



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



**QUESTIONS &
ANSWERS ON
PATIENT PRIVACY
AND CONSENT IN
THE ADDICTION AND
MENTAL HEALTH
SYSTEM IN ONTARIO**

*A Companion Piece
to Making Privacy and
Consent Rules Work
For Family Caregivers*

CHANGING
CARE
EMBRACE
J'EMBARQUE

SPRING 2018

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.

ABOUT EMBRACE

EMBRACE aims to improve the experience of family caregivers in the addiction and mental health system. Together with its project partners, Cornwall & District Family Support Group and Cornwall Hospital's Community Addiction and Mental Health Centre, EMBRACE recognizes the significant role of family caregivers as advocates, care providers, and allies on the patient recovery journey. EMBRACE brings family caregivers and health providers together to co-design sustainable solutions that allow family caregivers to provide the best possible support to their loved ones while sustaining their own well-being. More than 200 family caregivers and 300 health providers across Cornwall, Stormont, Dundas, Glengarry and Akwesasne, Ontario, have contributed to the EMBRACE project to date.

ACKNOWLEDGMENTS

The Change Foundation and EMBRACE acknowledge the contribution of Mary Jane Dykeman, of Dykeman & O'Brien LLP (DDO Health Law), to this document. Mary Jane has worked on issues relating to mental health, capacity, privacy and consent since the mid-1990s. She spent her early career on the implementation of *Ontario's Personal Health Information Protection Act, 2004*.

DISCLAIMER

This resource 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.

INTRODUCTION

In the Fall of 2017, The Change Foundation released *Making Privacy and Consent Rules Work For Family Caregivers*, a document that set out to:



- Explain the legal framework that applies to family caregivers and health 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 family caregivers need to know about the legal frameworks in order to get the information they are entitled to while supporting patients, as well as health providers' legal responsibilities around patient privacy, consent and disclosure; and
- Describe how common scenarios play out under Ontario's privacy and consent legislation.



Since its release, a number of requests for clarification have emerged within the specific context of addiction and mental health care. The EMBRACE project (one of The Change Foundation's four Changing CARE projects) led a consultative process to create this complementary question-and-answer resource. This companion piece to The Change Foundation's privacy report focuses on interactions between health providers and the family caregivers of those with mental health and addiction challenges.

The goal in developing this resource was to help family caregivers and health providers understand the requirements of Ontario's patient privacy and consent legislation and facilitate closer collaboration for the benefit of patients in the addiction and mental health system.



What prevents dialogue between family caregivers and health professionals?

It can be difficult for health professionals to respond to family caregivers' requests for information when:

- There is uncertainty about the legal authority of the family caregiver to access patient information
- A clear record of patient consent is not immediately available to give the family caregiver legal authority to access the information
- The speed at which patient care is delivered prohibits the health professional from making contact with the caregiver (unless the consent of a substitute decision-maker were required (e.g., if the patient is incapable to give consent))

Health professionals require patient consent prior to sharing health information with family caregivers (unless the family member is already recognized as the patient's substitute decision-maker).

Family caregivers need to know that the patient controls information sharing with the family (or if the patient is incapable, the substitute decision-maker holds control).



How can health professionals support a family member who is having difficulty locating a patient?

Under PHIPA, as long as certain conditions are met, Ontario hospitals and long-term care homes are able to:

- Confirm to a family caregiver whether or not the patient is at the facility
- Name the ward on which the patient is receiving care
- Disclose the general health status of the patient

Health professionals may also be able to deliver a message to the patients from the inquiring family members.

Health professionals can disclose the above basic information about the patient or resident to family caregivers, provided that the hospital or home has informed the patient or resident that this will occur (by posting a public notice or getting express consent) and the patient or resident has not objected.

Health professionals will deliver messages to patients/residents from inquiring family members and provide further information only if the patient consents.

Family caregivers need to know that a hospital or long-term care home is able to provide only this basic information unless the patient or resident has consented to sharing further details with family members or others.

Caregivers can request that healthcare staff deliver a message to the patient; however, if a patient has told the hospital or long-term care home not to share information with family or others, staff must be very careful not to confirm the patient's presence, since that is in itself personal health information.



Is there a limited timeframe within which patient information can be collected from a family caregiver?

No. If there is patient consent for the collection of information from a family caregiver, or the health professional has identified the legal authority to collect patient information from a family caregiver, the information can be collected at any time by the health professional.

With patient consent or legal cause, health professionals may collect patient information from a family caregiver at any time (it must be reasonable to rely on the patient consent given; if there is reason to think the consent is no longer valid, it should not be relied on).

