

Office of the Information and Privacy Commissioner for Nova Scotia

Know Your Rights Glossary: Privacy Terms Personal Health Information Act

Under Nova Scotia's *Personal Health Information Act (PHIA)*, you have the right to complain if you believe a health custodian has not followed the privacy rules set out in *PHIA* and its Regulations. This document is part of our series entitled, *Know Your Rights* and is intended to help the public understand what their rights are.

The *Personal Health Information Act* applies to healthcare providers and organizations that are entrusted with health information so they can provide health care to individuals.

The following describes several terms that appear frequently during the privacy complaint process. This glossary attempts to break down some of that jargon into clear language. However, it is intended solely as a guide, and though it strives to be as accurate as possible, you should look to the actual legislation for definitive interpretations.

If there is a **bolded** word within the Glossary entry, that term has its own Glossary entry.

Act – This is a short way of saying the Personal Health Information Act. We use this term to mean both **PHIA** and its **Regulations**.

Agent – A person who, with authorization of the **custodian**, acts for or on behalf of the custodian in terms of handling **personal health information**. The agent can only collect, use, or disclose personal health information according to the rules under the **Act** that apply to the custodian.

Appeal - see review request.

Applicant – The person who makes a **privacy complaint** to a **custodian**. Often referred to as **complainant**.

Capacity – Under the **Act**, capacity refers to the ability of a person to understand information that is needed to make a decision about the **collection**, **use** or **disclosure** of their own **personal health information** and the ability to understand the consequences of those decisions.

Circle of Care – This term is not found in the **Act**; however, it is a term used by some healthcare professionals. It describes a concept where the patient is at the centre of the circle of providers that provide them with health care. Healthcare professionals involved in the diagnosis, treatment and care of the patient are in the circle and can share information about the patient with each other to provide care. The Act allows this type of information sharing if it is the minimum amount necessary to provide health care to the individual. Any such sharing should be limited to a need-to-know basis, even amongst a circle of healthcare providers.

Collect/Collection – The action by a **custodian** to gather, acquire, receive, gain access to or obtain **personal health information**.

Commissioner – Short for **Information and Privacy Commissioner**.

Complainant – The individual who makes the **privacy complaint** to a **custodian** because they believe the custodian has not followed the rules under the **Act** about the **collection**, **use**, **disclosure**, **retention**, **notification** or protection of their own **personal health information**.

Consent – Consent means that the individual agrees to the **collection**, **use** or **disclosure** of their **personal health information** by a **custodian**. To provide consent, the individual must know the reason for the collection, use or disclosure as it relates to the specific information at issue and the consent must be voluntary. The **Act** outlines three methods for obtaining consent: **knowledgeable implied consent**, **express consent** and **deemed knowledgeable consent**.

Custodian – A regulated health professional or healthcare organization that keeps **personal health information** for the purpose of delivering health care, covered by the **Act.** Custodians are responsible to respond to **privacy complaints** and are responsible for keeping the personal health information of individuals safe from theft or loss and any **use** or **disclosure** that is not permitted by the Act.

Decision – When a **custodian** receives a **privacy complaint**, they must process it, investigate it, make a decision about it and then reply to the **applicant**. The response from the custodian is the decision and it should include confirmation of whether a **privacy breach** occurred. In this context, we do not mean a decision made about an individual's health care.

Deemed knowledgeable consent – In order to give consent a person must be knowledgeable about why the information is being **collected** and what it will be used for. A **custodian** can consider that a person is knowledgeable if the required conditions are present which include that it is reasonable in the circumstances for the custodian to believe that the individual knows the purpose of the **collection**, **use** or **disclosure** and knows that they have the right to give or withhold consent. The **Act** says that it is reasonable to believe an individual is knowledgeable if the custodian provides a notice that is likely to come to the individual's attention or the custodian explains the purpose to the individual, unless the custodian should have known that the individual has a limited ability to read or understand the notice.

Deemed refusal – A **custodian** has up to 60 days to respond to an **applicant**'s **privacy complaint** or they must take steps to extend the deadline. If they fail to do either, this is considered to be a failure to respond to the privacy complaint, also known as a "deemed refusal."

Disclosure – When a **custodian** makes **personal health information** available or releases it to another custodian, another organization or another person.

Electronic information system – A computer system that generates, sends, receives, stores or otherwise processes **personal health information**.

Electronic health record – An **electronic information system** that stores **personal health information** in digital form. It integrates data from multiple electronic information systems for the purpose of providing a comprehensive **record** of an individual's personal health information.

Express consent – Express consent requires the **custodian** to have a specific communication with a patient about **consent** for a specific purpose. The patient can give express consent verbally or in writing. To provide consent, an individual must always know the reason for the **collection**, **use** or **disclosure** and the consent must be voluntary. The **Act** requires the custodian to obtain express consent in certain circumstances.

Findings – At the conclusion of every **formal review**, the **Commissioner** will state the facts of the matter. These findings will clarify the issues that the **recommendations** will seek to resolve.

Formal review – If a **privacy complaint** is not closed by an **informal resolution**, it is forwarded to the **Commissioner** to complete the **review**. The Commissioner will consider all relevant factors and submissions provided by all the parties and will conduct research on the issue(s). Once she has considered this information, the Commissioner will make her decision in the form of a **Review Report**.

Identifying information – Information that directly identifies an individual, or information that could reasonably, under the circumstances, be used alone or in combination with other information to identify an individual.

