

# Personal Health Information Legislation for Nova Scotia

## Discussion Paper



Responses due by  
November 1, 2008

## TELL US WHAT YOU THINK

You will find the Discussion Document *Personal Health Information for Nova Scotia* online at [www.gov.ns.ca/health/](http://www.gov.ns.ca/health/).

Each section of the Discussion Paper includes a discussion of the issues and proposed legislative provisions. At the end of the section we identify a number of issues and ask questions in order to seek feedback from you.

We invite you to respond to the questions, or to contact us with any views you may have about the benefits of and issues associated with personal health information legislation.

**Online:** You will find the Discussion Document online at [www.gov.ns.ca/health/](http://www.gov.ns.ca/health/). You can provide answers and comments in the space provided after each question in the document.

**E-mail:** A Questions document which contains all the questions from the Discussion Document is available at [www.gov.ns.ca/health/](http://www.gov.ns.ca/health/). Responses and comments may be e-mailed to the *Personal Health Information Act* project at [phia@gov.ns.ca](mailto:phia@gov.ns.ca)

**Mail:** You can mail your responses to:

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## **PART 1 INTRODUCTION**

### **1.1 About the *Personal Health Information Act***

The Department of Health has developed this Discussion Paper to solicit feedback on the potential *Personal Health Information Act*. This Act would set out the legislative rules for collection, use, disclosure, retention and destruction of personal health information. It is intended to achieve the following objectives:

1. to create a privacy framework that is reasonable to apply and responsive to the current and future realities of health care delivery in Nova Scotia, including electronic health records;
2. to strike a balance between ensuring comprehensive protection of personal health information and allowing the health care sector to manage information appropriately to deliver and improve health care services;
3. to address gaps in privacy coverage and ensure the entire health care sector in the province operates under the same set of rules;
4. to enhance the accountability of individuals who collect, use and disclose personal health information by establishing and enhancing requirements for policies and practices for the protection of personal health information;
5. to provide individuals with the right to receive access to and request correction of personal health information about themselves;
6. to establish and enhance rules for collection, use and disclosure of personal health information in research; and
7. to serve as a solid foundation from which policies, guidelines and standards related to personal health information will flow.

### **1.2 About this document**

Each section of the Discussion Paper includes a discussion of the issues and proposed legislative provisions. At the end of the section we identify a number of issues and ask questions in order to seek feedback from you. We invite you to respond with any views you may have about the benefits of and issues associated with personal health information legislation.

**All potential provisions of the Act are not discussed in this paper - this paper covers the major policy issues which will form the framework of the legislation.**

The majority of the proposed legislative provisions are consistent with the *Pan-Canadian Health Information Privacy and Confidentiality Framework* ("Pan-Canadian Framework" - see page 3), and are based on the Ontario *Personal Health Information Protection Act*. The proposed provisions are intended to provide you with more detail on possible direction for each issue.

Please note that your submission will be considered a public document. It is subject to the provisions of the Nova Scotia *Freedom of Information and Protection of Privacy Act* and may be subject to disclosure.

## **PART 2. BACKGROUND**

### **2.1 Privacy legislation in Canada**

Since the late 1970s, provinces have enacted legislation to protect personal information held by public bodies<sup>1</sup>. Since that time, provinces and the federal government have introduced legislation that governs the collection, use, disclosure and retention of personal information in both public and private organizations.

Every province has legislation similar to Nova Scotia's *Freedom of Information and Protection of Privacy Act (FOIPOP Act)*, that applies only to information held by public bodies. In the past 11 years, two new areas of information governance have emerged:

- protection of information held by the private sector; and
- legislation specific to protection and use of personal health information.

A list of these two streams of legislation is attached as Appendix A.

### **2.2 Protection of personal health information in current Nova Scotia legislation**

In Nova Scotia, the *FOIPOP Act* regulates the access to and privacy of personal information held by public bodies, including the provincial government. Nova Scotia does not have one specific piece of legislation in place to protect the privacy of personal health information. Instead, personal health information is managed according to over 40 different pieces of legislation, including the *Hospitals Act*, the *Health Protection Act* and the *FOIPOP Act*.

Although the current legislation does provide protection and accountability, the rules are not always consistent. Additionally, some provider groups (e.g. physicians, dentists, optometrists) are covered by federal privacy legislation (the *Personal Information Protection and Electronic Documents Act*).

### **2.3 Pan-Canadian Health Information Privacy and Confidentiality Framework**

In 2003 the Federal/Provincial/Territorial Conference of Deputy Ministers of Health tasked its Advisory Committee on Information and Emerging Technologies to develop a *Pan-Canadian Health Information Privacy and Confidentiality Framework*. The objective of the *Pan-Canadian Framework* was to recommend a harmonized set of core provisions for the collection, use and disclosure of personal health information in both the publicly and privately funded health care sectors. The *Pan-Canadian Framework* recommended protecting the privacy and confidentiality of individuals with respect to their health information, while enabling the flow of information where appropriate to support effective health care, the management of the health system and an interoperable electronic health record.