Family caregivers need to know that in most cases, health professionals require patient consent to collect information from the family, unless there is other legal authority to do so.



Is there an expiry on patient consent to collect, share or disclose patient information with a family caregiver?

There is no expiry on patient consent to collect, share or disclose patient information with a family caregiver.

Health professionals are entitled to rely on a given consent to share patient information; there is typically no expiry.

When patient consent is withheld, health professionals can, and should, revisit the decision with the patient from time to time or anytime contact with a family caregiver would be beneficial.

Family caregivers need to know that health professionals are not required to discuss the details of patient consent (or lack of consent) with the family. A health professional may simply tell a family caregiver, "I do not have consent to share this information with you, but of course you can discuss this with the patient."



At what age can a child make their own decisions about treatment and information sharing?

A child of any age who passes the legal test for capacity can make decisions about their own treatment and information sharing. For children under age 16, PHIPA stipulates that the child or the parent can make decisions, whereas children aged 16 and up can make decisions independent of a parent. If a child is capable and the parents do not agree with his/her wish, the child's wish nonetheless prevails.

However, under PHIPA there is an exception; if a child under the age of 16 has previously consented to treatment under the *Health Care Consent Act* (or to counseling under the *Child, Youth and Family Services Act*) they can make any related information decisions.

Health professionals will give the patient choice preference over the family caregiver whenever possible.

Family caregivers need to understand that the wishes of their child may supersede their own preference, even if the child is a 'minor.'

Q6

What are some strategies to use when a capable patient instructs the health professional to stop providing patient information to the family caregiver?

While health professionals respect the patient's right to determine consent, they may benefit from discussing what has changed with the patient (e.g., 'I understand that you want to stop sharing all information with your family caregiver. Since we have already been sharing information about your medical appointments and involving your caregiver in discharge planning, let's walk through this together. Is there any information that you would allow us to share in order to support your care? For example, [...]').

When patients want to stop information sharing, health professionals need to know that a nuanced conversation about patient consent may lead to a middle ground that is beneficial to the patient, the family caregiver and the health system.

When the patient stops sharing information, family caregivers may be able to engage the patient in a discussion about basic information needs. If a patient understands which information you are proposing to share, and why it may be helpful to do so, he/she may reconsider the decision not to share.

Q7

What is a lock box?

A lock box is an informal term used to describe when a patient has instructed a health information custodian (such as a hospital) *not* to share their personal health information with specified health professionals.

A lock box is an express instruction from a patient to limit or shield some or all personal health information from select health care professionals or organizations (e.g., 'Do not share my information with Dr. X'; or 'Do not share it with my family doctor when I leave hospital').

Health providers should refer to their organization's policies and procedures for lock box documentation.

Family caregivers need to understand that the patient has the authority to prevent their health records from being shared for health care purposes, including to those involved in their care within an organization or externally. This is true even when it would be beneficial for these health professionals to have this information.



When a patient has withheld or withdrawn consent, what information can health providers discuss with family caregivers?

Unless the patient or resident says otherwise, under PHIPA, Ontario hospitals and long-term care homes are able to:

- Confirm to a family caregiver whether or not the patient is at the facility
- Name the ward or unit on which the patient is receiving care
- Disclose the general health status of the patient

In cases where consent is denied by a capable patient or resident, health professionals can lead family caregivers to appropriate reading material and community resources, such as family support groups.

If the family caregiver is known to the health system and has baseline knowledge of the patient or resident's health, the health professional can speak with the family caregiver in general terms, without discussing any specifics of the patient case (e.g., 'When there is a history of bipolar disorder, families often find it helpful to identify the early warning signs of major mood swings so that early intervention is an option').

In the absence of patient consent to share information, health professionals need to know that they can speak with the family caregiver and offer general information that may be helpful.

Family caregivers need to know that health professionals cannot discuss particulars about specific patients when consent is not given but may be able to provide helpful generalized information.



What is the obligation of the health professional to disclose a patient's personal health information in a case where there is a significant risk of serious bodily harm to a person or group of persons?

According to PHIPA section 40(1), "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."

The decision to disclose patient information in this case rests with the health professional as a discretion (not a duty). The disclosure can be to any person (e.g., to police or to an intended victim).

Health professionals should never feel restricted by privacy law when a patient poses a significant risk of serious bodily harm to self or someone else. It will be important to document the reasons that led to the disclosure.

