



THE **CHANGE**
FOUNDATION
ENGAGE, EXPLORE, EVOLVE

Making

PRIVACY AND CONSENT RULES

Work For Family Caregivers

FALL 2017



ABOUT THE CHANGE FOUNDATION

The Change Foundation is an independent health policy think-tank that works to inform positive change in Ontario's health care system. With a firm commitment to engaging the voices of patients, family caregivers, and health and community care providers, the Foundation explores contemporary health care issues through different projects and partnerships to evolve our health care system in Ontario and beyond. The Change Foundation was created in 1995 through an endowment from the Ontario Hospital Association and is dedicated to enhancing patient and caregiver experiences and the quality of Ontario's health care.

ACKNOWLEDGEMENTS

The Change Foundation acknowledges Mary Jane Dykeman, of Dykeman & O'Brien LLP (DDO Health Law), who prepared the background report on which this resource document is based and provided advice on this final version. Mary Jane has worked in health privacy since the mid-1990s and spent her early career on implementation of the Personal Health Information Protection Act, 2004.

The Foundation would also like to acknowledge the following family caregivers who reviewed a draft report and provided valuable feedback and insights that were considered in finalizing

the report. Their input was greatly appreciated. Their participation as a reviewer does not necessarily indicate their endorsement of this final report.

- Carole Ann Alloway
- Mike Bachner
- Marilyn Macaulay
- James Joyce
- Sylvia Smith
- Brenda Beard-Sangster
- Cynthia Harris
- Paula Rawlinson
- Laurel Lamarre

DISCLAIMER

This resource document is meant to provide general information to family caregivers and care providers on the privacy and health care consent requirements in Ontario. This resource is not intended to provide a comprehensive description of the privacy and consent legislation, nor to serve as a decision tool, or as legal or clinical guidance. For advice on particular situations—especially those that are complex—caregivers and providers should consult with privacy staff in local health or community care organizations or seek their own legal advice.



CONTENTS

- 4 Message from the President
- 6 Introduction
- 8 Ontario health care legislation on consent and privacy/disclosure
- 9 The legislation overview
- 10 The legislation in practice
- 11 Health care consent act, 1996
- 12 Personal health care information protection act, 2004
- 16 Key points for caregivers
- 17 Key points for providers
- 18 When the patient is incapable to give consent
- 21 Case example: Who makes a patient's treatment and information decisions?
- 22 Case example: Can I make an access request as my brother's family caregiver?
- 23 Case example: Why is the hospital giving my wife copies of her health records when they should know she will lose them?
- 24 Case example: Who is part of the "circle of care"?
- 26 Case example: Why is my son allowed to stop his health care team from sharing information with his parents?
- 27 Concluding comments
- Where to go for more help

MESSAGE FROM THE PRESIDENT

Family caregivers play an absolutely **essential role** in today's health care environment. The Change Foundation defines family caregivers as family, friends and neighbours who, collectively, **provide the vast majority of care**, support and enrichment to those who have health-related needs. Family caregivers are the sometimes hidden, and **often unacknowledged, engines of the health system**. Family caregivers spend an enormous amount of time, effort and resources supporting patients and helping them navigate their health care options and decisions. In many cases, caregivers also juggle the day-to-day logistics of the patient's health care journey. The ability to manage these logistics on behalf of a patient and to support them in making decisions is **dependent on the ready availability of reliable personal health information and related records**.

In 2015-16, The Change Foundation engaged with family caregivers, and health and community care providers across the province through our Caring Experience initiative, to understand the breadth and depth of caregiving in Ontario from both perspectives.¹ Family caregivers told us that they want more formal recognition of, and respect for, their caregiving role, and in some cases, they want to be part of a *circle of care*. They are concerned that they cannot access the information they need to support the person they are caring for. We heard from caregivers that providers often told them that they couldn't share health information for privacy reasons.

We also engaged with health care providers to understand what got in the way of their efforts to work effectively with family caregivers. Many providers reported that they were uncertain about privacy requirements. We heard from providers who were unclear whether they had the legal right to speak with caregivers to collect personal health information, and those who were not sure whether or when they are allowed to share personal health information with family caregivers.

In developing this resource, The Change Foundation set out to address these concerns and to:

- explain the legal framework that applies to caregivers and providers under Ontario's health privacy legislation—the ***Personal Health Information Protection Act, 2004*** (PHIPA);
- explain the consent requirements outlined in the ***Health Care Consent Act, 1996*** (HCCA);
- summarize what caregivers need to know about the legal frameworks in order to get the information they are entitled to in order to serve and support patients, as well as providers' legal responsibilities about consent and disclosure; and
- describe how some common scenarios play out under Ontario's privacy and consent legislation.



Our goal in developing this resource is to help family caregivers and care providers better understand the consent and privacy requirements in the legislation, so that they can work together to optimize care and support for patients.