In January 2005 the *Pan-Canadian Framework* was endorsed by the Federal/Provincial/Territorial Conference of Deputy Ministers of Health, including the Nova Scotia Deputy Minister, Department of Health.<sup>2</sup>

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<sup>1</sup> Public bodies include the provincial government, district health authorities, school boards and universities

<sup>2</sup> Saskatchewan and Quebec did not endorse the document.

The text of the Pan-Canadian Framework is available at: [http://www.hc-sc.gc.ca/hcs-sss/pubs/ehealth-esante/2005-pancanad-priv/index\\_e.html#intro](http://www.hc-sc.gc.ca/hcs-sss/pubs/ehealth-esante/2005-pancanad-priv/index_e.html#intro)

## **2.4 Canadian Standards Association *Model Code***

The development of privacy legislation in Canada is often guided by key purposes and principles. In 1996 the Canadian Standards Association (CSA) developed a Model Code for the Protection of Personal Information, that is the foundation for the federal *Personal Information Protection and Electronic Documents Act*. Other Canadian jurisdictions have incorporated the principles in their information legislation, and they are the basis for many privacy policies.

The Code is based on ten Fair Information Principles:

1. Accountability
2. Identifying Purposes
3. Consent
4. Limiting Collection
5. Limiting Use, Disclosure and Retention
6. Accuracy
7. Safeguards
8. Openness
9. Individual Access
10. Challenging Compliance

See Appendix B for more information on the CSA Fair Information Principles.

## **2.5 The electronic health record**

Nova Scotia is well underway in the development of the province's electronic health record system. Called SHARe (Secure Health Access Record), the system will create an electronic health record for all Nova Scotians. The record will contain patients' up-to-date health information to support decision-making and case management by health-care providers. The first phase of the SHARe system will be completed by Dec. 31, 2009.

Although the current legislative and policy framework does not make it impossible to implement an electronic health record, there are significant issues with the current framework: the rules for providers, records and facilities are not consistent and the current legislative framework was developed in a health care system that ran on paper records.

Comprehensive personal health information legislation is a key element in the development of the electronic health record.

## **PART 3. THE PERSONAL HEALTH INFORMATION ACT**

### **3.1 Purpose of the legislation**

The legislation has many objectives (see Part 1.1) but the major purpose is to provide a framework that strikes a balance between ensuring comprehensive protection of personal health information and allowing the health care sector to manage information appropriately to deliver and improve health care services.

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#### **PROPOSED PROVISION**

1. The purpose of this Act is to govern the collection, use, disclosure, retention and destruction of personal health information in a manner that recognizes both the right of individuals to protect their personal health information, and the need of health information custodians to collect, use and disclose personal health information to provide, support and manage health care.

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#### **Tell us what you think**

- Q1 Is this an appropriate statement of the purpose of the legislation? Why or why not?

### **3.2 Scope of the legislation**

The scope of personal health information legislation is determined by defining two areas:

1. those to whom the legislation applies; and
2. what information is covered.

#### **a. “Who” - health information custodians**

##### The Circle of Care

Personal health information is intended to improve the flow of information to support patient care and treatment. The principle is that the information will follow the individual where s/he goes in the healthcare system.

This is traditionally known as the “circle of care”. The Pan-Canadian Framework defines the circle of care as “the individuals and activities directly related to the health care and treatment of an individual”. This may include individuals and activities that provide care (e.g. hospitals, doctors, dentists) and individuals and activities that support care (e.g. funding bodies).

The circle of care supports the care and treatment of the individual by allowing information to flow under different rules than the rules for those outside the circle. By creating a circle of care, it would not matter whether care and treatment was provided in the private or public sector, or that services were publicly insured or not insured – the

requirements in the legislation would be based on the fact that they provide or support care to the individual.

#### “Health Information Custodians”

In Canada, health information legislation has created health information “custodians” or “trustees”<sup>3</sup> who are covered under the rules applying to the circle of care. For this paper, we will use the term “custodian”.

A “custodian” is generally defined as *“one who guards and protects or maintains”*. This concept is a good fit for the role of those individuals or organizations that collect our personal health information. Custodians of personal health information have certain responsibilities to the individuals whose information they hold. They also have certain rights that non-custodians would not have, and may exercise those rights to provide or support care to their patients, clients or residents.

It is difficult to develop a list of health information custodians that will cover every individual’s potential encounter with the health care. However, for clarity and consistency, it is important that individuals and the partners in the health care system understand which rules are in place for each type of care provider.