Family caregivers need to know that health professionals have the right (rather than the obligation) to disclose patient information in cases where there is a significant risk that serious bodily harm will otherwise result. A caregiver may be able to remind the health professional of this discretion, and urge that it be exercised.



Q10

When the family caregiver contacts a health professional by phone, letter or email to share information about the patient, what is the health professional's responsibility to document the contact/information?

Within the construct of patient consent and confidentiality, health professionals do not generally collect and document patient health information unless it comes directly from the patient, their substitute decision-maker, or other health care provider.

Health professionals need to identify a legally-supported reason to collect patient information other than from a caregiver, such as access to accurate or timely information (which could include a risk situation).

Family caregivers need to know that health professionals are generally required to collect health information from the patient (not the caregiver), but can also collect from a third party if they cannot get the information in a timely or accurate way.

If this happens, the patient could later instruct the health professional not to use information provided by family or a third party.



If a patient on a Form 1 under the *Mental Health Act* is acutely psychotic, difficult to control, and posing a threat to self or others, can a health professional administer medication even if they have not obtained patient consent?

Yes, but not for the purpose of treatment (because a capable patient, or the substitute decision-maker of an incapable patient, can refuse medication). Medication can be administered as a chemical restraint to control the situation in the moment. Once the risk to the patient or others subsides, the patient can no longer be held in a chemically restrained state.

Health professionals may chemically restrain a patient when there is a danger to that person or others, within limits and for a limited time until the risk passes. This is true even if the drug used to restrain is the same medication that the patient refused as a treatment.

Health professionals are encouraged to speak with the family caregiver and explain the difference between chemical restraint and active treatment.

Family caregivers need to understand that patient consent is not required to administer medication to patients (including on a Form 1) for the purpose of the chemical restraint. Caregivers are reminded that this is not part of a treatment plan, and that if capable, a patient is entitled to refuse a proposed treatment.

Q12

What recourse to collect patient information does the health professional have when treating a young adult in hospital under the *Mental Health Act*, Form 1?

The general rule in PHIPA is that information should be collected directly from a capable patient. However, section 36(1)(c) allows health professionals to collect information from a parent/guardian/caregiver if it is reasonably necessary for providing health care and it is not possible to collect it directly from the patient in an accurate or timely fashion. In addition, collateral information may be collected while the patient is on a Form 1.

Health professionals will want to document the alternate source(s) of patient information (e.g., 'I collected the following information from the parent/guardian/caregiver and here's why, [...]'). Health professionals should also be aware that the patient can later instruct them not to use the information that they collected in this manner.

The family caregiver may wish to take the initiative in this case, letting the health professional know:

- 'I understand patient information can be collected from an alternative source when the patient is unable to provide it in an accurate or timely manner.'
- 'I can provide important information about the observed health and behaviour of the patient.'
- A Form 1 authorizes collateral information to be collected.

Q13

How is a person experiencing a psychotic episode deemed capable of making treatment decisions?

Upon arrival in the health care system, the patient is presumed capable to consent to treatment.

Neither a mental health diagnosis nor a mental health episode, nor a person's age, can be used to determine a patient's capacity to make treatment decisions. Since treatment decisions fall under the *Health Care Consent Act*, a patient may even be detained against their will under the *Mental Health Act* and still be deemed capable of making their own treatment decisions.

Health professionals presume patients are capable of consent on arrival in the health system.

Family caregivers need to know that the health system will not prevent patients from making their own decisions because of a mental health diagnosis or psychotic episode.

Q14

What is the legal test for patient capacity to consent?

For both consent to treatment and for information-sharing purposes, the patient must be able to meet *both* prongs of the legal test for capacity:

1. Able to understand the information relevant to the treatment; and
2. Able to appreciate the reasonably foreseeable consequences of saying 'Yes' or 'No'.

Health professionals will want to document patient performance on both prongs of the legal test for capacity.

Family caregivers need to know that patients are presumed capable to consent to treatment, but health professionals may assess their capacity. Only if the patient is found to be incapable will a substitute decision-maker be asked to consent to care.

Q15

If the patient is deemed incapable of making treatment decisions, how does the health system select the substitute decision-maker?

The method of choosing a substitute decision maker is determined by the *Health Care Consent Act* and PHIPA. In Ontario, the highest ranked eligible substitute decision-maker(s) is chosen, as follows:

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

The health professional that is treating an incapable patient will refer to the patient record in order to identify the appropriate substitute decision-maker and possible alternative substitute decision-makers. The health professional may also reach out to the caregiver or another family member of the patient in order to identify the highest-ranked substitute decision-maker.

