

# **Operational Review of the *Personal Health Information Protection and Access Act***

**Discussion Paper**

**Department of Health  
January 2015**

Department Health

Operational Review of the *Personal Health Information Protection and Access Act*

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## Message from the Minister of Health

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Thank you for taking the time to read this discussion paper and for participating in this operational review of the Personal Health Information Privacy and Access Act (PHIPAA).

New Brunswickers have the right to access and request correction of their personal health information. At the same time, we need to make sure their personal health information is protected from misuse. Information about a person's health history is one of the most sensitive forms of information that exist and safeguarding that data is a responsibility that the Department of Health and New Brunswick's health-care partners and providers take seriously.

As part of the Act's provisions, PHIPAA must be reviewed four years after coming into force to ensure that this important piece of legislation remains effective and that it is administered in a way that continues to serve the needs of citizens. As part of our government's commitment to openness and transparency, we are seeking feedback from the public and stakeholders about how personal health information is shared and what impacts PHIPAA has had on the lives of individuals and our health-care system.

This discussion paper has been created to help stimulate the conversation about PHIPAA and the way it functions. It reflects challenges and questions that have been informally brought to the Department's attention over the last four years. However, the Department is open to any and all comments it might receive related to PHIPAA. I encourage you to read this discussion paper and send a submission to the Department.

Your contribution will provide valuable insight about PHIPAA's operations and is greatly appreciated.

Sincerely,

A handwritten signature in black ink that reads "V. Boudreau".

**Hon. Victor Boudreau**  
Minister of Health

# Introduction

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The Minister of Health, as the minister responsible for the *Personal Health Information Privacy and Access Act* (PHIPAA), is required by law to carry out an operational review of the Act that must be tabled in the Legislative Assembly by August 30, 2015. This review will examine how well the Act is functioning and what issues have been identified in its operation.

Input from the public and stakeholders is necessary for the review to be effective and this document has been created to stimulate discussion by providing background information on PHIPAA, its operations over the last four years and provides some suggestions for consideration by examining some aspects of PHIPAA that have been topics of discussion with departmental stakeholders over the last four years.

This discussion paper does not fully present the legislative provisions of PHIPAA. The Act may be read in its entirety on the Government of New Brunswick [website](#). The regulations which support the Act can also be found [online](#).

If you have any views on PHIPAA's operation or general thoughts about how personal health information is protected or shared, we welcome your feedback. Submissions can either be sent electronically or through regular mail. Please do not include any information about your personal health or that of your loved ones in electronic submissions.

Electronic submissions can be sent by e-mail to [healthconsultationsante@gnb.ca](mailto:healthconsultationsante@gnb.ca).

The mailing address is:

PHIPAA Legislative Review  
PO Box 5100  
Fredericton NB E3B 5G8

**All submissions should be received by March 31, 2015.**

## Your privacy is important

Please do not provide personal health information as part of this consultation. However, any personal health information or personal information provided is subject to PHIPAA and the *Right to Information and Protection of Privacy Act*. All of the information provided will be used to evaluate how PHIPAA is working and may be used to develop future legislative amendments.

It is important that your views and ideas are heard and understood, so you may be contacted to clarify your submission or to provide you with feedback. Your name will not be placed on any lists, including mailing lists, which are not related to this review.

# What Is Personal Health Information?

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Each day, thousands of New Brunswickers interact with our province's health-care providers. Whether they are seeking care from their pharmacists, family doctors or nurse practitioners; having routine blood tests done at the hospital; or attending a physiotherapy appointment; New Brunswickers share information about their personal health with health-care providers who use it to help patients get the care they need.

Information specific to an individual's health which could identify them is known as **personal health information**, including information that is oral, written or photographed. This information could be about someone's mental or physical health, family history or health-care history. This includes genetic information, registration information including Medicare numbers and date of birth, information about payments or eligibility for health care or health-care coverage, information about organ or tissue donation, test results, or information that identifies a patient's health-care provider or substitute decision-maker.

## Why Protect Personal Health Information in Legislation?

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Health information is considered to be one of the most sensitive forms of personal information. In addition to being used for patient care, it is sometimes used for financial reimbursement, medical education, research, social services, quality assurance, risk management, public health regulation and surveillance, health planning and policy development.