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#### **PROPOSED PROVISION**

1. **“Health information custodian”** means an individual or organization described in the following provision who has custody or control of personal health information as a result of or in connection with performing the person’s or organization’s powers or duties or the work described in the paragraph, if any:
  - (a) regulated health professionals who provide health care [see below];
  - (b) the Minister and the Department of Health;
  - (c) the Chief Medical Examiner;
  - (d) the District Health Authorities;
  - (e) the IWK Health Centre;
  - (f) the Psychiatric Review Board;
  - (g) any organization that provides emergency health care services and is funded by the Department of Health;
  - (h) a pharmacy licensed under the *Pharmacy Act*;
  - (i) any continuing care facility licensed by the Department of Health under the *Homes for Special Care Act*, or any continuing care facility approved by the Department of Health;

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<sup>3</sup> Alberta and Ontario health information legislation uses the term “custodian,” while the Manitoba and Saskatchewan legislation uses “trustee”.

- (j) any other individual or organization prescribed by Regulation as a health information custodian.

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“Regulated Health Professionals” are those providers who are governed by provincial legislation specific to their profession, and who have a college or other regulatory body to whom they are accountable for their professional activities and conduct. Regulated health professionals are only covered by the health information legislation if they are providing health care to an individual.

The current regulated health professionals<sup>4</sup> are:

- |                                  |                           |
|----------------------------------|---------------------------|
| Chiropractors                    | Occupational Therapists   |
| Dental Assistants                | Opticians                 |
| Dental Hygienists                | Optometrists              |
| Dental Technicians               | Pharmacists               |
| Dentists                         | Physicians                |
| Denturists                       | Physiotherapists          |
| Dieticians                       | Psychologists             |
| Licensed Practical Nurses        | Registered Nurses         |
| Medical Laboratory Technologists | Respiratory Technologists |
| Medical Radiation Technologists  |                           |

Consideration may also be given to including other organizations or professions that have custody of and control over personal health information within the scope of the legislation. For example, the Workers’ Compensation Board, schools, and other government departments (e.g. Department of Health Promotion and Protection, Department of Community Services, Department of Justice) may also have custody of and control over personal health information, although they may not be part of the traditional health care system and may not provide “health care” as it is defined by this Act.

There will also be provisions for agents of health information custodians, and for information managers.

**Tell us what you think**

- Q2 Is the provision describing “health information custodians” appropriate? Why or why not?
- Q3 Are there other persons or organizations who provide health care who should be considered as health information custodians under this Act?

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<sup>4</sup> The *Paramedics Act* passed in May 2005, and the *Midwifery Act* passed in November 2006. These Acts have not yet come into force.

## **b. “What” - definition of personal health information**

### What is “personal health information”?

In order to provide or support health care, health information custodians must collect information that will help them make reasonable decisions about diagnosis, treatment, placement in a health care facility, appropriate services, eligibility for services and benefits, and funding of health care.

This will include information about the individual’s own health, but may also include information about the health history of the individual’s family members or the individual’s financial information (e.g. to determine eligibility for benefits and services).

### Identifying information

Typically, health information legislation is intended to provide rules for the protection and use of personal health information. That means that the information must be information that identifies or can identify an individual. If it can’t identify or be linked to an individual, most people would agree that the individual’s privacy would not be at issue.

### What information can identify an individual?

Some identifiers are obvious, and include name, address, phone number and unique ID numbers (e.g. health card number, social insurance number).

Other information, either alone or in combination with other information, may also be identifying. That is why provinces like Ontario have implemented a definition of identifying information that anticipates that information may not always be viewed on its own, but may also be viewed in combination with other records.

In some cases, the environment may determine what is identifying, and information that could identify one person could not identify another. For example, a record that includes only a date of birth as an identifier may not identify a person in a large city, but could identify a person in a smaller community.

### Non-identifying information

Non-identifying health information - including aggregate information or information that has been de-identified by removing all potential identifiers - would generally not be covered by personal health information legislation.

### Recorded or unrecorded

Most information used in health care is recorded, either on paper or electronically. However, there are two types of information that are not recorded:

- oral communications (e.g. conversations); and
- electronic or digital images that are not recorded (e.g. transmission of telehealth consults).

Including unrecorded information in the legislation would require different rules for this information. For example, the provision that provides for an individual to request access to her health record (see Part 3.15) would not apply, as there would be no “record” of the communication. However, other rules related to when information may be disclosed or how it must be protected would apply to protect the unrecorded information.

