

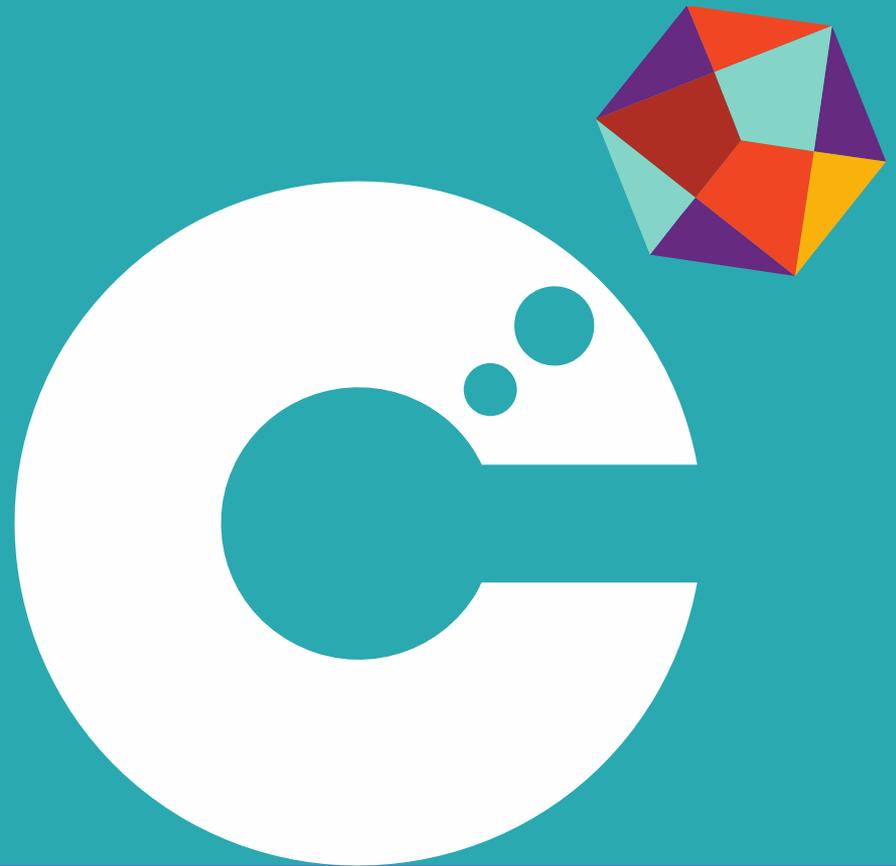


Making Privacy and Consent Rules Work for Family Caregivers

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March 8, 2018





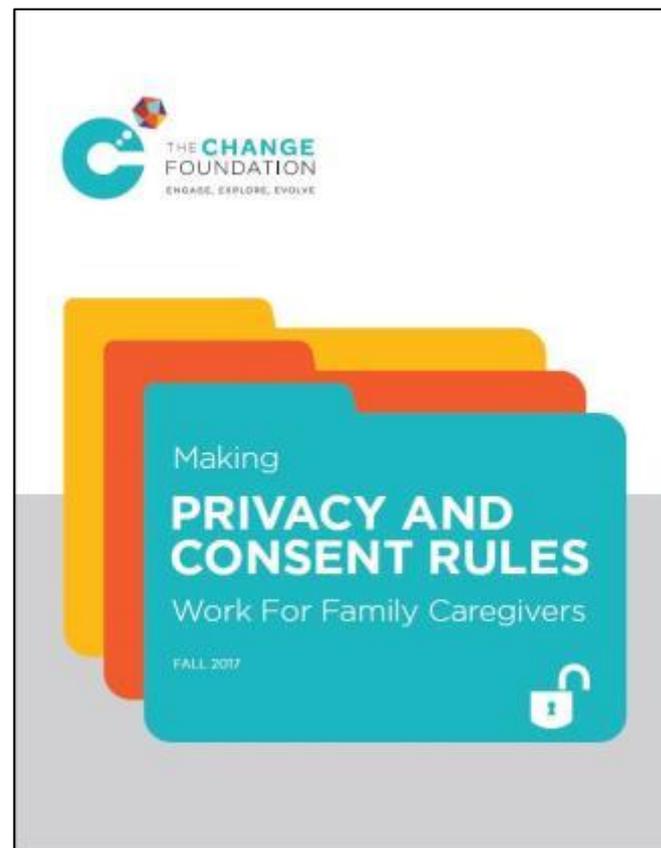
Agenda

- Introduction – Genevieve Obarski
 - The Change Foundation – why interested in Privacy & Consent
- Overview of Privacy & Consent Legislation – Mary Jane Dykeman
- Questions and Answers

Introduction

In 2015-16, we engaged with family caregivers, and health and community care providers across the province, to understand caregiving in Ontario from both perspectives.