Once the substitute decision-maker is identified, that individual will make care decisions and also control who has access to patient information, which may or may not include the current caregiver.

If two or more equally ranked substitute decision-makers disagree the Public Guardian and Trustee must act as the tie-breaker.

To identify the highest-ranked substitute decision-maker for a specific treatment decision, the health professional will review the patient chart and contact a family member for assistance, if necessary.

Once an appropriate substitute decision-maker(s) has been identified for the purpose of that treatment decision, the health professional will want to document this decision in a manner that can be understood and applied by any member of the patient care team.

Health professionals should never hesitate to share patient information with the substitute decision-maker(s).

Health professionals should anticipate questions about the substitute decision-maker role from family members.

Family caregivers need to know that their current role in patient support may not be maintained in the event that the patient is found incapable for a particular treatment.

In a case where the current caregiver is not the highest ranked substitute decision-maker on the above list, (s)he may not be offered the opportunity to make care decisions for the incapable patient.

Current caregivers could also find themselves equally ranked with other members of their family as substitute decision-makers for the patient, resulting in a shared decision-making role. If two or more substitute decision-makers cannot agree on a specific treatment, the Office of the Public Guardian and Trustee Treatment Decisions Unit will step in to 'break the tie.'



Q16

Is the family caregiver always appointed substitute decision-maker?

No. The caregiver may or may not be the substitute decision-maker; it depends on whether they are the highest-ranked person on the list of substitute decision-makers under section 20 of the *Health Care Consent Act*. In addition to establishing that prospective substitute decision-makers meet the minimum age requirement of 16 years, health professionals will verify the willingness, availability and legal capacity of individuals to make treatment decisions for the incapable patient; and also ensure that the person is not prohibited from acting because of a court order or separation agreement. Should a candidate be found *not* to meet one or more criteria to be a substitute decision-maker under the *Health Care Consent Act*, the health professional will bypass that person and move on to the next highest-ranked candidate(s) on the list.

Health professionals are able to determine the appropriate candidate for substitute decision-maker for treatment under the *Health Care Consent Act* along with information about the age, willingness to act, availability and capacity of the identified eligible candidates.

Family caregivers need to know that the health professional's selection of the substitute decision-maker is guided by the law and a screening process to ensure the individual meets the criteria to act in that role.

If a health professional bypasses a substitute decision-maker due to incapacity, there is no formal appeal process.



How does the health system respond when equally-ranked substitute decision-makers appear unable to reach consensus on a patient care decision?

Health professionals will advise equally-ranked substitute decision makers that they must work together and come to consensus on the proposed treatment.

If that appears impossible, the substitute decision-makers are further advised that the Office of the Public Guardian and Trustee's Treatment Decisions Unit will be asked to make the patient care decision in their stead. This sometimes breaks the deadlock, but not always.

If the family still remains deadlocked, the health professional will pursue the decision from the Office of the Public Guardian and Trustee Treatment Decisions Unit.

Health professionals should remind substitute decision-makers who cannot come to consensus on a proposed treatment for a patient that if they cannot, the law requires that the health professional turn to the Office of the Public Guardian and Trustee Treatment Decisions Unit, a public body to make this specific decision. It does not replace the substitute decision-makers for future decisions.

In this case, substitute decision-makers need to consider whether they can reasonably come to consensus and provide consent or not, recognizing that if they do not, their decision-making authority for this particular treatment will be taken away and given to a government body.

Q18

What can a health professional do when the substitute decision-maker is making decisions that are worrisome (e.g., not returning calls from the health professional and related organizations, and not being available to the health professional to provide patient care decisions)?

If the substitute decision-maker is not “willing” or “available” (in addition to the other criteria described above) to act in the role, the health professional is entitled to move on to the next highest-ranked person in the ranking. However, it is recommended that the substitute decision-maker be reminded of his/her duties under the *Health Care Consent Act*, so that he/she has an opportunity to fulfill them.

If the substitute decision-maker has made a series of poor decisions, the health professional should try to get to the bottom of what is driving the poor decision. For example, is the substitute decision-maker legally capable to make the decisions, according to the legal test (ability to both understand the information being provided as well as the ability to appreciate the reasonably foreseeable consequences of saying ‘Yes’ or ‘No’ to what is proposed). Or, is the substitute decision-maker capable but not acting in accordance with the principles for substitute decision-making under the *Health Care Consent Act*, including making decisions based on his/her own wishes rather than the prior capable wishes of the patient?

If the substitute decision-maker appears incapable of making decisions that are in the patient’s best interests, the health professional can apply to Ontario’s Consent Capacity Board, an arm’s length tribunal, and ask for a ruling which may result in the substitute decision-maker being removed for a specific treatment decision.