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## PROPOSED PROVISION

1. **Personal health information** means identifying information about an individual, whether living or deceased, if the information,
    - (a) relates to the physical or mental health of the individual, including information that consists of the health history of the individual's family;
    - (b) relates to the application, assessment, eligibility and provision of health care to the individual, including the identification of a person as a provider of health care to the individual;
    - (c) relates to payments or eligibility for health care in respect of the individual;
    - (d) relates to the donation by the individual of any body part or bodily substance of the individual or is derived from the testing or examination of any such body part or bodily substance;
    - (e) is a number, symbol or particular assigned to an individual to uniquely identify the individual for health care purposes; or
    - (f) identifies an individual's substitute decision-maker.
  2. **Identifying information** means information that identifies an individual or for which it is reasonably foreseeable in the circumstances that it could be utilized, either alone or with other information, to identify an individual.
  3. **Recorded and unrecorded**  
Personal health information includes information in both recorded and unrecorded forms.
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### Tell us what you think

- Q4 Is the proposed provision appropriate? Why or why not?
- Q5 Specifically, should both recorded and unrecorded information be covered, or should the legislation only apply to information that is recorded?

#### c. "What" - definition of health care

Personal health information may be collected, used and disclosed in many circumstances which are not related to the provision of health care. For example, a prospective adoptive parent must provide the Department of Community Services with complete medical examination forms to be approved for an adoption referral. Some employers may require medical information related to an employee's ability to perform specific workplace functions.

The personal health information legislation will not apply to every piece of personal health information in the province. It is only intended to cover the management of information which is collected, used or disclosed for health care related purposes.

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### PROPOSED PROVISION

1. "Health care" means an observation, examination, assessment, care, service or procedure in relation to an individual that is carried out, provided or undertaken for one of the following health-related purposes:
    - (a) the diagnosis, treatment or maintenance of an individual's physical or mental condition;
    - (b) the prevention of disease or injury;
    - (c) the promotion and protection of health;
    - (d) palliative care;
    - (e) the compounding, dispensing or selling of a drug, health care aid, device, product, equipment or other item to an individual or for the use of an individual, under a prescription; or
    - (f) a program or service designated as a health care service in the regulations.
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#### Tell us what you think

- Q6 Is the proposed provision appropriate? Why or why not?
- Q7 Specifically, are there any health care services that are not captured in the proposed provision that should be covered by personal health information legislation?

### 3.3 Consent for collection, use and disclosure of personal health information

Health care requires the establishment of appropriate consent rules for collection, use and disclosure of personal health information. These rules must provide patients with knowledge about and control over their personal health information without interfering with the appropriate exchanges of information that are required to provide and support health care and to operate the health system effectively.

#### a. Requirement for consent

In health care, consent is required for any collection, use and disclosure of personal health information. The exceptions to this requirement must be specifically outlined in legislation.

Collection, use and disclosure should be carried out in the most limited manner possible, and personal health information should not be collected, used or disclosed if other information would meet the intended purpose.

## **b. Elements of consent**

The Pan-Canadian Framework outlines a model of consent in common practice in health care in Canada: ***knowledgeable implied consent***.

*“Knowledgeable”* means that the individual knows the purpose of the collection, use and/or disclosure, and knows that s/he can give or withhold consent.

*“Implied”* means that the consent does not have to be express (i.e. communicated to the health information custodian verbally or in writing) but that the health information custodian may infer the consent where it is reasonable to do so.

Consent must also be voluntary, must relate to the information in question, and may not be obtained by deception or coercion. The consent must be given by the individual or the individual’s substitute decision-maker (see Part 3.5 *Substitute Decision-Maker*).

The knowledgeable implied consent model would apply only to health information custodians, and to disclosure between one health information custodian and another health information custodian.

These consent rules should apply to the collection, use and disclosure of an individual’s personal health information whether the information is recorded on paper records or in an electronic format.

Collection and use by and disclosure to a non-custodian would require express consent, unless otherwise provided for in the legislation.

In every case where consent (implied or express) is required, that consent may also be withdrawn or limited by the individual giving the consent.

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## **PROPOSED PROVISION**

### **Requirement for consent**

1. A health information custodian shall not collect, use or disclose personal health information about an individual unless,
  - a) it has the individual’s consent under this Act and the collection, use or disclosure, as the case may be, to the best of the health information custodian’s knowledge, is necessary for a lawful purpose; or
  - b) the collection, use or disclosure, as the case may be, is permitted or required by this Act.

### **Other information**

2. A health information custodian shall not collect, use or disclose personal health information if other information will serve the purpose of the collection, use or disclosure.