Cathy Fooks, President & CEO,
The Change Foundation

¹ See The Change Foundation's summary reports: *Stories Shared, Voices Heard-Family Caregivers*; *Stories Shared, Voices Heard-Health Providers*

INTRODUCTION

WITHOUT A DOUBT, THE PRESENCE OF A SUPPORTIVE PERSON DURING HEALTH CARE ENCOUNTERS ENHANCES THE FLOW OF RELIABLE INFORMATION EXCHANGED BETWEEN PATIENTS AND PROVIDERS. NOBODY BENEFITS IN A SITUATION WHERE CRITICAL INFORMATION IS NOT COMMUNICATED, IN PARTICULAR INFORMATION THAT WOULD BE HELPFUL OR NECESSARY FOR THE PROVIDER TO CREATE A CARE PLAN FOR THE PATIENT, OR INFORMATION THAT WOULD HELP THE CAREGIVER SUPPORT THE PATIENT.



Caregivers face many information challenges, including:

- having to make repeated efforts to get copies of health records from a variety of providers who are providing care to the person the caregiver is trying to support;
- being refused access to copies of test results or other health records;
- being ignored by providers when they have important insights and updates to provide about the patient's health.

Providers also face challenges, including:

- responding to a caregiver's request for information about the patient's care when there is no record to confirm that the caregiver is legally authorized to have the information (i.e., no signed consent from the patient and/or no notes in the provider's health care records with respect to the patient's verbal consent);
- identifying a primary caregiver in a family where multiple family members are involved in supporting the patient;

- working with family members of patients who are incapable of making treatment decisions, especially when there are disagreements about the best course of treatment, or when not all family members have the role of substitute decision-maker with legal authority to make treatment decisions.

For both caregivers and providers, all of the challenges and concerns noted above have health care consent and privacy implications. However, some of these examples also reflect broader concerns about interactions in health care, not all of which can be fully resolved by removing privacy barriers. This resource document focuses solely on the consent and privacy components in Ontario legislation and the relevance for caregivers.

Communication between caregivers and providers is often difficult. Even when we have the same goal in mind—the best care possible—we cannot seem to communicate fully.

Caregiver, The Caring Experience

REALITY CHECK: There is no consistent way across all parts of the health care system for a patient (or their substitute decision-maker) to provide a blanket consent for access to their health information. Another challenge is that in the current system, this process typically needs to be repeated with each provider, and sometimes needs to be re-introduced at subsequent appointments. Consent can be provided verbally or in writing, and should be documented in the patient's health record.



ONTARIO HEALTH CARE LEGISLATION ON CONSENT AND PRIVACY/DISCLOSURE

The focus of this resource document is on two pieces of Ontario legislation—how they relate to each other, and their relevance for caregivers who face challenges in getting access to a patient’s personal health information or giving relevant information about the patient to a provider. More broadly, it is a resource for providers in their ability to understand the challenges, barriers and associated frustrations faced by caregivers.

In Ontario, the ***Health Care Consent Act, 1996*** (HCCA) sets out rules for consent, capacity and substitute decision-making. The ***Personal Health Information Protection Act, 2004*** (PHIPA) enshrines privacy as a fundamental right for all Ontarians. This document explains the consent requirements set out in the HCCA, and the collection, use and disclosure requirements described in PHIPA.

The term caregiver doesn’t appear in either the HCCA or PHIPA. An understanding of the broader context governing consent both for health care and information-sharing purposes, as well as the rules set out in the legislation, will empower caregivers to take the right steps, help optimize care and support for patients, and improve experiences for patients, caregivers and providers.

THE LEGISLATION: AN OVERVIEW

The *Health Care Consent Act, 1996* (HCCA) sets out a framework for consent, capacity and substitute decision-making related to treatment, personal assistance services and admission to long-term care homes.² The HCCA reflects the premise that every person gets to decide what happens to his or her body. Accordingly, before treating a patient, the health care provider proposing treatment must ask the patient (or if the patient is incapable, his or her substitute decision-maker) to consent (i.e., agree to be treated). The Act outlines similar rules that apply to personal assistance services and to admission to long-term care.

The HCCA sets out rules for this consent. Consent must:

- be given freely and not obtained through fraud or deceit.
- relate to the treatment being proposed.
- be informed.

The patient must be advised about the benefits, risks and likely side effects, alternatives, likely consequences of refusing to consent (e.g., not having the treatment) and they must have the chance to ask questions about the treatment and have them answered.

The *Personal Health Information Protection Act, 2004* (PHIPA) enshrines privacy as a fundamental right for all Ontarians. The legislation presents rules for how health information custodians collect, use and disclose personal health information. These custodians are primarily health care organizations and health care providers (see box below). For simplicity's sake, throughout this report, custodians are referred to as providers or care providers. Personal health information is information that identifies the patient and includes information about a person's mental or physical health, as well as family history.