Technology is evolving and becoming more portable at an exponential rate while information becomes increasingly accessible. As a result, jurisdictions across Canada have enacted legislation to protect the privacy, confidentiality and security of personal health information.

In New Brunswick, the One Patient One Record concept and the development of the electronic health record also contributed to the need for PHIPAA. If every New Brunswicker is to have a single, electronic health record then rules are required to prevent unnecessary intrusions of privacy.

# How PHIPAA Protects Personal Health Information

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In 2010, the Government of New Brunswick enacted the *Personal Health Information Privacy and Access Act* (PHIPAA). PHIPAA provides a set of rules to protect the confidentiality of personal health information and the privacy of the individual to whom it relates.

PHIPAA does not apply unless the personal health information is being collected or used to provide health-care services, the planning and management of the health-care system or for delivering a government program or service. The legislation specifically excludes personal health information collected by employers (both public and private); insurance companies; regulatory bodies for health-care providers.

## Individual Rights and Custodial Responsibilities

Under PHIPAA, New Brunswickers have the right to be informed about why their personal health information is being collected, how it will be used and to whom it will be disclosed. Consent to collect, use and disclose one's personal health information can be withheld or withdrawn at any time, except in specific circumstances that have been set out in the Act. PHIPAA also provides New Brunswickers with the right to designate another person to make decisions about their personal health information and request to examine or receive a copy of their information. New Brunswickers may also request a correction of their personal health information once they have examined it.

PHIPAA establishes the rights of individuals and responsibilities of custodians when personal health information is lost, stolen or otherwise inappropriately destroyed, disclosed or accessed by an unauthorized person. If this happens and it is reasonable to conclude that the release of this information could be harmful or identifying, New Brunswickers have the right to be informed this **breach** of the Act has occurred.

When a breach occurs, PHIPAA provides New Brunswickers with the right to make a complaint to the **Access to Information and Privacy Commissioner**. They can also complain to the commissioner if they disagree when a request to access or correct their personal health information has been refused. More information about breaches of the Act and the role of Commissioner can be found further in this document.

New Brunswickers also have the right to refuse to provide their Medicare number to any person or organization that collects it as identification for a non-health related purpose.

The Act also sets out a legal framework for how personal health information is handled to make sure that these rights are respected.

The people and organizations that collect, maintain or use personal health information, to provide health care to New Brunswickers or for the planning and management of the health-care system and other government services, are called **custodians** under PHIPAA. Examples of custodians include:

- the Department of Health;
- regional health authorities;
- hospitals;
- health-care providers such as physicians, dentists, nurses, pharmacists;
- government departments and Crown Corporations;
- WorkSafe NB; and
- ambulance operators.

An **information manager** is a special type of custodian who manages personal health information on behalf of another custodian. Information managers process, store, retrieve, archive, dispose and de-identify or otherwise transform personal health information on behalf of another custodian. Examples of information managers include the information technology firms or document disposal companies. Information managers have the same responsibilities as other organizations under PHIPAA and are also required to sign a formal, written agreement with the custodian for whom they are providing the service explaining how they will secure and protect personal health information they hold.

Individuals or organizations working on behalf of a custodian are known as **agents** with respect to the collection, use or disclosure of personal health information. Examples of agents include employees of a custodian such as receptionists or assistants who work for physicians or in hospitals, contract employees and volunteers or organizations that provide health-care services on behalf of an employer. Agents are required to comply with the Act and sign a written agreement with a custodian to this effect.

PHIPAA sets out several rules for custodians to follow. For example, every custodian must:

- obtain consent to collect, use or disclose personal health information except in a limited number of situations such as a health emergency;
- only collect, use and disclose the minimum amount of information necessary to provide the service or benefit being offered;
- inform the patient about how they plan to use and disclose his or her information and make sure there are policies in place to ensure that personal health information is used and disclosed in accordance with the Act;
- put policies and practices in place that will protect the integrity, confidentiality, availability, security and accuracy of personal health information;
- make sure that information managers and agents are properly protecting the personal health information that they use and process;
- notify the Access to Information and Privacy Commissioner if identifiable personal health information is stolen, lost or used contrary to the Act.