### **Extent of information**

3. A health information custodian shall not collect, use or disclose more personal health information than is reasonably necessary to meet the purpose of the collection, use or disclosure, as the case may be.
4. If this Act requires the consent of an individual for the collection, use or disclosure of personal health information by a health information custodian, the consent:
  - (a) must be a consent of the individual;
  - (b) must be knowledgeable;
  - (c) must relate to the information; and
  - (d) must not be obtained through deception or coercion.
5. A consent to the collection, use or disclosure of personal health information about an individual is knowledgeable if it is reasonable in the circumstances to believe that the individual knows,
  - (a) the purposes of the collection, use or disclosure, as the case may be; and
  - (b) that the individual may give or withhold consent.

### **Notice of purposes**

6. Unless it is not reasonable in the circumstances, it is reasonable to believe that an individual knows the purposes of the collection, use or disclosure of personal health information about the individual by a health information custodian if the health information custodian posts or makes readily available a notice describing the purposes where it is likely to come to the individual's attention or provides the individual with such a notice.

### **Limiting or revoking consent**

7. A health information custodian that receives personal health information about an individual from the individual, the individual's substitute decision-maker or another health information custodian for the purpose of:
  - (a) providing health care;
  - (b) or assisting in the provision of health care to the individual,

is entitled to assume that it has the individual's implied consent to collect, use or disclose the information for the purposes of providing health care or assisting in providing health care to the individual, unless the custodian that receives the information is aware that the individual has expressly withheld or withdrawn the consent by giving notice to the disclosing custodian.

### **Complying with request**

8. A custodian must take reasonable steps to comply with the individual's notice to withhold or withdraw consent.

### **Consequences of limiting or revoking consent**

9. The custodian must inform the individual of the consequences of any such restrictions.

### **Notification of limited or revoked consent**

10. If the disclosing custodian does not have the consent of the individual to disclose all the personal health information about the individual that it considers reasonably necessary for

that purpose, the disclosing custodian shall notify the custodian to whom it disclosed the information of that fact.

### Exception

11. This section does not apply to personal health information that a health information custodian is required by law to collect, use or disclose.

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#### Tell us what you think

- Q8. Are the proposed provisions appropriate? Why or why not?
- Q9. Specifically, do you think that the definition of what is “knowledgeable” outlined in section 5 is reasonable?

### c. Express consent

The knowledgeable implied consent model is for the purposes of facilitating the flow of information within the “circle of care” for the care and treatment of an individual. Other collection, uses and disclosures would require express consent. For example, express consent would be required:

- for disclosure of personal health information by a health information custodian to a non-custodian (unless required or authorized by law)
- for disclosure of personal health information by a health information custodian to another health information custodian when it is not for the purposes of providing health care or services (unless required or authorized by law)
- for collection, use or disclosure of personal health information for fundraising activities
- for collection, use or disclosure of personal health information for market research
- for disclosure to the media.

### 3.4 Mature minors and consent

One complex area of health information is determining when a minor is able to consent to the collection, use, and disclosure of their personal health information.

In health care, a “mature minor” is a person under the age of majority who can understand and appreciate the nature and consequences of treatment and its alternatives<sup>5</sup>. By extension, a person under the age of majority may also be able to

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<sup>5</sup> See J. Gilmour, “Death, Dying and Decision-Making about End of Life Care”, *Canadian Health Law and Policy*, 3<sup>rd</sup> ed. (Downie, Caulfield and Flood, eds.) at p. 441.

understand and appreciate the nature and consequences of decisions related to the collection, use and disclosure of their personal health information.

The law in Nova Scotia takes several approaches to minors. The *Age of Majority Act* specifies that a person reaches the age of majority at age 19 years. This age is referenced in the *FOIPOP Act* as well, which states that the “legal custodian” of someone under the age of majority may exercise any power in the Act where, in the opinion of the public body, it would not constitute an unreasonable invasion of the privacy of the individual. The *Hospitals Act* does not deal with the age required to consent, and practice has been for the hospital to make a judgment as to the patient’s ability to consent.

No health information Act in Canada has an unqualified age cut-off for consent. Most provinces have an age at which the health information custodian must determine whether the individuals understand the consequences of their consent (or refusal to consent). The ages range from 14 to 18. This approach still requires judgment on the part of the health information custodian, and could be considered no different than having no age specified in the provision.

Determining whether minors can make decisions about their own personal health information requires that health information custodians use their professional judgment about the minors understanding of the implications of their action. In Alberta, guidelines suggest that the health information custodians consider factors including maturity, economic status (e.g. is the individual self-sufficient), living arrangements, mental state, risk assessment and the complexity and intrusiveness of the treatment situation and treatment modality.

Another aspect of consent by minors is recognizing that the minor may be able to consent to a certain use or disclosure, or to a use at a certain time, but not to others.

