodians must disclose personal health information if they reasonably believe that failure to do so could result in serious bodily harm to another person.**

At present, health care custodians are merely permitted, not required, by s. 40(1) of the *Personal Health Information Protection Act* to disclose an individual's personal health information when they believe on reasonable grounds that this is necessary for the purpose of reducing or eliminating a serious risk of significant bodily harm to a person or group of persons.

In order to ensure the safety of all members of society, however, it is recommended that s. 40(1) be rendered a positive legal duty.

**3. Amend Section 52(1)e)iii) of PHIPA to stipulate that:**

**The identities of those who provide second-hand health information to health information custodians and health care providers must be kept confidential from the individuals it concerns if the donors implicitly or explicitly expected or requested this at the time the information was given.**

Section 52(1)e)iii) of the *Personal Health Information Protection Act* presently allows the identities of third-parties who provided information in confidence to be withheld from an individual only if the health information custodian believes that it is appropriate under the circumstances at hand to maintain that confidentiality. Accordingly, some families report that even when they explicitly ask health care providers to maintain their confidentiality when providing supplemental information about an individual, that their identities are nevertheless revealed.

Section 52(1)e)iii) creates a provision whereby others can contribute supplemental information about an individual second-hand with some reassurance that they would not be

negatively affected for doing so. Unfortunately, the current option for discretion on the part of health information custodians to maintain confidentiality severely mitigates this protective inducement. Accordingly, it is recommended that s. 52(1)e)iii) of PHIPA be amended to stipulate that health information custodians must honor second-hand health information donors' implicit or explicit expectations that its source not subsequently be revealed to the party it concerns.

### **Recommendations Pertaining to Public and Professional Awareness**

Many families of mental health service consumers report that health care providers presently refuse to disclose vital personal health information to them, even when it is reasonably warranted under case circumstances and legally acceptable to do so. On the other hand, others report that their family members' health care providers do, indeed, make professional decisions on a case-by-case basis to disclose personal health information to them, when it is pertinent to treatment, recovery, or the reduction of personal risk, without the subsequent occurrence of any harm or upset.

This situation is indicative of two things. First, it is clear that in many cases, disclosure of consumers' personal health information may be made to their families without violating either the letter or the spirit of the *Personal Health Information Protection Act*. However, it also indicates that there are inconsistencies in the latitude health information custodians believe they have to disclose or collect this personal health information.

Accordingly, it is often not the wording of the *Personal Health Information Protection Act*, but rather its interpretation by health care providers that negatively impacts families. A general lack of understanding about the true limitations of a health information custodian's ability to share information has created a culture of over-cautiousness which sometimes impairs sensible, responsible, and balanced compliance with privacy legislation. There is therefore a need for further clarification on what information and under which circumstances the personal health information of consumers can be disclosed to or collected from their families, to ensure full compliance with the *Act*.

The Schizophrenia Society of Ontario therefore makes the following recommendation which pertains to public and professional awareness:

4. **Require the Office of the Information and Privacy Commissioner/Ontario to conduct a professional education campaign focused on the sharing of personal health information between health information custodians and family members. This campaign should consist of information on the following topics:**
  - a) **The circumstances under which health information custodians can share an individual's personal health information with families;**
  - b) **The circumstances under which health information custodians can collect personal health information about individuals indirectly;**
  - c) **The circumstances under which health information custodians must protect the identity of someone who has provided health information for the record; and**

- d) The “lockbox” provisions which allow a consumer to choose what information they want shared and what they do not, and with whom.

***The circumstances under which health information custodians can share an individual’s personal health information with families:***

Health information custodians should be explicitly informed about the specific circumstances in which it is permissible to share information with family members so that no doubt remains in mind that it is, indeed, in some cases possible to do so. In addition, an effort should be made on the part of the Office of the Information and Privacy Commissioner/Ontario to inform health information custodians that it is unacceptable to automatically refuse to share personal health information with consumers’ families as a general practice. In other words, health information custodians should be urged to use the standard practice of asking for consent before making such decisions, or in some cases, considering the question of whether or not it is possible and warranted to share personal health information with family members without consent.

***The circumstances under which a health information custodians can collect personal health information about individuals indirectly:***

Many families of mental health service consumers report that health information custodians and their agents are reluctant to engage in any form of communication with them whatsoever, including even the passive acceptance of supplemental, second-hand personal health information which could assist the individual’s treatment and recovery. However, other families alternatively relate that their family members’ health care providers do accept such information.

It is legally permissible to at least passively accept second-hand information, providing that the conditions set out in section 36(1)b) of the *Personal Health Information Protection Act* are met. This subsection states that a health information custodian may collect personal health information about an individual indirectly if the individual consents to this collection, or if the information to be collected is reasonably necessary for providing health care to the individual and not reasonably possible to be collected directly from the individual accurately, completely, or in a timely manner.

