

CONSENT, CAPACITY, AND SUBSTITUTE DECISION-MAKERS

Note: This chapter deals with consent related to the collection, use, and disclosure of personal health information, and not consent to treatment. The Act has not changed the consent to treatment rules.

CONSENT

The Act provides for three primary models of consent to the collection, use and disclosure of personal health information:¹

1. express consent;
2. knowledgeable implied consent; and
3. no consent.

Consent must be obtained from an individual by a custodian if the custodian is collecting, using or disclosing the individual's personal health information unless the collection, use or disclosure is permitted without consent or required without consent by *PHIA* (section 11).

Later in this Chapter we will look at the provisions of the Act that permit the collection, use or disclosure of personal health information without consent.

¹ Other types of consent are discussed in Chapter 5: *Collection, Use and Disclosure of Personal Health Information*.

GENERAL RULES OF CONSENT

Consent for the collection, use or disclosure of personal health information by a custodian under the *Act*, whether express consent or knowledgeable implied consent, must meet the following requirements (section 13):

- it must be given by the individual;
- it must be knowledgeable;
- it must be related to the specific information at issue; and
- it must be voluntary.

EXPRESS CONSENT

Express consent is not defined in *PHIA*. However, the *COACH Guidelines for the Protection of Health Information* define “express consent” as follows:

*“Voluntary agreement with what is being done or proposed that is unequivocal and does not require any inference on the part of the organization seeking consent. Express consent may be verbal or written.”*²

Consistent with the *COACH Guidelines* definition, under *PHIA*, express consent can be written or oral (section 16).

Express consent of the individual to whom the personal health information relates is required in a number of different sections of the *Act* for collection, use and disclosure of that personal health information.

Express consent of the individual to whom the personal health information relates is required for the collection and use of personal health information for fund-raising activities as well as for market research and marketing any service for a commercial purpose (sections 32 and 34).

Express consent of the individual to whom the personal health information relates is required for the disclosure of the information (section 43):

² *COACH Guidelines for the Protection of Health Information* (December 15, 2006) at p. 332. COACH is Canada’s health informatics association. See www.coachorg.com or the Appendix 4: *Resources* section for information about purchasing the *Guidelines*.

- by a custodian to a non-custodian (unless required or authorized by law);
- by a custodian to another custodian if it is not for the purpose of providing health care (unless required or authorized by law);
- for fund-raising activities;
- for market research or marketing any service for a commercial purpose;
- to the media; or
- to a person or organization for the purpose of research (unless provided for in section 57).³

EXAMPLE

A hospital's fund-raising foundation would like to use a testimonial from a patient in a new fund-raising brochure. The hospital would require express consent from the patient before giving the foundation the patient's contact information.

KNOWLEDGEABLE IMPLIED CONSENT

Consent is "knowledgeable" when it is reasonable in the circumstances for the custodian to believe that:

- the individual knows the purpose of the collection, use or disclosure, as the case may be; and
- the individual knows that s/he may give or withhold consent. (section 14)

If the individual then proceeds to pursue services, the custodian may infer that the individual is consenting to the collection, use and/or disclosure of the personal health information.

To ensure that consent is "knowledgeable," a custodian must either provide written or verbal information directly to the individual, post a notice, or distribute brochures describing the purpose of the collection, use and disclosure of personal health information that are readily available to the public (section 15(1)).

³ See Chapter 7 – *Research*

See Chapter 3: *Duties of a Custodian* at page 2 for information on the content of a “Notice of Purposes”.

EXAMPLE

Downtown Pharmacy has developed a poster that clearly explains the general purposes of its collection, use and disclosure of personal health information. The pharmacy hangs the poster next to the counter where prescriptions are dropped off and where all individuals using the pharmacy will see it.

Taylor gives a prescription written by his physician to the pharmacy technician on duty. The poster is right beside the counter. The pharmacist can reasonably assume that the Taylor has consented to the collection, use and disclosure of the personal health information for the purposes outlined in the poster.

Providing written information, posting notices or distributing brochures is not sufficient if the custodian should have known that the individual cannot read or cannot understand the notice (section 15(2)). If the custodian determines that an individual requires assistance understanding the notice, the custodian may assist the individual by using an interpreter (if available), or explaining the information in the notice directly to the individual as best s/he can.