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## PROPOSED PROVISION

### Capacity to consent

1. Sections 2 to 6 apply to individuals below, at, or above the age of majority.
2. An individual is capable of consenting to the collection, use or disclosure of personal health information if the individual is able,
  - (a) to understand the information that is relevant to deciding whether to consent to the collection, use or disclosure, as the case may be; and
  - (b) to appreciate the reasonably foreseeable consequences of giving, not giving, withholding or withdrawing the consent

### Different information

3. An individual may be capable of consenting to the collection, use or disclosure of some parts of personal health information, but incapable of consenting with respect to other parts.

### Different times

4. An individual may be capable of consenting to the collection, use or disclosure of personal health information at one time, but incapable of consenting at another time.

### Presumption of capacity

5. (1) An individual is presumed to be capable of consenting to the collection, use or disclosure of personal health information.
- (2) This presumption includes disclosure to a parent, guardian, or substitute decision-maker where applicable.

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#### Tell us what you think

- Q10 Are the proposed provisions appropriate? Why or why not?
- Q11 Specifically, is it appropriate to continue the current approach that leaves it to the health information custodian to decide the minor's ability to consent in the circumstances?
- Q12 Should there be an exact age stated in the legislation at which minors can be considered to have the ability to consent to the collection, use and disclosure of their personal health information? If so, what would be an appropriate age?
- Q13 If this approach were implemented, what would be appropriate factors for health information custodian to consider when determining when minors can consent to the collection, use and disclosure of their personal health information?

### 3.5 Substitute decision-maker

Most decisions about the collection, use and disclosure of their personal health information will be made by the individuals themselves. However, there will be occasions when a substitute decision-maker will be required to act on the individual's behalf.

This may occur when the individual is unable to make these decisions because of a health condition, where the individual is unavailable to consent (e.g. out of the province), or where the individual is deceased.

In these circumstances, provincial laws, including the *Hospitals Act*, the *Involuntary Psychiatric Treatment Act*, and the *Personal Directives Act* have incorporated a hierarchy of individuals who would be asked to make information decisions on behalf of the individual. It is the Department of Health's intention to ensure that the hierarchy in the *Personal Health Information Act* is generally consistent with other provincial legislation.

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#### PROPOSED PROVISION

1 (1) For the purpose of this Act, consent to the collection, use and disclosure of personal health information may be given or refused on behalf of an individual by a substitute decision-maker who has capacity and is willing to make the decision to give or refuse the consent from the following in descending order:

- (a) a person who is authorized or required by law to act on behalf of the individual;
- (b) the individual's guardian appointed by a court of competent jurisdiction;

- (c) a person who has been authorized in writing to give consent by the individual;
  - (d) the spouse or common-law partner, if the spouse or common-law partner is cohabiting with the patient in a conjugal relationship;
  - (e) an adult child of the individual;
  - (f) a parent of the individual;
  - (g) a person who stands *in loco parentis* to the individual;
  - (h) an adult sibling of the individual;
  - (i) an adult grandparent 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; or
  - (m) the Public Trustee;
- (2) Where a person in a category in subsection (1) fulfils the criteria for a substitute decision-maker as set out in subsection (4) but refuses consent on the patient's behalf, the consent of a person in a subsequent category is not valid.
- (3) Where two or more persons who are not described in the same clause of subsection (1) claim the authority to give or refuse consent under that subsection, the one under the clause occurring first in that subsection prevails.
- (4) A person referred to in clauses 1(c) to (h) shall not exercise the authority given by that subsection unless the person
- (a) has been in personal contact with the patient over the preceding twelve-month period;
  - (b) is willing to assume the responsibility for consenting or refusing consent;
  - (c) knows of no person of a higher category who is able and willing to make the decision; and
  - (d) makes a statement in writing certifying the person's relationship to the patient and the facts and beliefs set out in clauses (a) to (c).
2. The substitute decision-maker shall make the decision:
- (a) in accordance with the patient's prior capable informed expressed wishes; or
  - (b) in the absence of awareness of a prior capable informed expressed wish, in accordance with what the substitute decision-maker believes to be in the patient's best interests.
3. Whoever seeks a person's consent on a patient's behalf is entitled to rely on that person's statement in writing as to the person's relationship with the patient and as to the facts and

beliefs mentioned in clauses 1(4)(a) to (c), unless it is not reasonable to believe the statement.

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### Tell us what you think

Q14 Are the proposed provisions appropriate? Why or why not?

## 3.6 Collection of personal health information

Health information custodians have an obligation to collect information from or about individuals only for purposes that are appropriate to their role in providing and supporting care to the individual, and which are permitted by law. When collecting personal health information, health information custodians must ensure they can articulate the purpose for which the information is being collected, and only collect the information necessary to meet this purpose.