PHIPA sets out requirements for the collection, use and disclosure of personal health information, along with other requirements.

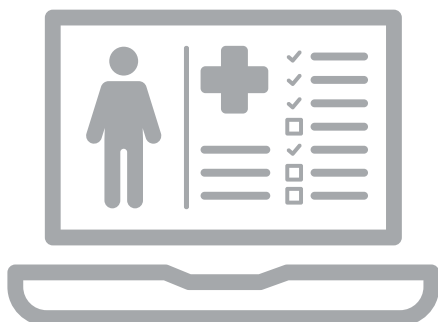
Health Information Custodians include:

- hospitals
- long-term care homes
- retirement homes
- community mental health and addiction agencies
- community health centres
- physicians or other providers (e.g., physicians in private practice, some Family Health Teams or physicians in Family Health Organizations)

² *The Substitute Decisions Act, 1992*, another piece of Ontario legislation, describes other types of capacity: (i) capacity to sign a power of attorney for personal care or for property; (ii) capacity to make personal care decisions (e.g., certain decisions about housing, nutrition and shelter that do not fall under the HCCA); and (iii) capacity to manage one's property.

These requirements include:

- **Safeguarding requirements.** Providers must protect records through physical (e.g., clean desk policies, locked cabinets), administrative (e.g., security policies, practices) and/or technical safeguards (e.g., access audits of electronic systems, firewalls).
- **A framework for access to and correction of records of personal health information.** Patients have a general right to access records of personal health information in the custody and control of a provider, with limited exceptions.
- **An oversight mechanism.** The Information and Privacy Commissioner of Ontario (IPC) provides oversight of providers with powers to investigate alleged violations and contraventions of PHIPA.



THE LEGISLATION: IN PRACTICE

Many patients in Ontario are capable to consent to the collection, use and disclosure of their personal health information. They also have rights to access their personal health information.

For patients who have been deemed incapable (see criteria on next page), those rights are given to their substitute decision-maker. To keep it simple, throughout this report a *patient* refers to a *capable patient*. We use the term *incapable patient* when addressing the unique circumstances for caregivers with family members who fall into that category. An overview of the unique challenges faced by patients, caregivers and providers when a substitute decision-maker is *involved* is provided on page 18.

A caregiver's access to the patient's personal health information requires patient consent. A patient can consent for their caregiver to have access to their personal health information. This could involve access to the actual health records, or it may also give the caregiver the ability to participate in discussions with the provider about the patient's care, giving and receiving information. **However, no matter how much involvement a caregiver has, a patient must make their own treatment decisions. They can ask or rely on a caregiver for advice or their help in making the decision, but they must ultimately make the treatment decision themselves.**

HEALTH CARE CONSENT ACT, 1996

Consent and Capacity Provisions.

Under the *Health Care Consent Act*, patients are presumed to be capable of consenting to treatment, personal assistance services (e.g., washing, dressing, grooming, eating) or for admission to a long-term care home. The Act sets out the criteria for determining if a person is capable of giving consent and these criteria are similar to the criteria set out in PHIPA.

For the purposes of the HCCA, capacity to consent does not depend on age: there is no minimum or maximum age at which one has or loses capacity to consent. As well, a particular diagnosis does not in and of itself determine whether an individual is capable to give or withhold consent.

The **legal test for capacity to consent** under the HCCA consists of:

- the ability to understand the information relevant to making the decision, and
- the ability to appreciate the reasonably foreseeable consequences of consenting or not consenting.

Patients must pass both parts of this capacity test to be deemed capable of making their own decisions.

Capability can fluctuate. Patients may be capable at one time and not another; or be incapable and then become capable again. For example, if a patient has just had surgery and is on heavy pain medication, he or she may be incapable to consent to further treatment at that time. As the pain medication is decreased and the patient becomes stronger, he or she may regain mental capacity according to the legal test set out above.

As well, patients may be capable with respect to one treatment and not another. For example, a patient may be capable of consenting to have a bone set after breaking a leg, but at the same time be incapable of consenting to proposed psychiatric medications based on the denial of having a mental illness (i.e., he or she may be able to understand the information provided that is relevant to the mental illness, but be unable to appreciate the reasonably foreseeable consequences of taking the medication, namely that hallucinations will be reduced).

Patients are presumed to be capable to consent, but providers should be mindful of when a patient's capacity to give consent for treatment, personal assistance services or admission to a long-term care home should be assessed. Family caregivers will also need to be aware of whether the patient they are supporting is capable to make these decisions because if the patient is incapable, the provider will turn to the patient's highest ranked substitute decision-maker under the HCCA (discussed later) and this may change the family dynamic.

