

## Rights of Access and Correction

### *Why Create a Right of Access and Correction?*

As health records become more comprehensive and more widely shared, individuals require assurance about what goes in a record, whether it is accurate, and where and to whom the information is going. Accuracy of records, and perceived transparency by those who manage records, improved confidence and public trust - and ultimately improved effectiveness and efficiency of a healthcare system. Setting out rights of access and correction in privacy legislation is a basic way to promote accuracy.

It has been said (by *Halamka et al.*) that “by placing the patient at the center of healthcare data exchange and empowering the patient to become the steward of their own data, protecting patient confidentiality becomes the personal responsibility of every participating patient.” And, according to Justice Michael Kirby, participation is the most notable and important privacy protection safeguard; he has remarked:

If you can have access to information about yourself, check it, ... correct it when it is wrong, you have a most powerful weapon to protect your privacy . . . It is privacy used as a sword . . . To protect and assert [one's] own personal interests from the inquisitiveness of ... others. (*Australian Law Reform Commission. Freedom of information Discussion Paper*).

### *Access v. Disclosure*

Under privacy legislation, the concept of access is distinguished from the concept of disclosure. In the ordinary healthcare system, custodians and affiliates are either disclosing health information proactively or in response to a request. Access focuses on the latter types of situations, and specifically where the requesting party is the individual who is the subject of the information being disclosed. In others words, where an individual requests health information, that individual, for the purposes of HSPL is *accessing* health information and the custodian or affiliate is *disclosing* health information.

In some limited cases, an individual other than the individual the information is about may access that information. This is because privacy legislation invariably includes a provision where any right or power given to an individual under the Act may be exercised by an authorized and lawful representative of that individual. A common example is where a parent, as a lawful guardian, exercises the access right of his or her child to obtain the health records of that child.

***Access Rights, Not New: Already Acknowledged in Canadian (Common) Law***

In 1992, because of the famous case of *McInerney v. Macdonald*, the Supreme Court of Canada recognized an individual's right to ownership over the contents of a health record and distinguished this from ownership rights over the physical chart. The access provisions under HSPL build on these common law rights and grant individuals a statutory right of access to health information.

***Layout of Access Obligations in HSPL***

In most HSPL the Part that deals with access right starts with a key provision that confers the right of access. For example this type of provision would read: "An individual has a right of access to any record containing health information about the individual that is in the custody or under the control of a custodian".

The remaining provisions under the Part of the HSPL that deals with access specify a process for making a request and impose certain obligations on custodians who must respond to the request. For example, these provisions would include such matters as:

- an obligation to make every reasonable effort to assist an applicant and respond openly, accurately and completely;
- a certain time limit (e.g. 30 days) for responding to a request;
- a list of acceptable situations, and rules to follow, for when custodians (and/or affiliates) require extensions of time; and
- options for how access will be granted, usually by examining the record or obtaining copies.

In general, the access Part of HSPL would parallel the access provisions contained in the *Access to Information and Protection of Privacy Act*.

### ***Access Right Not Absolute***

The right to access, as set out in *McInerney v. Macdonald* as well as in HSPL, is not absolute. There are many cases when granting full access may not be in an individual's best interest and, in some cases, be dangerous. Therefore, HSPL usually sets out a list of situations when access *may* be refused, and when it *must* be refused. Note however that, under most HSPL, if the health information (to be refused) can be reasonably severed from a record, an individual has the right to access the remainder of the record.

Examples of discretionary powers to refuse disclosure (when access *may* be refused) include if the disclosure could reasonably:

- be expected to:
  - i. result in immediate and grave harm to the applicant's mental or physical health or safety;
  - ii. threaten the mental or physical health or safety of another individual;
  - iii. pose a threat to public safety, or
- lead to the identification of a person who provided health information to the custodian explicitly or implicitly in confidence and in situations where it is appropriate that the name of the individual who provided the information be kept confidential.