Implied consent - see knowledgeable implied consent.

Informal resolution – A result or outcome of the **review**. Informal resolution normally happens when the investigator helps the parties come to an agreement on actions that resolve the matter, and it no longer needs to go to the **Commissioner** to complete the **formal review**. If the issue(s) under review cannot be resolved informally, the file moves to the Commissioner to complete the formal review. Informal resolution helps to close more files faster than would otherwise be the case if every issue continued to a formal review.

Information and Privacy Commissioner – The head of the **OIPC.** The Commissioner is the only person who can issue **findings** and **recommendations** in response to **privacy complaints**. Formerly known as the "**Review Officer**" which is the title used in the **Act**.

Investigate – The **Act** uses the phrase "conduct a **review**". It refers to the procedures used by the **Commissioner** and **OIPC** staff to determine the **custodian**'s compliance with the Act.

Knowledgeable implied consent – A method for the **custodian** to obtain **consent** where it is assumed or implied by the circumstances and the individual's actions. This type of consent does not require the custodian to have a specific communication with the individual about consent if the conditions for knowledgeable implied consent are there. The **Act** only allows a custodian to rely on knowledgeable implied consent in circumstances directly related to providing health care.

Minimum amount – The principle, also a requirement in the **Act**, that **custodians** limit the **collection**, **use** and **disclosure** of **personal health information** to the minimum amount necessary to achieve the purpose for which it was collected, used or disclosed. In other

words, custodians and healthcare workers are only allowed to have the minimum amount of personal health information they need to know to do their job.

Notification – A communication, usually in writing, from a **custodian** to an individual to inform the individual about the unauthorized **collection**, **use** or **disclosure** of the individual's **personal health information**. If a custodian discovers that a breach of personal health information (also known as a **privacy breach**) has the potential to cause harm or embarrassment to the individual, the custodian is required to notify the individual at the first reasonable opportunity. When the custodian discovers that a breach of personal health information does not have the potential to cause harm or embarrassment to the individual, they only need to notify the **Commissioner** and not the individual.

OIPC – Short for Office of the Information and Privacy Commissioner.

Oversight – The responsibility and power to **investigate** and assess a **custodian**'s compliance with the **Act**. The **Information and Privacy Commissioner** provides oversight of the Act.

Personal health information – Identifying information about an individual's health or health care, whether living or deceased, in both recorded and unrecorded forms.

PHIA - Short for Personal Health Information Act.

Privacy breach – An incident where **personal health information** is **collected**, **retained**, **used**, **disclosed** or disposed of in ways that do not comply with the requirements of the **Act**.

Privacy complaint – A written communication from the **complainant** to the **custodian** conveying the complainant's concerns that the custodian has not followed the privacy rules required in the **Act** in relation to the individual's own **personal health information**. Custodians must **investigate** and respond to privacy complaints within 60 days (or less depending on their policy) by issuing a **decision**. An individual must file a privacy complaint with a custodian, and wait for the decision, before they can file a **review request** with the **Commissioner**.

Reasonable – Not excessive or extreme, but feasible, practical and fair.

Recommendations – When a **review request** results in a **review report**, in addition to the **findings**, the **Commissioner** will make whatever recommendation(s) considered appropriate to solve the issues identified in the findings. It is up to the **custodian** to determine whether or not to accept the recommendations.

Record – The thing that holds the **personal health information** about an **applicant**.

Record of user activity – For any **electronic information systems** they use, **custodians** must create or maintain a record of user activity which can be requested under the **Act** by **applicants** at no charge. A record of user activity shows when and which users of the electronic information system have viewed or accessed the applicant's **personal health** information.

Regulations – Provides more detailed rules on the how to practically apply the Personal Health Information Act.

Request for Review - See review request.

Review – A short way to refer to the **review request** process.

Review Officer – This was the title formerly used by the **Information and Privacy Commissioner** and that is used in the **Act**.

Review Report - This is the formal document, which may be issued privately or publicly, written by the **Commissioner** at the conclusion of the **formal review**, which includes background, findings and recommendations.

Review request - A formal, written document that identifies the concerns with the **decision** made by a **custodian** in response to a **privacy complaint** that the **applicant** wants the **Commissioner** to **investigate**. A **request for review** can be made on the **OIPC**'s Privacy Complaint Form, but it can also be in a letter so long as the letter provides the information necessary to proceed, such as: the details of the privacy issue or concern, the name of the custodian that the privacy complaint was submitted to, and a copy of the custodian's response to the privacy complaint. Formally, it is called a **request for review** or **appeal**.

Retention – The length of time a **custodian** stores both electronic and paper **personal health information record**s before securely destroying them. **Custodians** must have a retention schedule.

RUA – Short for **record of user activity**.

Third party – Any person or group of people who is not the **applicant** or the **custodian**.

Use - Reference to or manipulation of personal health information by the custodian or an **agent** of the custodian that is keeping the information. Use includes viewing personal health information but does not include **disclosure** of personal health information.

QUESTIONS?

This guide was prepared by the Office of the Information and Privacy Commissioner for Nova Scotia. Whether you are an applicant, custodian, public body, municipality or a third party, we encourage you to contact us if you have any questions about the privacy complaint process in Nova Scotia.

> Phone: 902-424-4684 Toll Free (NS): 1-866-243-1564 TDD/TTY: 1-800-855-0511 Fax: 902-424-8303 Email: oipcns@novascotia.ca