If the patient is capable, which is presumed and the case for most patients, the patient makes the decisions about treatment, personal assistance services or long-term care home admission.

PERSONAL HEALTH INFORMATION PROTECTION ACT, 2004

Consent, Capacity and Substitute Decision-Making Provisions.

Personal Health Information Protection Act establishes a framework for obtaining the patient's consent for the collection, use and disclosure of personal health information. The legislation includes a **legal test for capacity to consent** that is consistent with the HCCA legal test for capacity to consent (as presented earlier). However, in contrast to the HCCA, PHIPA includes rules about **age of consent**, particularly in relation to children under the age of 16. If the patient is under 16, he or she is entitled to make decisions about whether to consent to the collection, use or disclosure of their personal health information, but a parent may also step in to make that decision. If the two do not agree, the child's wish prevails. If the information relates to treatment that a child under 16 capably has consented to (e.g., mental health services), the parent has no right to make the decision about sharing the information.³ If 16 or older, the capable youth makes all of the information decisions, unless the youth chooses to delegate the decision to the parent.

³ The same applies if the child under 16 capably consented to participate in counselling under the Child and Family Services Act. In that case the parent doesn't get to make the related information decisions.

In addition to providing consent or withholding consent for providers to share information with a caregiver, PHIPA requires that a provider obtain **express consent** (written or verbal) from a patient before disclosing the patient's personal health information to some third parties—for example to an employer or to an insurer. The legislation also permits **implied consent** in a number of situations, including when the personal health information is received from another provider, or from the patient or the patient's substitute decision-maker. However, implied consent is not allowed if the provider is aware that the patient or substitute decision-maker has withheld or withdrawn consent. (These requirements are discussed in the following sections on collection and disclosure provisions).

Under PHIPA, there are also instances where **no consent is required** for a provider to collect, use or disclose personal health information, including the use of personal health information for internal administrative purposes (such as risk or error management), or for teaching and training purposes (e.g., in an academic hospital or cross professional training in various clinical settings). However, the provider is not allowed to use personal health information if other, non-identifying information will suffice, or if personal health information is required, the provider must use only as much as is required in the

circumstances. These are called the general limiting principles in PHIPA and are designed to protect the patient's privacy.

Over the past years, there has been some discussion in Ontario of expanding the definition of *health information custodian* or *circle of care* to include a patient's family members. To date no such changes have been made to PHIPA. It is frustrating for caregivers that they don't have ready access to the patient's personal health information, however, PHIPA is built on a framework of consent—the consent of the patient, or if the patient has been deemed incapable, of the patient's highest-ranked substitute decision-maker.

The Rules About Collection of Health Information

The PHIPA rules related to the collection of personal health information stipulate that information is to be collected directly from the patient. However, the legislation permits **collection of personal health information from someone other than the patient, if the patient consents; or in limited other circumstances**. Patient consent is required for the caregiver to attend clinical meetings with the health care provider, to be part of conversations, or to have access to records of personal health information.

As well, **if a provider cannot get information from the patient directly in a timely or accurate manner, then the provider can get the information indirectly from the caregiver, even without patient consent**, but only if it is needed to provide care to the patient. This is important for facilitating communication between caregivers and providers, and ensuring that patients get the necessary care.

However, PHIPA also stipulates that **if the patient comes back to the provider to tell them to not use the information they collected indirectly (from someone else, based on the need for timely and accurate information), the provider is not allowed to use the information going forward.**⁴

For example:

- If a patient is brought to hospital in a paranoid state and refuses to provide information, the provider's staff can turn to the caregiver who brought the patient to the hospital to obtain information; the patient may later choose to restrict the use of this potentially valuable information.
- If the caregiver shares personal health information with the family physician and the patient becomes aware of, and is

unhappy with, the physician collecting it from the caregiver, the patient can require the family physician not to use that personal health information. In that case, the information cannot be used unless there is some other legal authority to do so.

The Rules About Disclosing Health Information

PHIPA permits **disclosure of personal health information if the patient consents to the sharing of information**. Providers typically have a Release of Information form for a patient to sign, or they may simply make a note in the patient's health record that personal health information can be shared with the caregiver. When the patient's consent is recorded in these ways, the barriers to appropriate information sharing with caregivers can be significantly reduced.

When granting consent, the patient may place limits on what can be shared. For example, a young adult patient may decide that his or her parents can have a discharge summary to help prepare them for the patient returning to live at home, since they are the caregivers who will, for example, be taking the patient to

⁴ The exception to this is if there is other legal authority that permits the collection of *collateral* information (such as a Form 1 signed under the *Mental Health Act*).

various appointments. But that same young adult patient may refuse to consent to his or her parents having the full health record of their past admissions to hospital, and this refusal must be respected by the provider if the patient is deemed capable.