Examples of mandatory obligations to refuse disclosure (when access *must* be refused) include if:

- the health information is about an individual other than the applicant, unless the health information was originally provided by the applicant in the context of a health service being provided to the applicant;
- the health information sets out procedures or contains results of an investigation, a discipline hearing, a practice review or an inspection relating to a healthcare professional; or

- the disclosure is prohibited by another enactment or law

### *Recovering for Processing Access Requests*

Given all the possible access requests that can be made, and the work involved by custodians and affiliates to ensure all of the obligations are met (such as reviewing each record to ensure mandatory obligations to refuse access would not be breached if access is granted), HSPL commonly provides that the right of access is subject to the payment of fees. This serves two functions: i) help control frivolous and vexatious access requests; and ii) help custodians and affiliates recover (financially) for human resources expended and other expenses incurred from processing access requests.

Commonly, HSPL sets out obligations about how and when fees can be imposed. For example:

- the right to charge fees does not permit a custodian to charge a fee in respect of a request for access to an applicant's own health information, except for the cost of producing the copy;
- a custodian may require an applicant to pay a basic fee (e.g. \$25.00) before a request will be processed;
- a custodian must give an applicant a fee estimate of the total fee for services before providing the services;
- a custodian may excuse an applicant from paying all or part of a fee if, in the opinion of the custodian, the applicant cannot afford the fee or for other circumstances provided for in the regulations;
- the processing of a request ceases when a fee estimate is sent and resumes when a certain percent (e.g. 50%) of the fee is paid (the balance owing at the time the information is delivered to the applicant); and
- a custodian may excuse an applicant from paying fees where in the opinion of the custodian it is fair to excuse payment.

### *Correction Requests*

Equally important is that the HSPL set out a right of correction for health information in the custody or control of a custodian or affiliate. As with access request, the Part of the HSPL that deals with correction requests would start by setting out a key provision such as “an individual who believes there is an error or omission in that individual's health information may in writing request that the custodian that has the information in its custody or under its control correct or amend the information.”

Again as with the obligations for access requests, HSPL would set out related obligation to process this request, including, for example, such matters as:

- within a certain time period (e.g. 30 days) the custodian must decide whether or not it will make or refuse to make the correction;
- if the custodian decides to make the correction, the custodian must within the prescribed time period:
  - 1) make the correction or amendment;
  - 2) give notice to the applicant that the correction has been made;  
and
  - 3) notify any person to whom the information was disclosed during a certain time period (e.g. 1 year) before the correction was made;  
and
- If the custodian decides not to make the correction, the custodian must within certain time period (e.g. 30 days) give the applicant written notice of the decision and include reasons for the refusal.

Of course, a request for correction is not (like a request for access) be absolute. HSPL invariably provides that a custodian or affiliate may refuse to make a correction or amendment respecting a professional opinion or observation made by the healthcare professional.

### ***Access & Correction Case Examples***

To help guide the discussion on the topic of rights of access and correction, the Panels are asked to consider and share views on how such right may and/or ought to apply and operate in the following scenarios:

- A. A psychiatrist notes that his patient is suffering from paranoid delusions. The psychiatrist feels that his comments will anger the patient and worsen his condition.
- B. A social worker recorded that she had concerns about the parenting skills of a particular patient. Now, twenty years later, the patient wants to see their health record.
- C. A healthcare providers accidentally documents a full assessment of patient X in patient Y's chart, the assessment included details about patient X's addition issues and abusive relationships. An access request for a copy of patient Y's chart is made patient Y. A year later, patient X learns there was a mistake and makes an access request for a copy of patient Y's chart.
- D. A woman is aware that she has a deteriorating health condition, but is extremely positive about her future. Her medical record contains her information about her being abused as a child. The patient is aware of this, but has never been able to recall the specific details of this abuse. The medical records contain graphic descriptions of the injuries suffered.
- E. A wife applies to a pharmacy for access to her husband's health records. The couple is separated but not divorced. The wife indicates she requires the information immediately (and cannot wait 30 days) because the information is needed to process their income tax return which is due the next day.
- F. A health record details that, that, according to several hospital personnel, a patient is are extremely 'difficult' to manage. The patient disagrees with this statement.
- G. A record contains a note several years old from a consultant querying whether a mother has intentionally injured her child. It had not proved to be the case but the note was not up-dated.
- H. A child's record contains the name of a neighbor who called in suspected child abuse. When the neighbor called, he specifically asked that his identity not be revealed. The parents of the child want to see a copy of the child's record.