Health professionals work closely with substitute decision-makers for the best possible patient outcome. In certain circumstances, health professionals have the authority to pursue an alternate substitute decision-maker or apply to the Ontario Consent Capacity Board.

When determining who the next highest-ranked substitute decision-maker(s) is, the health professional will want to document this decision in a manner that can be understood and applied by any member of the patient care team.

Family caregivers need to understand that health professionals are required by law to turn to the appropriate substitute decision-maker when a treatment, information or admission to long-term care decision is required. The family caregiver may be the one to assume this role, but only if they are highest-ranked on the list.



Can the patient determine who makes their health decisions if they become incapable to make their own treatment, information or admission to long-term care decisions?

While capable, the patient may select their own substitute decision-maker by working with a lawyer to take one among several steps, such as signing a power of attorney for personal care.

Or, even once incapable, the patient can apply to the Consent and Capacity Board with a request to name a “representative,” who ranks close to the top of the list of substitute decision-makers. This application will not be considered if a legal Guardian or Power of Attorney for personal care is already in place, but the application can be made by the patient even if (s)he is deemed incapable (or it could be made by a third party, such as the family caregiver, to ask the Consent and Capacity Board to name him/her as the patient’s representative).

Health professionals may be asked to provide patients with information about their legal options to determine their own substitute decision maker(s). It is important that clear information be provided, but that it not appear as though the health professional is providing formal legal advice. It is always possible to say, ‘We have provided you with some basic information and you are, of course, free to seek legal advice.’

Family caregivers need to know that patients have legal options and legal recourse should they wish to determine their own substitute decision-maker(s).



While capable, can the patient request that medical treatment be administered for a future mental health episode, even if at that later time the patient refuses treatment?

Yes. In a case where the patient recognizes a pattern of psychotic episodes during which (s)he routinely declines treatment and experiences an extended period of illness, the patient may decide to consult a lawyer to put a so-called 'Ulysses' contract into place (an option available under the *Substitute Decisions Act*).

The Ulysses contract is a special kind of Power of Attorney for personal care because the patient effectively gives their consent to be treated in the future. It is a fairly intrusive mechanism, for obvious reasons, and one that will need to be reviewed carefully with a lawyer.

While health professionals need to take care not to look as though they are providing legal advice to patients, they can support patients seeking to break out of a negative episodic pattern by raising the 'Ulysses' contract and suggesting that if they are interested, they will need to consult a lawyer.

Family caregivers may find it helpful to learn about the Ulysses contract (as well as powers of attorney for personal care more generally), as legal options that are available to the patient.



PHIPA carries potential monetary fines for the inappropriate collection, use and disclosure of patient personal health information. What are these fines?

According to PHIPA section 72(1), an individual health professional who “wilfully collects, uses or discloses personal health information in contravention of PHIPA or its regulations” may face a fine of up to \$100,000. Organizations that are health information custodians, such as hospitals, may face fines of up to \$500,000.

Since PHIPA came into effect in November 2004, no such fines have been levied against an individual health professional in the province of Ontario. Only rare cases of egregious breaches have been pursued. For example, a case in which patient information was provided to a third party insurance seller, which resulted in a successful prosecution in the courts for securities fraud, and a significant fine, as well as a class action lawsuit being filed. There have also been a number of prosecutions by the Attorney General for privacy breaches, resulting in fines and reputational damage, mainly related to ‘snooping’ cases.

Health professionals need to know that no such fines have been levied against an individual health professional in the province of Ontario. These fines are rare and have only been levied in egregious cases.

Family caregivers need to know that health professionals are bound to work within the law governing patient information.

WHERE TO GO FOR MORE HELP

- The Change Foundation's *Making Privacy and Consent Rules Work For Family Caregivers* report:
<http://www.changefoundation.ca/caregiver-privacy-consent-report/>
- The Change Foundation's *Making Privacy and Consent Rules Work for Family Caregivers* webinar: <https://youtu.be/-UjhJYpEOpQ>
- The Change Foundation's *Making Privacy and Consent Rules Work For Family Caregivers* webinar for the Embrace project:
https://www.youtube.com/watch?v=n9OIK_BW7z0
- 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>
- *Community Mental Health and Addictions Privacy Toolkit*:
<http://www.addictionsandmentalhealthontario.ca/our-work/#privacy-toolkit>
- Changing CARE: EMBRACE: <https://cornwallhospital.ca/en/embrace>
- 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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