Providers may also be permitted or required by law to disclose personal health information **without consent of the patient**. For example:

- when there is a reasonable belief that a person can no longer safely drive, a mandatory report must be made under the *Highway Traffic Act*;
- to report a child in need of protection under the *Child and Family Services Act* (mandatory disclosure); and
- to eliminate or reduce a significant risk of serious bodily harm under PHIPA (discretionary disclosure, sometimes referred to as a “discretion to warn,” such as when the individual is likely to self-harm or poses a risk to others).⁵

The Rules About Access to Health Information

The courts have established that the physical or electronic records of personal health information belong to the provider, but that the information in the records belongs to the patient. The provider merely holds the information in trust, on behalf of the patient.⁶ A patient has the right to access the record and to request corrections to the record.

Caregivers have a right to know what’s in a patient’s records only if the patient consents. To facilitate access to records by patients or their substitute decision-makers or caregivers, providers may establish processes such as requiring that a form be filled out, establishing timeframes, or applying fees (e.g., fees for copies of x-rays).

⁵ Under PHIPA, a health care provider is permitted (but not required) to disclose an individual’s personal health information to any person, in order to reduce or eliminate a significant risk of serious bodily harm. Since the disclosure is not mandatory, it is called a “discretion” to warn, rather than a “duty” to warn.

⁶ *McInerney v. MacDonald* [1992] 2 S.C.R. 138. There are limited exceptions to this right of access. One exception would be in cases where granting access creates a risk of serious harm to the treatment or recovery of the patient or a risk of serious bodily harm to the patient or a third party.

KEY POINTS FOR CAREGIVERS



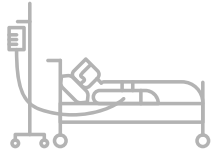
- It is reasonable for a caregiver to ask the patient to consent to the provider sharing personal health information with the caregiver.
- Caregivers should ask the provider for a copy of their written consent or Release of Information form for the patient to sign, or ask the provider to document the patient's consent in the health record and make sure that the provider's staff is aware of the documented consent.
- Even when the patient has consented that their information can be shared, some caregivers still struggle to get timely information from providers. **Sometimes providers need reminders that they are permitted to share certain information with caregivers based on the consent the patient has given.**
- If a provider refuses to give a patient the right of access to the patient's own health record, or refuses to disclose it to a caregiver with the patient's consent, the provider may also need to be reminded of their duties under PHIPA. Specifically, the courts (and now PHIPA) have clearly stated that personal health information belongs to the patient and is held in trust for the patient by the provider, even though the physical (paper or electronic) records belong to the provider. It is only in very limited circumstances that this right of access to the health record can be denied by the provider.

KEY POINTS FOR PROVIDERS



- For the caregiver to fully understand their rights to participate in someone else's health care appointments, have access to and share their health information, it's important to understand the perspective of the provider. These points help to clarify the obligations of the provider in receiving information from caregivers, as well as sharing with caregivers.
- Providers may face situations where a caregiver comes with a patient to an appointment and the provider is unsure whether the patient wants the caregiver to be present for the sharing of information. **If the provider has concerns that the patient is uncomfortable in this situation, the provider should pause and have a conversation only with the patient to clarify whether the patient gives consent for information to be shared with, or collected from, the caregiver.** This may include asking the caregiver to leave the room for this conversation.
- **Providers should train their staff to ask patients, periodically throughout their care, if there is anyone the provider is allowed to share their personal health information with,** either verbally or by sharing the actual health records.
- **A provider is allowed to establish timeframes and procedures, in accordance with PHIPA, about granting access to records, as well as to charge reasonable fees for providing copies of health records.** PHIPA also creates special rules related to a patient's request to correct information in the health record.

WHEN THE PATIENT IS INCAPABLE TO GIVE CONSENT



If the patient is deemed incapable, the provider must turn to the patient's substitute decision-maker to make decisions on the patient's behalf, including consenting to (or declining) proposed treatment. In that case, the substitute decision-maker can also make related information decisions, including giving consent for the caregiver to receive the patient's personal health information.

The *Health Care Consent Act, 1996*, outlines the legal test for capacity to consent (as previously presented). If the patient is deemed incapable under the Act, the patient will have a **substitute decision-maker**. Under the HCCA, the substitute decision-maker makes decisions about treatment, personal assistance services, and long-term care admission. Under PHIPA, the substitute decision-maker provides consent for the collection, use or disclosure of personal health information.

The HCCA sets out a hierarchy of eligible substitute decision-makers.⁷ A similar hierarchy is also found in PHIPA for information decisions. The person permitted by law to make decisions on behalf of a patient found to be incapable is the person closest to top of

the list. In most situations, the highest-ranking substitute decision-maker will be one or more family members. There is no need to go to court. To be eligible to act as a substitute decision-maker, the person must be:

- willing and available
- at least 16 years of age
- not prohibited by court order or separation agreement, and
- capable to make the decision required (e.g., proposed treatment under the HCCA, or collection, use or disclosure of personal health information under PHIPA).