“CIRCLE OF CARE”

The circle of care supports the care and treatment of individuals by allowing information to flow under different rules than the rules for those outside the circle. It allows custodians to assume an individual’s knowledgeable implied consent to collect, use or disclose personal health information for the purpose of providing health care, unless a custodian knows that an individual has expressly withheld or withdrawn consent pursuant to section 17 (see below).

The term “circle of care” is not used in the legislation, but is used in the health sector to refer to the custodians who provide or support care to an individual in each instance of care provision. The term “circle of care” is defined in Industry Canada’s guidelines for the health sector as follows:

“Individuals and activities related to the care and treatment of a patient. Thus, it covers the health care providers who deliver care and services for the primary therapeutic

benefit of the patient and it covers related activities such as laboratory work and professional or case consultation with other health care providers.”⁴

Under the “circle of care,” it does not matter whether care and treatment is provided in the private or public sector, or that services are publicly insured or not insured – the personal health information will follow the individual where s/he goes in the health care system.

However, the information may only be disclosed by a custodian to another custodian (or his/her agent) within the circle of care. If the individual is also receiving care and treatment from a person or organization not designated as a custodian under *PHIA*, express consent must be obtained from the individual.

The *Act* sets out minimum standards for consent that custodians must obtain for the collection, use and disclosure of personal health information. Unless the *Act* requires express consent or makes an exception to the requirement for consent, knowledgeable implied consent may be accepted as consent (section 12).

However, a custodian may decide to go further than the minimum standard and require express consent if the custodian believes it is appropriate.

Finally, it is important to remember that a circle of care is different for each instance of care provision.

EXAMPLE

Tessa receives care in a hospital for a broken leg. The custodians within her circle of care will include agents of the custodian involved in treating or supporting treatment of the broken leg such as paramedics, health records staff, the nursing staff, physicians, and physiotherapists.

If Tessa is treated three months later for a concussion, her circle of care will change to those agents of the custodian involved in treating Tessa’s concussion (e.g. health records staff, nurses and physicians in the neurological service). The care providers involved in the treatment of the broken leg are not permitted to use or have disclosed to them the personal health information related to Tessa’s concussion unless there is a reasonable reason to do so.

⁴ Industry Canada, *PIPEDA Awareness Raising Tools (PARTs) Initiative for the Health Sector, Questions and Answers*, question 12. Available at <http://www.ic.gc.ca/eic/>

The same would be true for information disclosed from custodian to custodian.

EXAMPLE

If the hospital (a custodian under *PHIA*) referred Tessa to a physiotherapist in private practice outside of the hospital (also a custodian under *PHIA*) to receive services for her broken leg, the physiotherapist would not be part of the circle of care for any subsequent hospital treatment that Tessa received for her concussion.

WITHDRAWAL OF CONSENT

An individual may request to limit or revoke consent for the collection, use or disclosure of personal health information in the custody or control of a custodian by giving notice to the custodian (section 17(1)). In the context of electronic health records, this limitation or revocation of consent is often referred to as a “lockbox”; the terms “consent directives” and “masking” are also used in reference to both paper and electronic records.

An individual may request to limit or revoke his/her consent at any time, but it is not retroactive (section 17(2)). This means that if an individual informs a custodian that s/he is withdrawing consent to have information disclosed to one of his/her health providers, the custodian is not required to request that any information previously disclosed to the other provider be returned.

However, pursuant to section 17(5), the custodian must inform the provider named by the individual that the individual’s record is not complete, meaning the custodian considers that the information disclosed to that provider is not what is “reasonably necessary” for the care of the individual.

The custodian must also inform the individual of the consequences of limiting or revoking consent (section 17(4)), including the fact that the other provider may decide that s/he is not confident in providing care to the individual without understanding what information has been withheld.

EXAMPLE

François receives a referral from his optometrist for eye surgery. François has asked that the optometrist not disclose to the surgeon that he occasionally takes medication to help him sleep.

The optometrist would have to evaluate whether this information is reasonably necessary for the surgeon to know, and if so, must inform the surgeon that the record is not complete. The optometrist would also have to discuss with François the consequences of not disclosing this information, including the fact that he may not receive appropriate and safe care, or that the surgeon may refuse to treat him at all.