Accordingly, health information custodians should be made fully aware of these conditions, and urged to accept information from families when the conditions are met in case circumstances. The adoption of this recommendation and adherence to its message would ensure that health care providers have all the necessary information to make treatment decisions.

***The circumstances under which health information custodians must protect the identity of someone who has provided health information for the record:***

Presently, many health information custodians elect to, or believe that they are compelled to disclose to their clients not only that they have obtained health information about them, but from whom. Though this in many cases is good clinical practice, and a protection of

individuals' rights to their own health information, there are circumstances under which a third party providing information may feel at risk of harm if their identity is revealed.

Recommendation #3 stated that section 52(1)e)iii) of the *Personal Health Information Protection Act* be reworded to compel health information custodians to refrain from revealing the identities of parties who provide supplemental information about a patient when such confidentiality was implicitly or explicitly expected at the time it was given. In addition to this, the educational campaign should reiterate to health information custodians that they are, indeed, permitted under the *Act* to withhold the identity of those who have provided health information from their clients under certain circumstances. Steps to ensure this confidentiality would undoubtedly do much to allow families to share relevant, important information with health care providers without concern of for risk of harm or other repercussions should their identity be revealed.

***The “lockbox” provisions which allow a consumer to choose what information they want shared and what they do not, and with whom:***

As previously discussed, uncertainty about the appropriateness of disclosing consumers' personal health information to their family members causes many health information custodians to refrain entirely from making any such disclosures whatsoever as a matter of standard practice. Many health professionals fear legal and professional repercussion in the event that such disclosure is made, should the individual subsequently decide to object to this sharing of information.

Reluctance to disclose health information where reasonable and appropriate could be diminished by increasing awareness among health care providers about the so-called “lockbox” provisions contained in ss. 37(1)a), 38(1)a), and 50(1)e) of the *Personal Health Information Protection Act*. Health information custodians should be urged to actively make consumers aware that these particular rights exist and encourage them to therefore indicate what their preferences are in terms of which parties may have access to which parts of their personal health information, rather than maintaining an “all or nothing” approach to sharing information.

Further to this, health information custodians should also be made aware that s. 19(1) of the *Act* prevents them from being retroactively held liable for authorized personal health information disclosures, even if consent is later withdrawn. This, too, would contribute greatly to the alleviation of their fears, and thereby help to reduce the culture of over-cautiousness under which the *Act* frequently operates at present.

**Conclusion**

In summary, the Schizophrenia Society of Ontario makes four recommendations to the Standing Committee on Social Policy which is reviewing the *Personal Health Information Protection Act*. Specifically, the Committee is urged to foster a more sensible, balanced, and responsible approach to privacy access and protection by:

- Amending Section 38(3) of PHIPA to impose a duty to inquire such that health care facilities shall ask individuals who are patients or residents within them, when they receive inquiries from external parties, whether they may disclose personal health

information [as currently listed in s. 38(3)] before actually disclosing or refusing to disclose it to the external parties at hand, with the caveats that:

- (a) the duty to inquire be suspended upon receipt of consent to disclose in instances where subsequent inquiries are received by approved external parties;
  - (b) the individual be permitted at any time to withdraw consent at any time, in which case the duty shall again be in effect; and
  - (c) the individual may qualify at any time the specific types of information that shall be given to particular parties without triggering the duty to inquire, so long as consent to disclose is not revoked entirely.
- Amending Section 40(1) of PHIPA to impose a duty that health information custodians must disclose personal health information if they reasonably believe that failure to do so could result in serious bodily harm to another person;
  - Amending Section 52(1)e)iii) of PHIPA to stipulate that the identities of those who provide second-hand health information to health information custodians and health care providers must be kept confidential from the individuals it concerns if the donors implicitly or explicitly expected or requested this at the time the information was given; and
  - Requiring the Office of the Information and Privacy Commissioner/Ontario to conduct a professional education campaign focused on the sharing of personal health information between health information custodians and family members, targeting the following specific areas:
    - a) The circumstances under which health information custodians can share an individual's personal health information with families;
    - b) The circumstances under which health information custodians can collect personal health information about individuals indirectly;
    - c) The circumstances under which health information custodians must protect the identity of someone who has provided health information for the record; and
    - d) The "lockbox" provisions which allow a consumer to choose what information they want shared and what they do not, and with whom.

Thank you for considering this submission. If you have any questions, please do not hesitate to contact Robert Ryan, Policy Analyst, at (416) 449-6839 ext. 244 or rryan@schizophrenia.on.ca.

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