Everyone in Ontario has a default substitute decision-maker, whether or not they have signed a *Power of Attorney for Personal Care*. This is because the HCCA sets out a hierarchy of substitute decision-makers, and providers are required to turn to the highest-ranked individual(s) for consent to treatment, personal assistance services or admission to long-term care.

In most situations the substitute decision-maker is a family member but, as the list indicates, there are other possibilities.

- Most patients will not have a Court appointed guardian, although this is

⁷ See Section 20 of the Health Care Consent Act, 1996.



somewhat more common for persons with a developmental disability.

- Providers should ask whether the patient has a signed Power of Attorney for Personal Care, and for a copy of it.
- In very few cases, patients will have a representative appointed by the Consent and Capacity Board.
- Ontario's Public Guardian and Trustee (PGT) is the substitute decision-maker of last resort, when a patient has nobody else in the HCCA hierarchy to make decisions. It is important to note that the PGT also steps in if two or more equally ranked substitute decision-makers do not agree (e.g., an incapable patient's two adult children disagree on proposed treatment, and the PGT becomes the decision maker).

If the patient is incapable to provide consent, a substitute decision-maker must be identified (see box) and they are responsible for providing the information-sharing consent.

To be clear, if there is a substitute decision-maker for treatment under the HCCA, there is no need to turn to PHIPA to determine who

Hierarchy of eligible decision-makers

1. Court appointed guardian
2. Attorney under a power of attorney for personal care
3. Representative appointed by the Consent and Capacity Board
4. Spouse or partner
5. Child or parent; parent or other person with custody; Children's Aid Society in place of parent
6. Parent with right of access
7. Brother or sister
8. Any other relative
9. Public Guardian and Trustee

the substitute decision-maker is for health information related decisions; the treatment substitute decision-maker automatically makes those decisions. If there is no substitute decision-maker under the HCCA, the PHIPA framework must be applied. As noted earlier, the legal test for capacity to collect, use or disclose personal health information is consistent with the legal test for capacity to consent to treatment under HCCA (page 11).

If the caregiver is also the patient's substitute decision-maker, they have all of the rights of the patient in terms of giving personal health information to the provider and accessing the health information and records of the patient.

The substitute decision-maker is also entitled to all of the relevant personal health information needed to make the treatment decision in question and may have recourse against a health provider who refuses to provide them with the appropriate information (e.g., a complaint to a health regulatory college or to the organization's client relations office, or to the Information and Privacy Commissioner of Ontario, who is the regulator under PHIPA).

If the caregiver is not the substitute decision-maker, the substitute decision-maker may consent to the provider sharing information with the patient's caregiver(s).

In some cases, a longstanding family caregiver who has been supporting a capable patient may find that when a patient's health declines and he or she becomes incapable to give consent to treatment, the family caregiver ends up not being the substitute decision-maker based on the hierarchy set out in the HCCA (see box on age 19). In this case, the caregiver

should check in with the substitute decision-maker and request the substitute decision-maker's consent for providers to share the patient's personal health information with the caregiver.

If a substitute decision-maker is appointed as a result of being named in a *Power of Attorney for Personal Care*, or as a guardian of the person, that person has a general duty under the *Substitute Decisions Act* to foster regular personal contact between incapable patients and their supportive family members and friends, and must consult with them from time to time.

If the patient is incapable, it is the patient's substitute decision-maker who has a right to access the health care record and to request corrections to the record. The substitute decision-maker is the person who would then give consent for the caregiver to give information to providers, or to receive the patient's personal health information from the provider.



WHO MAKES A PATIENT'S TREATMENT AND INFORMATION DECISIONS?

I am a family caregiver and I take my mother to most if not all of her medical appointments. My mother says she cannot be bothered sorting out all of the details of her health situation, and wants me to make all of her decisions. This sounds great to me, but her doctor says she has to make these decisions since she is capable to do so. Who is right?

- Because she is capable, your mother must make her own decisions regarding proposed treatment as required under the *Health Care Consent Act, 1996*. Treatment decisions cannot be delegated. As a caregiver, you can support her and work through the decision with her. With your mother's permission, you can also talk to her health provider about the risks and benefits of the proposed treatment, and what alternatives there may be. However, you cannot make the decision about treatment for her even if she wants you to. That decision must be made by your mother, or if she becomes incapable to make it, by her substitute decision-maker (which could someday be you).
- By contrast, the *Personal Health Information Protection Act, 2004* allows for you, with your mother's consent, to make any **information-related decisions** on her behalf (e.g., giving consent to her health records being released to an insurance company). Your mother can inform her health providers (via note or phone call) that she has given consent for you to make these information-related decisions or she can offer to complete any form that the provider requires to confirm this consent so that staff know to call you when there is an information-related decision to be made. Caregivers should ask for a copy of any written consent form to facilitate the ability to make information-related decision especially when your mom isn't with you.
- If your mother is deemed **incapable** to make treatment decisions, the health care team will turn to the highest-ranked substitute decision-maker in the hierarchy under the *Health Care Consent Act, 1996*. That may be you, and if it is, you'll also be asked to make any related health and information decisions. If the substitute decision-maker is someone else, the provider should ask that person how they would like to handle the sharing of information (i.e., for consent to release personal health information records to you as a family caregiver).