- We heard from caregivers that providers often told them that they couldn't share health information for privacy reasons.
- We heard from providers that they were uncertain about privacy and consent rules.
- Privacy and consent legislation was often used as an overarching reason as to why patient information could not be shared with the family caregiver, even in cases when consent had been given by the patient.



Caregivers face many information challenges, including:

- Having to make repeated efforts to get copies of health records from a variety of providers 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.

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



Providers also face challenges:

- Hard to respond to a caregiver's request for information about the patient's care when there is no record that the caregiver is legally authorized to have the information;
- Hard to identify a primary caregiver in a family where multiple family members are involved in supporting the patient;
- Hard to work with family members of patients who are incapable of making treatment decisions, when there are disagreements within the family about the best course of treatment.



“Making Privacy and Consent Rules Work for Family Caregivers” – A Change Foundation Report

A primer on the current legislation:

- Consent requirements set out in the *Health Care Consent Act, 1996*
- Collection, use, disclosure requirements set out in the *Personal Health Information and Protection Act, 2004*

- Including descriptions of:
 - Legal test for capacity to consent
 - Rules about collection, disclosing and accessing personal health information
 - Rules when the patient is deemed incapable to consent, and the hierarchy of substitute decision-makers

- As well as:
 - Five case studies to illustrate the application of the rules
 - Information on “Where to go for more help”



Making Privacy and Consent Rules Work for Family Caregivers

Mary Jane Dykeman

Consent to Collect Information from Caregivers

Some caregivers are frustrated that healthcare providers won't speak with them— or don't want them in the room. Who is right?

- Healthcare providers may be concerned that they don't have consent to collect information a caregiver wants to share
 - If the provider cannot get the information directly from the patient in a timely or accurate way, he/she can collect it from the caregiver (patient can later say, don't use it)
 - Exercise caution in relying on this clause (“I'm sorry, but I need to pause the discussion because it's not clear that I have consent or other legal authority to speak with you”)
 - If collected PHI already e.g. from family member after patient says don't talk to them
 - Person can certainly complain to IPC if they find out it is in the record, even if no legal duty to report an unauthorized collection
 - May be better to just let them know this happened in error and work with them on solutions

Other important tips

- A provider can always disclose personal health information to any person to reduce or eliminate a significant risk of serious bodily harm
- Practice may be to speak to the patient alone at least initially – otherwise, providers to “read the room”

Sharing Information with Caregivers

What strategies can be used when a patient capably tells the provider not to share information with the caregiver?

- Take a nuanced approach:
 - Don't just take No for an answer
 - Ask patients about their concerns, and work to reduce them
 - Point out that their caregiver needs certain information to be able to support them
 - See if there is a middle ground – i.e., select notes, reports or a discharge summary will be shared, not the whole record

And if the answer is still No?

Healthcare providers:

- Can offer supportive information for families (even if the patient does not want family involved) such as links to resources
- May be able to confirm that patient or resident is in hospital or long-term care (special rules exist only for hospitals & LTC homes)
 - unless patient says otherwise, can share fact that person is a patient/resident, location & status
- Contact a relative, friend or potential SDM if a patient is injured, incapacitated or ill and unable to give consent

Tell me a little bit about a patient's capacity to consent. And consent for what? Treatment? Information-sharing?

- The patient is presumed capable
- No minimum or maximum age for legal capacity to consent to treatment (special rules for children under PHIPA on information decisions)
- Can be capable for one treatment and not another
- Does not depend on diagnosis, e.g., schizophrenia
- If capable, makes own treatment decisions (may refuse)
- Informed consent rules apply

Legal Test for Capacity

What is the legal test for capacity to consent? How important is it to get the legal test for capacity right?

The patient must be able to meet both prongs of the test:

- Able to understand the information relevant to the treatment; and
- Able to appreciate the reasonably foreseeable consequences of saying Yes or No
 - *It is a cognitive test – query whether a person could be extremely ill or psychotic and still be capable to consent*
 - *Similar legal test for consent to collect, use and disclose personal health information under PHIPA – treatment SDM becomes PHIPA SDM*

Substitute Decision-Making

If the patient is incapable, who is their substitute decision-maker (SDM)?

SDMs are ranked under the HCCA and PHIPA legislation:

1. Guardian of the person
2. 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 (SDM of last resort)

Substitute Decision-making

Why is it so important for a caregiver to know who will be the patient's substitute decision-maker (SDM)?

- Caregivers may become the patient's SDM if the patient becomes incapable
- It becomes more complicated if a caregiver is asking a healthcare provider to share the patient's information and is not the SDM – information sharing decisions require SDM consent
- With consent, the healthcare provider shouldn't hesitate to share information with the caregiver (signed form not required under PHIPA, but may be required by policy)

Substitute Decision-Making

Can anyone be an SDM?