## Breaches of PHIPPA: Management and Frequency

*What I may see or hear in the course of the treatment or even outside of the treatment in regard to the life of men, which on no account one must spread abroad, I will keep to myself holding such things shameful to be spoken about.*

*Hippocratic Oath, 4<sup>th</sup> Century B.C.E.*

Since the time of antiquity, health professionals have considered that patient information is to be held confidentially and only shared as required to provide care specific to the patient in question. This is still a true statement in 21st Century New Brunswick where health-care providers are bound by PHIPAA and their own codes of ethics. On its website, the Nurses Association of New Brunswick has published a Code of Ethics for Registered Nurses developed by the Canadian Nurses Association which states: “Nurses recognize the importance of privacy and confidentiality and safeguard personal, family and community information obtained in the context of a professional relationship.”<sup>1</sup>

In fact, the disclosure of personal health information “attracted the most interest among those who reported”<sup>2</sup> to the New Brunswick Task Force on Personal Health Information in 2007. In their final report providing recommendations to the Minister of Health on new legislation respecting personal health information in the province (this legislation would be introduced and approved in 2009 as PHIPAA), task force co-chairs Jean-Guy Finn and Kevin Malone noted “genuine concerns that the personal and therapeutic relationship between the patient and the health care professional might be eroded by fear that PHI (personal health information) could be released improperly to other parties without consent.”<sup>3</sup>

Breaches can and do happen, however. In its annual report, the Office of the Access to Information and Privacy Commissioner reported that it opened 153 files with respect to PHIPAA in 2011-12, including 28 reported breaches of privacy, 26 complaints from the public for breach of privacy, and seven access complaints.<sup>4</sup>

“A **privacy breach** occurs when there is improper collection, use or disclosure of personal health information in contravention of the *Personal Health Information Privacy and Access Act*. Examples of privacy breaches include stolen computers containing personal health information, lost mail, misplaced files or unauthorized access to personal health information.”<sup>5</sup>

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<sup>1</sup> Canadian Nurses Association. “Code of Ethics for Registered Nurses.” *New Brunswick Nurses Association – Professional Practice*. 2008 Centennial Edition. Web. 3 Oct. 2014.

<sup>2</sup> New Brunswick. Department of Health. *Personal Health Information in New Brunswick: Balancing Privacy Rights and Access Requirements*, p. 37. DH, 2007. Print.

<sup>3</sup> Ibid.

<sup>4</sup> New Brunswick. Office of the Access to Information and Privacy Commissioner. *Annual Report 2011/2012*, p.11. Fredericton: Legislative Assembly. August 2013. Web. 3 Oct. 2014.

<sup>5</sup> New Brunswick. Office of the Access to Information and Privacy Commissioner. “Reporting of Privacy Breach.” *Forms and Checklists – Office of the Access to Information and Privacy Commissioner* – New Brunswick. December 2010. Web. 3 Oct. 2014.

In an effort to “gauge the effectiveness of practices put in place to protect the health-care information belonging to New Brunswickers, and to provide guidance on how they could be improved,”<sup>6</sup> Access to Information and Privacy Commissioner Anne E. Bertrand requested custodians of personal health information report all types of breaches to her office regardless of their nature or size. She found these breaches of privacy were largely caused by inattention and human error as opposed to people looking at another individual’s personal health information without authorization. “Our investigations revealed that many errors took place when handling sensitive information stored on electronic and portable devices,” she wrote.<sup>7</sup> Two of the five reports investigating breaches of PHIPAA that have been published on the Commissioner’s website document the actions of individuals who were satisfying their curiosity by intentionally looking at the personal health information of others. Two reports pertain to personal health information stored on lost portable electronic devices and one pertains to inattention and human error.<sup>8</sup>

## Role of the Access to Information and Privacy Commissioner

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The position of **Access to Information and Privacy Commissioner** was created in 2010 when PHIPAA and the *Right to Information and Protection of Privacy Act* came into force.