A custodian is required to take reasonable steps to comply with an individual's request to limit or revoke consent (section 17(3)). Each individual circumstance will determine what is reasonable.

EXAMPLE

A nursing home holds their residents' personal health information records in an electronic information system. Kenneth, a resident of the home, informs the administrator that he doesn't want the nursing home's physiotherapist to have access to specific information in his nursing home record.

The nursing home's electronic system does not have the technological means to withhold the information, and the system is not scheduled to be upgraded for another two years. The upgrade will include the ability to mask the residents' information on request.

It would not be reasonable for Kenneth to expect that the custodian incur the costs of upgrading immediately to meet his request. However, it would be reasonable to expect that the custodian explain to Kenneth that only persons involved in his care would have information disclosed to them. If the physiotherapist is involved in Kenneth's care, he would have the option not to use the physiotherapist's services. However, the nursing home would be required to inform him of any consequences of limiting access to his records, including the possibility that he may not be provided with physiotherapy.

The revocation of consent does not apply to collection, use and disclosure of personal health information that a custodian is required by law to collect, use or disclose (section 17(6)).⁵

⁵ See Chapter 5: *Collection, Use and Disclosure of Personal Health Information* for information on revocation of consent

EXAMPLE

Section 38(1)(c) authorizes a custodian to disclose information to a regulated health profession body for the purposes of carrying out its duties in Nova Scotia under a provincial *Act*.

A complaint has been received against Cheryl, a dentist. Darren, one of her patients, requests that the information in his dental record not be disclosed to the Provincial Dental Board.

This request could be denied under section 38(1)(c), as the Provincial Dental Board may require Darren's records to aid in its investigation against Cheryl Smith carried out under the Board's authority in the *Dental Act*.

WHEN CONSENT IS NOT REQUIRED

The *Act* provides for circumstances where personal health information may be collected, used or disclosed without consent.⁶

In circumstances where disclosure without consent is permitted by the *Act*, a custodian is not obliged to disclose information to a third party unless required to do so under another law or enactment. In addition, the custodian may choose to obtain the individual's consent for the disclosure or give notice to the individual of the disclosure (section 10(2)(c)).

CAPACITY TO CONSENT

For the consent of an individual to be valid, the individual must have the *capacity* to consent. In the context of *PHIA*, capacity means:

- the ability to understand information that is relevant to the making of a decision related to the collection, use or disclosure of personal health information and
- the ability to appreciate the reasonably foreseeable consequences of a decision or a lack of a decision. (section 3(b))

⁶ See Chapter 5: *Collection, Use and Disclosure of Personal Health Information* for information on the collection, use and disclosure of information without individual consent.

Any capable individual, regardless of age, may consent or withdraw consent for the purpose of the Act (section 18). The capacity of an individual must be considered in each instance consent is being sought. An individual may have the capacity at a particular time to consent to the collection, use or disclosure of some parts of personal health information, but may be incapable of consenting at another time (section 19).

Where an individual is deemed to have the capacity to consent to the collection, use and disclosure of personal health information, such consent includes disclosure to a parent, guardian or substitute decision-maker where applicable (section 20).

MATURE MINORS

Under the provincial *Age of Majority Act*, a person ceases to be a minor when they reach the age of nineteen years. This age is recognized by some provincial legislation, while other provincial legislation provides for benefits and rights when an individual reaches a younger age.⁷

PHIA recognizes the common-law principle of “mature minors,” which recognizes that the capacity to consent is incremental and situational. The capacity of each individual minor must be considered in the context of each episode of care. A 17-year-old may have the capacity to consent to (or withhold) disclosure of information related to one issue while lacking the capacity to consent to disclosure related to another.

EXAMPLE

Sixteen-year-old Jenny may have the capacity to consent to receive a prescription for oral contraceptives and to request that the information related to this health care service not be disclosed to her parents. If Jenny is diagnosed with cancer which requires ongoing treatment, she may not have the capacity to make a decision about the treatment.