CAN I MAKE AN ACCESS REQUEST AS MY BROTHER'S FAMILY CAREGIVER?

Now that my parents are getting older, I am the primary family caregiver for my brother who has a chronic illness. He has asked for my help to see and get copies of his health records at the local hospital and a couple of other community health care providers. But nobody seems to want to talk to me. I am getting very frustrated with the roadblocks we've been experiencing.

- You may be experiencing roadblocks if your brother is capable to direct his own health care, as he has to make the initial request to access his personal health records, as outlined in PHIPA. He can either get his health information from a provider informally at his next appointment or the provider can require him to make a formal written access request for the records he wants. Providers may request fees for access depending on the records requested. If you are at an appointment with your brother, you can ask for the form to fill out, which your brother would sign.
- Once the records are ready, **your brother's information can be released to you only with his consent**. You will need to confirm whether the provider requires verbal consent that can be documented on your brother's file, or written consent. Hospital and other care providers should have a process for patients (or if incapable, their substitute decision-maker) to give consent for a third party (in this case you) to access the patient's health records. If your brother is capable, you could pick up the form for him, or have the provider mail it to you, and help him fill it out. **Although treatment decisions cannot be delegated**, under PHIPA your brother could consent to have you make his **information decisions (e.g., to decide with whom/ which organizations or individuals his health care information can be shared)**. You will need to confirm whether the provider requires verbal consent that can be documented on your brother's file, or written consent, so that you can make a request on his behalf.
- If you eventually become your brother's substitute decision-maker (in accordance with the hierarchy under the *Health Care Consent Act, 1996*), you would be permitted to make the request to access his records under PHIPA. You would not need his consent; you would have the right to make the request as his substitute decision-maker.



WHY IS THE HOSPITAL GIVING MY WIFE COPIES OF HER HEALTH RECORDS WHEN THEY SHOULD KNOW SHE WILL LOSE THEM?

My wife's geriatrician has said she remains capable on all fronts, despite a diagnosis of Alzheimer's and deficits that are becoming clearer to me every day. I am concerned that staff at the hospital where she receives a lot of her care, including diagnostics, give her copies of her files to take to appointments with other health providers. I am her caregiver and nobody is listening to me—even when I say, she won't remember you gave her the documents, or that the documents need to go to her next appointment.

- The caregiver could talk to his wife about her giving consent for her personal health information to be shared with him.
- The geriatrician could seek permission from his wife to provide the files directly to the caregiver in order to make sure the records are available at the next appointment. If the capable wife agrees, there is no issue.
- The provider could re-consider whether the patient is actually capable to make decisions about her personal health information, in order to ensure she gets the care she needs and that other providers get the documents required to facilitate good care.
- If the caregiver eventually becomes the substitute decision-maker, the caregiver will make his wife's treatment and health information decisions, including with whom the patient's personal health information can be shared.



WHO IS PART OF THE “CIRCLE OF CARE”?

I am a nurse working in a mental health unit of a hospital. My patient insists he does not want any reports about his stay on this unit to be given to his family doctor. His family caregiver is his spouse, who took me aside to tell me that as part of the “circle of care” the instruction is that I must forward the reports to their family doctor, or otherwise to hand it over to be given directly to the doctor by the spouse.

- Under PHIPA, members of the “circle of care” are not caregivers or substitute decision-makers; they are providers involved in the provision of health care to the patient—either within the provider organization (e.g., different units of a hospital) or externally (e.g., providers in the community). Sharing personal health information with other providers within the “circle of care” is often done with the patient’s implied consent, and allows, for example, a patient’s nurse to share information with the patient’s dietitian, a family physician to share information with the specialist, and so on. It would also allow the nurse at the hospital to share information with the patient’s providers at other health care organizations, or with the family doctor based in the community. However, since the nurse is aware that the patient has withdrawn consent, she cannot disclose the information to the family doctor.
- Since the patient is able to make his own health care and information decisions (i.e., is capable), he gets to decide what information is released, and to whom. As such, he can decide not to share his personal health information with his family doctor, and to have the information placed in a Lockbox (see description on page 25). The reports also cannot be given to the spouse, without the patient’s consent, unless the spouse someday becomes the patient’s substitute decision-maker.
- It is important to acknowledge the critical role that the spouse is carrying out as the caregiver, and to acknowledge how frustrating this situation must be. The spouse may want to try to persuade the patient of the importance of sharing the information with his family doctor. The family doctor can also raise this issue with the patient, to talk to the patient about why it may be important for his spouse to have at least some pertinent information, e.g., to best support his care.