The commissioner oversees the rules governing both Acts. As it pertains to PHIPAA, the commissioner receives, reviews, investigates and reports on complaints brought under the Act, monitors how the Act is administered, reviews privacy impact assessments conducted by custodians that are public bodies, informs the public about the Act, promotes best practices and provides advice to custodians, makes recommendations with regard to the Act, and reviews any matter referred to the commissioner by the Executive Council.

The role is quasi-judicial in nature as the commissioner is an independent officer of the Legislative Assembly with all of the powers, privileges and immunities conferred on a commissioner under the *Inquiries Act*. The commissioner conducts investigations confidentially, has the right to examine and copy any record in the custody of a custodian, is protected from legal action and is required to make an annual report to the Legislative Assembly on the performance of his/her duties or exercise of his/her powers under the act. The commissioner does not have order-making authority.

### Consultation of the Commissioner

While PHIPAA requires this operational review to be undertaken by the Minister, the Department of Health feels it is imperative the commissioner be an active participant in the process. The Department will ensure the commissioner is given ample opportunity to provide feedback to the process.

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<sup>6</sup> New Brunswick. Office of the Access to Information and Privacy Commissioner. *Annual Report 2011/2012*, p.19–20. Fredericton: Legislative Assembly. August 2013. Web. 3 Oct. 2014.

<sup>7</sup> Ibid.

<sup>8</sup> New Brunswick. Office of the Access to Information and Privacy Commissioner. *Reports of the Commissioner’s Findings – Office of the Access to Information and Privacy Commissioner – New Brunswick*. Web. 10 Oct. 2014

# Discussion Topics

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In anticipation of the operational review, the Department of Health has been informally compiling a list of questions and issues that have arisen since PHIPAA was enacted in 2010. Generally, these items are matters that require clarification to make the administration of the Act more efficient or effective. A similar list has been provided to the Department by the Commissioner.

However three recurring topics require further examination:

- the definition of custodian under the Act;
- consent, both expressed and implied; and
- privacy impact assessments.

## Definition of Custodian

As stated previously, PHIPAA sets out the responsibilities of those who collect, maintain or use the personal health information of New Brunswickers. These individuals are called custodians, information managers or agents.

The definition of “custodian” has been the subject of many questions over the last four years.

PHIPAA defines a custodian as “an individual or organization that collects maintains or uses personal health information for the purpose of providing or assisting in the provision of health care or treatment or the planning and managing of the health care system or delivering a government program or service...”<sup>9</sup> The legislation then goes on to list a variety of individuals or organizations that are considered custodians. This includes public bodies, health care providers, the Minister of Health, health partner organizations such as the regional health authorities and Ambulance New Brunswick, information managers, health care facilities such as hospitals and clinics, research data centres , researchers and nursing homes.

### Co-custodians

In practice, people and organizations who are designated as a custodian under PHIPAA often work together to deliver a program or service. In these cases, it can be difficult to determine who is the ultimate custodian of the personal health information being handled. PHIPAA does not recognize this phenomenon in its provisions which leaves a question as to how custodians are intended to respond to these situations.

### The ‘Russian Doll’ Problem

The structure of the Act has also lead to a “Russian doll” problem where one custodian is functioning within a larger structure that is also deemed a custodian under the Act. For example, health-care facilities are designated as custodians inside PHIPAA. However, hospitals and community health centres fall under the responsibility of a regional health authority (RHA), which is also considered to be a custodian. As all public health-care facilities in New Brunswick are part of one of the province’s two regional health authorities, the question has arisen as to whether the dual designation is necessary.

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<sup>9</sup> Personal Health Information Privacy and Access Act. *Acts and Regulations of New Brunswick*, P-7.05. New Brunswick. *Office of the Attorney General*. 2014. Web. 21. Oct. 2014.

## Information Managers

Information managers also hold a dual designation under PHIPAA that has been questioned as to its necessity. An information manager is a special type of custodian who manages personal health information on behalf of another custodian. Information managers process, store, retrieve, archive, dispose and de-identify, or otherwise transform personal health information on behalf of another custodian. Information managers are, for example, information technology firms or document disposal companies. Information managers in New Brunswick have the same responsibilities as other custodians under PHIPAA and are also required to a formal, written agreement with the custodian for whom they are providing the service explaining how they will secure and protect personal health information they hold.

