



# SAFEGUARD

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## In This Issue:

- Dignity, Respect and Privacy of Vulnerable People
- Transferring Records to an Information Manager
- Complaints and Breach Notifications

### Dignity, Respect and Privacy of Vulnerable People by Commissioner Michael Harvey

In recent months, privacy breaches involving pictures of vulnerable individuals have been widely reported in the media. While, due to ongoing and potential investigations, I cannot discuss these specific breaches in this message, I want to take this opportunity to draw attention to the special care that we must afford to people that are receiving care and who may be vulnerable. The messages that I wish to get across are first, that the assessment of the privacy responsibilities of a custodian are based on what is reasonable, and that means that the context of each situation must be understood; second, that the nature of health care settings are such that there are numerous contextual factors, many arising from the vulnerability of the client, that must be considered when assessing privacy; and finally, that individual custodians, employees of organizational custodians and indeed all of us, should regularly reflect that the principle of privacy is inherently linked to dignity and therefore we can be guided by common decency, respect and kindness.

The *Personal Health Information Act (PHIA)* requires that custodians, including Regional Health Authorities, have reasonable safeguards in place to protect personal health information. The purpose of the Act establishes rights of individuals and accountabilities for custodians. *PHIA* also requires that custodians develop policies and procedures to support compliance with the Act. If you are an employee in the health sector and you're unsure about whether there are policies for you to follow, you should contact your employer.

*PHIA*, along with the *Adult Protection Act* and the *Children, Youth and Family Act*, can be understood to provide a broad framework for the protection of vulnerable minors and adult people that are vulnerable, as well as varying complaint and appeal rights, and investigatory and other authorities. *PHIA* does not itself explicitly require a higher duty of care for the privacy of vulnerable individuals than for the general population. For that matter, it may be better to avoid a category-based approach to even defining who is vulnerable. There is no question that children, youth and seniors and people with disabilities of all ages are more likely to be vulnerable than others but any of us can be vulnerable at any stage of our lives during certain situations. It is important

that custodians reflect on the context of every situation when assessing how to equitably provide protection to vulnerable people. This matters for statutory compliance: what is *reasonable* and thus required by law, is context dependent.

Vulnerability is of particular concern in health care settings. From a patient or client's perspective, the medical condition itself and/or the specifics of the care required for it may hinder our capacity to protect our own privacy as we normally would. We may be unfamiliar with the system, the setting, the caregivers, and the lingo. There are likely to be real or perceived power imbalances between us and our health care providers. We are likely to face stress about the medical conditions that have led us to receive care. Matters involving family, other loved ones and caregivers may complicate the situation. The care that we receive may be provided alongside others receiving care, not to mention their families and others. We may be forced to wear clothes that are not familiar or comfortable for us. Any of these circumstances, and many more, could push us into a situation that feels vulnerable. A custodian should consider the context and how it may inherently increase the risk of privacy invasiveness and undermine an individual's ability to protect their privacy. They then should consider what measures in each circumstance can reasonably be taken to address these factors.

When assessing the context faced by a vulnerable person and the privacy implications, we encourage custodians to consider the true roots of privacy. Privacy is commonly understood too narrowly as an imperative to protect information about a person from disclosure to others. Privacy is better understood as an individual's ability to *control* information about themselves, and thus is fundamentally linked to their ability to control their circumstances – their autonomy and their dignity. This is why, in health care settings, contextual factors that may unavoidably be diminishing their autonomy and dignity make preserving privacy, to the greatest extent possible, such an important imperative.

The statutes cited above – *PHIA*, the *Adult Protection Act*, and the *Children, Youth and Families Act* are only a few that are relevant for custodians, their staff, volunteers and other individuals in a health care setting. The self-regulatory colleges of the health professions can also investigate privacy breaches under their respective legislation, with implications for professional licences. Depending on the breach, impacted individuals could start a class-action lawsuit or seek recourse under the *Privacy Act*. Criminal code violations would be investigated by law enforcement. At a minimum, there would likely be disciplinary consequences depending on the custodian's human resources or privacy policies. But while all custodians should be aware of these statutory considerations, the most important thing on a day to day basis is to be guided by common sense ethics and decency about how to preserve the autonomy and dignity of our fellow human beings.

As we live together in a just and caring society, if one of us is harmed, we are all harmed. If we lose trust in the system, the harms will be far-reaching. When the leaders in our health care organizations promote – and demonstrate through their own actions – a culture based on dignity and respect, then we all benefit. The stakes are high and we encourage those working in health care to remember the power that they hold and the good work they do. Let us continually strive to do better together.

## Transferring Records to an Information Manager

OIPC has received a number of inquiries regarding custodians who have transferred patient records to a records management company. These companies are frequently located out-of-province and charge fees to obtain copies of the records.