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### PROPOSED PROVISION

1. **Collect**, in relation to personal health information, means to gather, acquire, receive, gain access to or obtain the information by any means from any source, and "collection" has a corresponding meaning;
2. When collecting personal health information directly from the individual the health information custodian must take reasonable steps to inform the person of the purpose for which the information is being collected and of the specified legal authority for the collection.
3. A health information custodian may collect information:
  - (a) for a lawful purpose related to the authority of the health information custodian;
  - (b) if it is expressly authorized by an enactment of the province/territory or federal level;  
or
  - (c) if the information relates directly to and is necessary to carry out the health information custodian's authorized purpose/use as stipulated in the jurisdiction's legislation governing health information.
4. A health information custodian must collect personal health information directly from the individual from whom the information is being collected except in the following types of circumstances:
  - (a) the individual authorizes collection from someone else;
  - (b) when the individual has had a substitute decision maker appointed;
  - (c) where the health information custodian believes, on reasonable grounds, that collection from the individual who is the subject of the information would prejudice the

interests of the individual, the purposes of collection, the safety of any other individual, or would result in the collection of inaccurate information;

(d) where collection from the individual who is the subject of the information is not reasonably practicable; and

(e) where collection is for any of the following purposes:

- i. assembling a family or genetic history where the information collected is to be used in the context of providing a health service to the individual from whom the information is being collected;
- ii. determining the eligibility of an individual to participate in a program of, or to receive a benefit, product or health service from, a health information custodian, and the information is collected in the course of processing an application made by or for the individual who is the subject of the information; and
- iii. verifying the eligibility of an individual who is participating in a program of, or receiving a benefit, product or health service from, a health information custodian to participate in the program or to receive the benefit, product or service.

#### **Scope of collection**

5. The collection of personal health information by a health information custodian shall be limited to the minimum amount of information necessary to achieve the purpose for which it is collected.
  6. Section 5 does not apply to personal health information that a health information custodian is required by law to collect.
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#### **Tell us what you think**

Q15 Are the proposed provisions appropriate for the protection of privacy in limiting collection of personal health information? Why or why not?

### **3.7 Use of personal health information**

Similar to the rules for collection, health information custodians do not have unlimited use of the personal health information they collect. In general, the information must be used for the purpose for which it was collected. There are circumstances where use for a compatible purpose may be permitted. These circumstances must be outlined in the legislation as permitted uses with no consent.

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## PROPOSED PROVISION

### Definition

1. **Use**, in relation to personal health information in the custody or under the control of a health information custodian or a person, means to handle or deal with the information, but does not include to disclose the information, and “use”, as a noun, has a corresponding meaning.
2. For the purposes of this Act, the providing of personal health information between a health information custodian and an agent of the custodian is a use by the custodian, and not a disclosure by the person providing the information or a collection by the person to whom the information is provided.

### Use of information

3. A health information custodian shall not use personal health information about an individual unless:
  - (a) it has the individual's consent under this Act and the use is necessary for a lawful purpose; or
  - (b) the use is permitted or required by this Act.
4. A health information custodian shall not use personal health information if other information will serve the purpose of the use.
5. The use of personal health information in its custody or under its control by a health information custodian shall be limited to the minimum amount of information necessary to achieve the purpose for which it is used.
6. Section 5 does not apply to personal health information that the health information custodian is required by law to use.

### Permitted uses

7. A health information custodian may use personal health information about an individual:
  - (a) for the purpose for which the information was collected or created and for all the functions reasonably necessary for carrying out that purpose;
  - (b) for a purpose for which this Act, another Act or an Act of Canada permits or requires a person to disclose it to the health information custodian;
  - (c) for planning or delivering programs or services that the health information custodian provides or that the health information custodian funds in whole or in part, allocating resources to any of them, evaluating or monitoring any of them or detecting, monitoring or preventing fraud or any unauthorized receipt of services or benefits related to any of them;
  - (d) for the purpose of risk management, error management or for the purpose of activities to improve or maintain the quality of care or to improve or maintain the quality of any related programs or services of the health information custodian;
  - (e) for educating agents to provide health care;
  - (f) for the purpose of disposing of the information or modifying the information in order to conceal the identity of the individual;

- (g) for the purpose of seeking the individual's consent, when the personal health information used by the health information custodian for this purpose is limited to the individual's name and contact information;
- (h) for the purpose of a proceeding or contemplated proceeding in which the health information custodian or the agent or former agent of the health information custodian is, or is expected to be, a party or witness, if the information relates to or is a matter in issue in the proceeding or contemplated proceeding;
- (i) for the purpose of obtaining payment or processing, monitoring, verifying or reimbursing claims for payment for the provision of health care or related goods and services;
- (j) for research conducted by the health information custodian, in accordance with [*the Act's provisions on research*]; or
- (k) subject to the requirements and restrictions, if any, that are prescribed, if permitted or required by law or by a treaty, agreement or arrangement made under an Act or an Act of Canada.