In other Canadian jurisdictions, information managers are not custodians. Instead, they are recognized as a person or organization working on behalf of a custodian who is obligated to protect the personal health information it manages according to the terms of its contract with the custodian who is responsible for the integrity and protection of the data.

## Are All Custodians the Same?

PHIPAA recognizes all custodians of personal health information as equals within the law, excepting that public bodies are held to some additional requirements. Whether the custodian is the Minister of Health, an independent researcher, or an information manager, each custodian has generally the same rights (e.g., to disclose personal health information they receive, to another person as the Act may allow) and the same responsibilities (e.g., to safeguard the information) but some stakeholders have wondered whether this is appropriate. For example, if personal health information is disclosed by a hospital to a researcher to complete a study, should the researcher have the right to further disclose that information to another researcher?

## Special Custodians

PHIPAA doesn't make provisions for recognizing long-standing relationships between custodians or provisions for custodians with robust privacy policies and practices. Some custodians have expressed a concern that privacy assessment process will become less meaningful, if they are felt to be duplicative or redundant.

## Knowledgeable Consent: Implied and Expressed

PHIPAA permits a custodian to do anything with personal health information as long as it has the **knowledgeable consent** of the person to whom the information relates. This consent can be withdrawn at any time except in limited cases outlined in the Act.

If informed consent has not been obtained, then the custodian can only collect, use or disclose personal health information if and as specifically permitted to do so by the Act.

There are two types of consent: implied or expressed.

Once personal health information has been provided to a custodian, PHIPAA states that custodian is entitled to assume, unless it's not reasonable in the circumstances to do so, that they have the individual's **implied consent** to share it with other custodians or persons to provide care.

Consent to the collection, use or disclosure of personal health information is **expressed** if the custodian asks the individual to provide the information; the individual knows how the information will be collected, used or disclosed; and provides that permission in writing.

### An Example of Expressed Consent

A local hospital foundation is raising money to buy a new piece of equipment for the hospital and seeks out a patient to tell their story as an example of how the new machine would have improved their health-care experience. The foundation is required to seek out this patient's expressed consent in writing before it is able to use the story to support its campaign.

### An Example of Implied Consent

A family doctor wishes to refer a patient to an orthopedist because she suspects her patient may require a knee replacement. The patient knows the referral is being made. PHIPAA permits the doctor to assume she has her patient's implied consent to disclose only as much personal health information as the specialist needs to provide care to the patient.

In addition, if a custodian has posted or provided a notice of how they plan to use personal health information in a place where it is likely to come to an individual's attention, a custodian is allowed to assume in good faith that they have an individual's consent to collect, use and disclose their data.

Managing patient consent issues can be a challenge for custodians, especially as information technology continues to develop. Periodically, New Brunswick custodians have encountered situations in which personal health information they have collected for

one purpose could be used for another purpose, but consent to do so would need to be sought retroactively.

Provisions in the Act to manage conditional consent and consent directives also lack clarity. It is clear that an individual has the right to withdraw consent or place conditions upon the use of their information, but the legislation lacks direction for custodians on how these requests should be managed.

## Privacy Impact Assessments

PHIPAA requires public bodies to conduct a **privacy impact assessment** (PIA) when a new means of collecting, using or disclosing personal health information, or a change to this means, is being considered. PIAs are also necessary to create or change an integrated service, program or activity, when a personal health information system or communications technology is being created or modified, or when data matching is being performed. These PIAs may be reviewed by the commissioner.

Across the country, legislative provisions for PIAs with respect to the protection of personal health information are inconsistent. While all of the jurisdictions that have statutes specific to personal health information encourage PIAs in certain circumstances, they are only required by law in British Columbia, Alberta, and New Brunswick. Legislation in Prince Edward Island and the Northwest Territories includes provisions for PIAs, but these statutes have not yet been proclaimed.