SDMs must be all of the following:

- Willing
- Available
- 16 years of age (unless parent is making decision for his/her child)
- Not prohibited by court order or separation agreement
- Capable with respect to the proposed treatment

Substitute Decision-Making

What if there is more than one SDM and they don't agree?

- Equally ranked SDMs *must* reach a decision about treatment
- If they cannot agree, Public Guardian and Trustee *must* make the decision
- Staff sometimes get pulled into family dynamics
- SDMs need to know that if they cannot agree, they will lose power to make the treatment decision

Special Rules re: Children

What about age limits for consent to treatment? For information-sharing?

- Again, no age for treatment consent (test for capacity only)

If the child is incapable, SDM makes treatment and info decisions, otherwise:

- 16 and up? Child decides
- Under 16, either he/she *or* the parent can give the consent to collect, use or disclose personal health information
- Exceptions are if the information relates to
 - treatment under HCCA to which child consented *or*
 - counseling that the child participated in, in his/her own right
- If child is capable and parents do not agree with his/her wish, child's wish prevails

Special Rules – Mental Health

Are there any special rules around information-sharing that apply in a mental health setting?

- Under PHIPA generally, providers need legal authority to collect, use or disclose a patient's personal health information
- That means
 - express or implied consent of the capable patient (or SDM), or
 - in some cases, no consent is required under PHIPA or another law, e.g., *Mental Health Act* collateral information collected on a Form 1
- If a patient is detained in hospital under the *Mental Health Act* or as a forensic patient, s. 35(2) of that Act kicks in and consent is not required (provider can collect, use and disclose what they need – no lockbox allowed, collection from third parties as necessary)

“Lockbox”

We keep hearing about the term “lockbox”. Can you explain it?

- A lockbox is not a term found in PHIPA
- It is called an “express instruction” from the patient to a healthcare provider to not share certain personal health information with specific other providers, inside or outside the provider’s organization
- Patients get frustrated because they think a lockbox means nobody will ever see their information – it doesn’t

Access to Patient's Health Records

Do caregivers have their own rights to access the patient's health record? What if some of the information in the health record is about the caregiver?

- Family history (including about the caregiver) is personal health information of the patient under PHIPA
- The caregiver has no right of access unless:
 - the caregiver becomes the SDM
 - the patient (or SDM) consents to share the records with the caregiver

Sharing of Personal Health Information - Maria

- Maria is 85 years old, with a diagnosis of early stage Alzheimer's
- Her husband, George, is not very engaged in her care
- She continues to live at home (for now) and her daughter who lives locally coordinates all medical appointments, among other things
- Who will make treatment decisions for Maria?

Sharing of Personal Health Information - Maria

- Maria's daughter Rachelle makes and brings her to an appointment but is upset that test results not received
- The original provider is saying, they need a signed consent to transfer to the receiving provider (or that it expired or had to be in writing, not verbal)
- Who gives consent for information sharing?(George, Maria, SDMs?) Why not based on implied consent?
- Maria says that Rachelle makes all of her treatment and information decisions – can you rely on this? She says she will sign a form now, while capable, for future.

Maria through to end of life

- Maria is admitted to hospital
- When asked for consent to treatments proposed for Maria, Rachelle is erratic and arguably making quite poor decisions:
 - Must the team rely on her? Can she be removed or bypassed?
 - Is she capable?
 - Or is she simply not acting in best interests of Maria and not complying with principles for substitute decision-making? (Form G application to Consent and Capacity Board)
- Maria dies with no will; release of her health records? (estate trustee or “person responsible for administration of the estate”)

Sharing of Personal Health Information - Andrew

- The patient, Andrew, is worried his healthcare provider will share his health information with his parents (or, collect info from them)
 - Is there a difference between a parent telling the provider something versus the provider telling the parent something?
 - What if the provider is worried about breaching privacy? (consequences?)
- Does Andrew's age matter?
- What if Andrew is in the Emergency department, suicidal – does the clinical team have authority to collect information from family?
- What if Andrew:
 - Is on a Form 1 under the *Mental Health Act*?
 - Is detained on a Form 4?
 - Says, I want a “lockbox”? (not a formal term under PHIPA)
 - Can he be chemically restrained even if capable refuses treatment?

Andrew, cont'd

- Andrew lives at home for a while, and even takes his treatment
- As soon as he starts to feel better, he starts skipping his medication - then stops entirely
- Soon his behaviours return; next steps for this family?
 - Form 1 application for a psychiatric assessment
 - Form 2 application to a Justice of the Peace
 - Police powers, *Mental Health Act*, s. 17
 - Community treatment orders
- Detention, examination, observation, assessment up to 72 hours – Andrew is home without warning at 20 hours
- Could Andrew sign something while capable to permit sharing of information (or treatment) in future when he is unwell and refusing? (Ulysses contract)

QUESTIONS?



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