Under *PHIA*, custodians have certain obligations for the records in their custody and/or control. For example, section 13 establishes requirements for information practices, policies and procedures. Section 13(3) states,

*The information policies and procedures referred to in subsection (1) shall include appropriate measures to address the risks associated with the storage of personal health information, taking into account the manner and form in which the personal health information is recorded, the location of storage and the degree of sensitivity of the personal health information to be protected.*

These obligations apply, even if the information is moved out-of-province or to a records management company. The custodian does not cease to be a custodian in relation to the records just because they leave practice; the records must be transferred to another custodian for their obligations to end.

Custodians are able to hire information managers; a records management company would likely be considered an information manager in many of the situations described to our Office. Section 2 defines information managers as follows:

- (l) "information manager" means a person or body, other than an employee of a custodian acting in the course of his or her employment, that
- (i) processes, retrieves, stores or disposes of personal health information for a custodian, or
  - (ii) provides information management or information technology services to a custodian;

However, section 22(6) establishes, "Nothing in subsection (4) or (5) relieves a custodian from its obligations under this Act and the regulations in respect of the personal health information disclosed by the custodian to the information manager, and the personal health information that has been disclosed to an information manager under an agreement under subsection (2) is considered to continue in the custody and control of the custodian for the purpose of this Act and the regulations."

We often get asked if consent is required before files can be moved. *PHIA* establishes many disclosures of personal health information without consent of the patient; one of these is for succession planning (section 39(1)(i) and (j)).

Section 52 provides individuals with the right of access to their own personal health information. Custodians are able to charge a reasonable fee for access to a file; this continues to apply when custodians have outsourced information management to a records management company.

This Office examined the issue of "reasonable fees" in [Report AH-2012-001](#). While a different context, the Commissioner found that the \$50.00 fee to provide individuals with their own personal health information was unreasonable and recommended that individuals be charged a maximum fee of \$25.00 for requests of up to 50 pages, which fee would include various tasks associated with searching for and providing access to the requested information. After the first 50 pages, the Commissioner recommended a photocopy fee of no more than \$0.25 per page. The Commissioner also strongly recommended that personal health information be provided to individuals free of charge at the point of care, except where the requested information is not easily located or voluminous in nature. Further, the Commissioner recommended that the fee be waived or substantially reduced in all cases where it truly represents a barrier to access.

Some oversight bodies have also issued guidance and expectations that should be considered; for example, the College of Physicians and Surgeons of Newfoundland and Labrador has resources online, such as:

- <https://cpsnl.ca/wp-content/uploads/2022/09/Closure-of-Medical-Practice-and-Extended-Leave-from-Practice-2017-1.pdf>;
- [By-Law-6-Medical-Records.pdf \(cpsnl.ca\)](#).

While in another jurisdiction, the Office of the Privacy Commissioner of Canada issued a [Report](#) about a medical record storage company that contains valuable considerations. The Report highlighted the difference between accessing a record and obtaining a copy of a record. In Newfoundland and Labrador, section 51 establishes an individual's right of access to a record containing personal health information, with few exceptions. Section 57 establishes a custodian's right to charge a reasonable fee for providing a copy of a record; there is no mention of fees for providing access.

Even if records are transferred to an information manager, there may be other custodians with the information a person is seeking, such as a specialist, a general practitioner, or a Regional Health Authority (RHA). Regardless of which custodian the information is requested from, however, all custodians are able to charge a fee to provide a copy of personal health information. For example, an RHA has custody and control of records for hospital stays and the Centre for Health Information has custody and control of information contained within their eHealth system HEALTHe NL. For further information on how to obtain access to or a copy of this personal health information, please contact your respective RHA or the [Centre for Health Information](#).

#### Key Points:

- [Section 22](#) of *PHIA* permits custodians to enter into an agreement with an information manager; this does not relieve the custodian of their obligations under the *Act* (see subsection 22(6)).
- [Section 57](#) of *PHIA* confirms that a custodian may charge a *reasonable fee* for providing a copy of a record in response; this extends to their information manager.
- There is nothing in *PHIA* that establishes a right to charge a fee for providing access to personal health information.
- Consent of the patient is not required to transfer information to the information manager.

## Complaints and Breach Notifications

Between August 1 and October 31, 2022, OIPC received seven breach notifications from five different custodians. During this same time frame, a total of four *PHIA* complaints were received by OIPC involving three custodians. One breach involved a phone message left on the wrong number, one involved a mail out that did not arrive at the intended destination and another involved a physician dictating notes with a different patient in the room. Two breach reports involved the collection of patient images; in one situation, the image briefly appeared on a social media platform, in another, an image was potentially disclosed to co-workers. Breaches involving the pictures have been subject to media reports.

One intentional breach was reported by Eastern Health; an employee snooped in the demographic information of a client.