

# Personal Health Information: Navigating the Law

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## A Maze of Rules

Older adults, and their families and friends, can find *Ontario's Personal Health Information and Protection Act* perplexing and frustrating. The basic rules about the collection, use and disclosure of personal health information are simple enough. The first rule is that a health information custodian (e.g., doctor, nurse, pharmacy, Community Care Access Centre) shall not collect, use or disclose personal health information without the consent of the individual in respect of whom the personal health information is collected or created. The second rule is that the individual has a right to access and correct his or her own personal health information. However, there are exceptions, and exceptions to the exceptions, that sometimes leave us all bewildered. We wish to draw a map through some of the important passages in this maze of rules.

## What is Personal Health Information?

Personal health information would include any information regarding your individual health care, including medical records (e.g., hospital, doctor, dentist and long-term care home<sup>1</sup> records) and your OHIP number.

## Express and Implied Consent

The rules about consent for the collection, use or disclosure of personal health information to a third party are very similar to other aspects of consent, capacity and substitute decision-making law. Where consent is required, it must come from the individual, be knowledgeable, relate to the health information in question, and not be obtained through deception or coercion.

Consent can be express or implied, but express consent is always needed where disclosure is made to a person that is not a health information custodian, or to a health information custodian for a purpose other than providing or assisting in providing health care.

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<sup>1</sup> The Office of the Information and Privacy Commissioner has developed a specific fact sheet entitled *Long-Term Care Homes: Consent and Access under the Personal Health Information Protection Act, 2004* which can be obtained online or from their office.

*THIS MEANS* that if your doctor wants to disclose your personal health information to another doctor for a health care related purpose, your consent to this disclosure can be implied from your having consented to the original health care. (If you do not want information shared with other health professionals, you may have to take special steps to prevent this.) However, if your doctor wants to transmit your personal health information to your spouse, partner or other family members, or to a health practitioner who is not participating in your care, then your express permission is needed.

Also, anyone who has the right to give consent also has the right to refuse consent or withdraw consent that was previously given. Giving, refusing or withdrawing consent to the disclosure of personal health information is the personal choice of any individual.

### **Substitute Consent**

If an individual is not mentally capable of understanding information and appreciating the reasonably foreseeable consequences of giving, withholding or withdrawing consent, substitute consent can be given or refused by a substitute decision-maker. Mental capacity for this purpose is decided by the health information custodian, whose decision can be reviewed by the Consent and Capacity Board.

If substitute consent is needed, it must be given or refused by the highest ranked person on the list, as specified in the legislation. The hierarchy, from highest to lowest, is as follows: a guardian of the person or of property, an attorney for personal care or for property, a representative appointed by the Consent and Capacity Board, a spouse or partner, a child or parent, a brother or sister, or any other relative related by blood, marriage or adoption. If there is no one else willing or available, the Public Guardian and Trustee may give or withhold consent.

*THIS MEANS* that if an older adult is mentally capable of making his or her own decision, no one else can give or refuse consent on his or her behalf. On the other hand, if a person lacks mental capacity, there will always be a substitute decision-maker.

### **Information Sharing between Health Information Custodians**

Despite the rule that personal health information may not be disclosed without consent, a health information custodian is allowed to disclose personal health information to another health practitioner if: (i) it is reasonably necessary to provide health care, and (ii) it is not reasonably possible to obtain the individual's consent in a timely manner. An exception to this exception is that this type of disclosure is not allowed if the individual has expressly told the custodian not to make the disclosure.

### **Disclosures if a Person is Injured or Ill**

The disclosure of personal health information without consent is also allowed for the purpose of contacting a relative, friend or potential substitute decision-maker of the individual, if the individual is injured, incapacitated or ill and unable to give consent personally.

*THIS MEANS* that if an adult is seriously ill to the point of incapacity, consent is not needed to notify his or her friends and family.

### **Disclosures for Facilities Providing Health Care**

A facility that provides health care may also disclose some limited information about a patient or resident of the facility if, at the first reasonable opportunity after admission, the individual is given the opportunity to object to such disclosures and does not do so. The information that may be disclosed is limited to:

1. The fact that the individual is a patient or a resident in the facility;
2. The individual's general health status described as critical, poor, fair, stable or satisfactory, or in similar terms; and
3. The location of the individual in the facility.

*THIS MEANS* that a hospital or long-term care home may disclose these basic facts without consent, unless the individual has objected to this type of disclosure.

### **Disclosures about Deceased Individuals**

A health information custodian may disclose personal health information about an individual who is deceased in the following situations:

1. To identify the individual;
2. To inform anyone whom it is reasonable of the fact that the individual is deceased, and, where appropriate, the circumstances of death; and
3. To the spouse, partner, sibling or child of the individual who need the information to make decisions about their own health care or their children's health care.

*THIS MEANS* that the law has some flexibility to disclose critical information about deceased individuals.

### **Disclosures about Risks of Harm**

Most importantly, a health information custodian may disclose personal health information about an individual if the custodian believes on reasonable grounds that the

disclosure is necessary for the purpose of eliminating or reducing a significant risk of serious bodily harm to a person or group of persons.

*THIS MEANS* that if a health practitioner knows that a person is at risk of causing serious bodily harm to him or herself or to others, the health practitioner may disclose health information about that risk with or without consent.

### **Accessing Your Own Information**

An individual has the right to access his or her own personal health information, except in some limited circumstances.

*THIS MEANS* that a health practitioner is always free to discuss personal health information about the individual with the individual. An individual may also make a written request to the health information custodian for access to his or her health information. The health information custodian must respond as soon as possible and no later than 30 days after receiving the request. If the request cannot reasonably be met within that time, the health information custodian must give written notice of extension for another 30 days. If the custodian does not respond or refuses a request for access, the individual can make a complaint to the Information and Privacy Commissioner. Frivolous or vexatious requests can be refused.

A reasonable fee for access can be charged if the custodian first gives the individual an estimate of the fee. Due to the discretion given to custodians to charge fees, the amount being charged varies widely across the province. If you think that the charge is too high, you can ask it to be lowered. If the custodian will not do so, you can make a complaint to the Information and Privacy Commissioner.

### **Corrections**

An individual may make a request in writing for a health information custodian to correct inaccurate or incomplete personal health information. Similar to access requests, a reply is required within 30-days, or within another 30-day extension. Again, frivolous and vexatious requests can be denied.

*THIS MEANS* an individual can disagree with the information recorded by a health information custodian about him or herself and ask for it to be changed.

The health information custodian is required to correct a record if the individual demonstrates, to the satisfaction of the custodian, that the record is incomplete or inaccurate and the individual gives the custodian the necessary information to correct the record. A custodian who corrects a record must tell the individual what corrections were made.

However, a custodian may refuse to correct personal health information that he or she did not create, or that is a professional opinion or an observation of a health care provider. If a custodian refuses to correct a record, the custodian must give reasons for the refusal within 30, or if extended, 60 days. The individual may make a complaint about a refusal to the Information and Privacy Commissioner.

## **Conclusion**

There are many other details and nuances to Ontario's personal health information protection law. However, the outline of this information may help older adults and their friends and families, to understand some of the major themes that allow them to exercise control over their own personal health information.

You can obtain more information about this topic by contacting the Information Privacy Commissioner at: 2 Bloor Street East, Suite 1400, Toronto, Ontario, M4W 1A8, 416-326-3333 (Toronto area) or 1-800-387-0073. Their website can be found at <http://www.ipc.on.ca/english/Home-Page/>.