- The situation can and should be re-visited in the future. The patient may change his mind and agree to the sharing of information with the family physician and/or his spouse. You could also determine whether the patient is actually capable and, if not, whether the spouse should be designated the substitute decision-maker (as long as s/he is the highest-ranked person in the hierarchy of substitute decision-makers set out above). Although there is no specific timeframe within which the issue should be raised, a health provider could confirm the patient's instructions at any subsequent visit, and raise again why it would be of benefit to share the information with the patient's spouse.
- If the patient is found incapable to consent to treatment, and his spouse becomes his substitute decision-maker, s/he can make all of his information-related decisions. The provider would rely on the implied or express consent of the spouse to release the record to the family physician. In this case, the provider would have the express consent of the spouse (the substitute decision-maker), so the information may well be released to the family physician. However, substitute decision-makers must follow the wishes the patient made while capable; so his spouse would have to take those wishes into consideration.



“LOCKBOX” is not a term used in PHIPA. It is an informal reference to a patient's (or substitute decision-maker's) express instruction to a provider to not share personal health information with providers. When information is placed in a lockbox, it is physically or electronically shielded from select providers who would otherwise receive it as part of providing care to the patient. The lockbox can shield information either from providers within an organization (e.g., dietitian in a hospital) or from other providers (e.g., family doctor not connected to a hospital).



WHY IS MY SON ALLOWED TO STOP HIS HEALTH CARE TEAM FROM SHARING INFORMATION WITH HIS PARENTS?

My son has struggled with mental illness for a number of years now. When he is on his medication, he gladly gives consent to his health care team to share information with his mother and me. His pattern, however, is that he will eventually go off his prescribed medication because he believes he is well and no longer needs it. Eventually he deteriorates and ends up hospitalized, and refuses to let the hospital staff call us. We have seen this pattern repeated over the years, until eventually he gets treatment and the cycle starts all over again.

- It will be up to the health providers at the hospital to determine whether your son is capable to consent to treatment under the legal test for capacity set out in the *Health Care Consent Act, 1996*. If he is capable, the caregiver will have no formal role as a substitute decision-maker for treatment decisions (or for related information decisions).
- It is upsetting to caregivers that patients are allowed to shut them out when the caregiver only wants to help, and may not even know that the patient has been hospitalized. Health providers are encouraged to explore with patients why it may be helpful to have the team engage with the worried caregivers, and explain the limits, if any, on what is proposed to be shared.
- If the son in this scenario is deemed capable and decides not to share the fact that he is in hospital with his parents, they can call the hospital. Staff may be able to point them to other available supports and resources.

CONCLUDING COMMENTS

Inconsistency of communications and barriers to providing or sharing information with health care providers is one of the biggest complaints that family caregivers have in trying to support their family member in various health care settings. It is clear that the lack of understanding of the privacy and confidentiality restrictions, by patients, caregivers and providers, contributes significantly to communications challenges.

When family caregivers, patients and care providers better understand the privacy and consent requirements and capacity provisions set out in the *Personal Health Information Protection Act, 2004* and the *Health Care Consent Act, 1996* they can work together to optimize care and support for patients. Open communication and information sharing between caregivers and providers can happen when the patient has given consent to the sharing of information with the caregiver, or when the provider works with the substitute decision-maker of an incapable patient.

Although there is no single and easy solution to address this problem, understanding the process for consent, and the true constraints of the various pieces of legislation, is the first step in understanding how to make it easier to share information between patients, caregivers and providers where the law allows this to happen.

Ensuring the proper consents are in place to share information is imperative. Unfortunately, the consent process may need to be repeated with each health care provider, and sometimes might need to be done multiple times within the same health care organization.

In our view, empowering caregivers with knowledge about the legislation will give them the tools to work with the providers in the health system, and to facilitate their role as a family caregiver.

WHERE TO GO FOR MORE HELP

- Information and Privacy Commissioner of Ontario: www.ipc.on.ca/health
- Advocacy Centre for the Elderly: www.ancelaw.ca
- Psychiatric Patient Advocate Office: <http://www.sse.gov.on.ca/mohltc/ppao/default.aspx>
- Consent and Capacity Board: www.ccboard.on.ca
- Patient Ombudsman: <https://patientombudsman.ca>
- Depending on the situation you are facing, you may consider contacting the Privacy Officer and/or the Patient or Client Relations office of the specific health care organization



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