Section 69 of British Columbia's *Freedom of Information and Protection of Privacy Act* requires PIAs to be conducted and established policies in that province ensure they occur for any new legislation, information system or policy.<sup>10</sup> Alberta's *Health Information Act* is more inclusive. Section 64(1) of that Act states that "each custodian must prepare a privacy impact assessment that describes how proposed administrative practices and information systems relating to the collection, use and disclosure of individually identifying health information may affect the privacy of the individual who is the subject of the information."<sup>11</sup> PIA requirements in New Brunswick are broader still, but are specific to public bodies or custodians prescribed by regulation. Under PHIPAA, public bodies must conduct PIAs when any new or modified means of collecting, using or disclosing personal health information, is being considered.<sup>12</sup>

The purpose of a PIA is to examine the proposed use of the data and determine whether it will be used in accordance with PHIPAA and that appropriate business processes have been developed to protect the information.

However, many questions about PIAs have been posed by New Brunswick's custodians because the Act does not define or establish guidelines for PIAs. As well, custodians find it onerous to conduct PIAs for every new collection, use, or disclosure of personal health information and every change in these methods. The data matching sections are also unclear.

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<sup>10</sup> *Freedom of Information and Protection of Privacy Act. Revised Statutes of British Columbia 1996*, 165. British Columbia. Queen's Printer. 2014. Web. 15 Oct. 2014.

<sup>11</sup> *Health Information Act. Revised Statutes of Alberta 2000, H-5*. Alberta. Queen's Printer. 2014. Web. 15 Oct. 2014.

<sup>12</sup> *Personal Health Information Privacy and Access Act. Acts and Regulations of New Brunswick*, P-7.05. New Brunswick. *Office of the Attorney General*. 2014. Web. 15. Oct. 2014.

# Conclusion

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As stated in previous sections, the Department of Health has been informally collecting feedback from stakeholders and noting potential improvements to PHIPAA since it was enacted in 2010 in preparation for this operational review. Generally, these items are matters that require clarification to make the administration of the Act more efficient or effective. A similar list has been provided to the Department by the Commissioner.

Numerous questions and comments have been received about the roles and responsibilities of custodians, consent, and PIAs, which is why these topics have been outlined in detail in this discussion paper.

The Department of Health is interested in feedback about PHIPAA from stakeholders, patients and other New Brunswickers about how PHIPAA impacts their lives and their professional responsibilities and how it can be improved. A series of questions has been developed to assist anyone who wishes to make a submission, but feedback on all aspects of PHIPAA will be gratefully received. All of the information provided will be used to evaluate PHIPAA's operation and may be used to develop future legislative amendments.

Submissions can either be sent electronically or through regular mail. Please do not include any information about your personal health or that of your loved ones in electronic submissions.

Electronic submissions can be sent by e-mail to [healthconsultationsante@gnb.ca](mailto:healthconsultationsante@gnb.ca).

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**All submissions should be received by March 31, 2015.**

## Questions for Discussion

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1. Generally, do you believe that PHIPAA has enhanced individual privacy and clarified rules concerning access to personal health information? Why or why not?
2. Health-care providers have important responsibilities under PHIPAA, as custodians or agents. How has PHIPAA changed the way providers use, collect or disclose personal health information? Do you think providers understand their responsibilities?
3. What has been your experience with accessing or correcting personal health information?
4. Have you ever questioned whether to seek health-care services or actually refused to share relevant personal health information due to a privacy concern?
5. The definition of a custodian under PHIPAA includes regional health authorities, health-care facilities and health-care providers. How have custodians managed the concept of a custodian working within/for another custodian? Does this concept enhance individual privacy?
6. Is an information manager an agent of a custodian or a custodian? Do you believe that a legal agreement between an information manager and a custodian adequately protects privacy or is the dual designation appropriate?
7. How have custodians managed conditional consents and consent directives? Should processes and policies developed to manage this issue be codified?
8. PHIPAA requires a PIA for every new collection, use or disclosure of personal health information. This sometimes presents a challenge for custodians. What changes would you like to see made to the Act's provisions with respect to PIAs?
9. As an officer of the Legislative Assembly, the Access to Information and Privacy Commissioner is independent from the Government of New Brunswick. Do you have any suggestions for changes to the role of the Office of the Access to Information and Privacy Commissioner?