⁷ For example, the *Freedom of Information and Protection of Privacy Act* provides that the guardian of an individual under the age of majority may exercise the individual’s rights unless it would be an “unreasonable invasion” of the individual’s privacy, while the *Adult Protection Act* defines an “adult” as being or appearing to be sixteen years of age or older.

In that circumstance, it may be reasonable for the physician to disclose the diagnosis and treatment information to Jenny's parents, even if she objects.

SUBSTITUTE DECISION-MAKER

Where an individual lacks the capacity to consent or refuses the collection, use and disclosure of personal health information, a substitute decision-maker may make that decision on behalf of the individual.

A hierarchy of substitute decision-makers is outlined in section 21(2) of the Act. The hierarchy is:

- (a) a person who is authorized by or required by law to act on behalf of the individual;
- (b) the individual's guardian appointed by a court of competent jurisdiction;
- (c) the spouse of the individual;
- (d) an adult child of the individual;
- (e) a parent of the individual;
- (f) a person who stands in loco parentis to the individual;
- (g) an adult sibling of the individual;
- (h) a grandparent of the individual;
- (i) an adult grandchild of the individual;
- (j) an adult aunt or uncle of the individual;
- (k) an adult niece or nephew of the individual;
- (l) any other adult next of kin of the individual;
- (m) the Public Trustee.

The criteria for choosing a substitute decision-maker are set out in section 21(5). The criteria are:

- a) the potential substitute decision-maker has been in contact with the individual throughout the preceding twelve-month period; or if the individual has not been in contact, a court order has been granted to waive the twelve-month period;
- b) the potential substitute decision-maker is willing to accept the responsibility;
- c) the potential substitute decision-maker knows of no person of a higher category who is able and willing to make the decision; and
- d) the potential substitute decision-maker certifies in writing the potential substitute decision-maker's relationship to the individual and the facts that meet the criteria set out above.

Once a substitute decision-maker is chosen by the custodian, section 22 states that the substitute decision-maker shall make decisions based on the following:

- the prior expressed wishes of the individual. However, the substitute decision-maker may also act according to what s/he believes the individual would have wished had the specific circumstances been known to the individual. In doing this, the substitute decision-maker would base his/her decision on what s/he knows about the values and beliefs of the individual, and any written or oral instructions;

Note: The written or oral instructions would not necessarily be related to the specific care decision where the substitute decision-maker has to act. It may be related to previous care decisions made by the individual.

- in the absence of instructions, the substitute decision-maker would base his/her decision on what s/he knows about the values and beliefs of the individual, and any other written or oral instructions;

Note: The written or oral instructions would not necessarily be related to the specific care decision where the substitute decision-maker has to act. It may be related to previous care decisions made by the individual.

- where the substitute decision-maker does not know the wishes, values and beliefs of the individual, the substitute decision-maker may make decisions that s/he believes would be in the best interest of the individual.

The person seeking consent on an individual's behalf is entitled to reply on the potential substitute decision-maker's statement in writing as to his/her relationship with the individual and as to the criteria outlined in section 21(5) outlined above, unless it is not reasonable to believe the statement.

EXAMPLE

Michelle, a family physician, has been treating Daphne for 20 years. Daphne now lacks the mental capacity to make decisions for herself.

Michelle know from prior discussions with Daphne that she has two adult children, Kelly and Derek, who meet the criteria to be a substitute decision-maker. However, only Derek has stepped forward and says that he is the only child who can act for his mother.

It would not be reasonable for Michelle to believe Derek's statement. It would be reasonable for her to make further inquiries to determine if Kelly would be willing to be considered as a potential substitute decision-maker.

Once a custodian has determined who will act as the individual's substitute decision-maker, the custodian shall only accept the consent of the chosen substitute decision-maker. However, there can be different substitute decision-makers for different custodians, and even different substitute decision-makers for the same custodian in different circumstances.

EXAMPLE

In the example above, Daphne's physician spoke to Kelly and determined that she was the appropriate substitute decision-maker for her mother for her current hospitalization.

Six months later, Daphne is admitted to the hospital again, but Kelly is out of the country and will not be returning for two weeks. In this case, if Michelle determines that Derek still meets the criteria for substitute decision-maker, she can recognize him as the new substitute decision-maker for her current hospitalization.