#### **Agents**

8. If section 7 authorizes a health information custodian to use personal health information for a purpose, the health information custodian may provide the information to an agent of the health information custodian who may use it for that purpose on behalf of the health information custodian

#### **Scope of use**

9. A health information custodian shall limit the use of personal health information in its custody or under its control to those of its employees and agents who need to know the information to carry out the purpose for which the information was collected or a purpose authorized under this Act.

#### **Uses with no consent**

10. A health information custodian may use personal health information about an individual without the individual's consent:
  - (a) for the purpose of determining or monitoring/verifying the eligibility of the individual to receive health care/health services or benefits;
  - (b) for the Minister or another health information custodian to determine or provide funding or payment to the health information custodian for provision of health care;
  - (c) for the purpose of planning, monitoring, evaluation, resource allocation, audit or preventing fraud for programs or services that the health information custodian delivers or funds in whole or in part;
  - (d) for the purpose of health service provider education;
  - (e) for the purpose of ensuring quality or standards of care, including providing for use and disclosure for risk management purposes, for quality of care committees or similar bodies, or standards of care within the health information custodian organization;
  - (f) for the purpose of modifying the information to conceal the identity of the individual;

- (g) for the purpose of contacting a relative or friend of the individual, if the individual is injured, incapacitated or ill and unable to give consent personally and the disclosure is not contrary to the express request of the individual;
- (h) for the purpose of conducting an audit of the information if the person conducting the audit agrees in writing to destroy the information at the earliest opportunity after the audit is concluded and does not disclose the information to any person except as required to accomplish the audit or to report unlawful or improper conduct by the health information custodian or a health services provider; or
- (i) for a purpose as required or authorized by a federal or provincial/territorial enactment, treaty, agreement or arrangement made under any of those Acts.

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**Tell us what you think**

Q16 Do you agree with the proposed provisions? Why or why not?

### **3.8 Disclosure**

#### **a. General**

Health information custodians have an obligation to disclose personal health information only for purposes that are appropriate to their role in providing and supporting care to the individual, and which are permitted or required by law. As with collection and use, the custodian must only disclose the amount of personal health information necessary to meet the stated purpose for disclosure.

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#### **PROPOSED PROVISION**

##### **Definition**

1. **Disclose**, in relation to personal health information in the custody or under the control of a health information custodian or a person, means to make the information available or to release it to another health information custodian or to another person, but does not include to use the information, and “disclosure” has a corresponding meaning;
2. A provision of this Act that permits a health information custodian to disclose personal health information about an individual without the consent of the individual,
  - (a) does not require the custodian to disclose it unless required to do so by law;
  - (b) does not relieve the custodian from a legal requirement to disclose the information; and
  - (c) does not prevent the custodian from obtaining the individual’s consent for the disclosure
3. A health information custodian shall not disclose personal health information if other information will serve the purpose of the disclosure.

4. The disclosure of personal health information in its custody or under its control by a health information custodian shall be limited to the minimum amount of information necessary to achieve the purpose for which it is disclosed.
5. Section 4 does not apply to personal health information that the health information custodian is required by law to disclose.

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**Tell us what you think**

Q17 Are the proposed provisions appropriate? Why or why not?

**b. Disclosure of personal health information without consent**

There are some circumstances where it may be appropriate to allow a health information custodian to disclose information without the individual's consent, and even if the individual may wish to withhold or limit his/her consent.

The circumstances under which this would be appropriate would be exceptional and would be required to be outlined in legislation.

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**PROPOSED PROVISION**

**Disclosures without consent**

1. A health information custodian may disclose personal health information about an individual without the individual's consent:
  - (a) to another health information custodian where the health information custodian disclosing the information has a reasonable expectation that the disclosure will prevent fraud, limit abuse in the use of health services or prevent the commission of an offence under an enactment of a province/territory or Canada;
  - (b) to persons acting on behalf of the individual including:
    - i a person who is legally entitled to make a health care decision on behalf of the subject individual;
    - ii a legal guardian;
    - iii a personal representative appointed in writing;
    - iv the administrator of an estate, if the use or disclosure is for the purposes of the estate; or
    - v someone to make decisions in circumstances where the individual is deceased.
  - (c) to a health professional body or a prescribed professional body that requires the information for the purposes of carrying out its duties under an Act regulating the profession;

- (d) to any person if the health information custodian believes on reasonable grounds that the disclosure will avert or minimize an imminent danger to the health or safety of any person;
  - (e) to an official of a penal or other custodial institution in which the individual is being lawfully detained if the purpose of the disclosure is to allow the provision of health services to the individual and to assist the institution or the facility in making a decision concerning the placement of the individual into custody, detention, release, conditional release, discharge or conditional discharge under existing provincial/territorial/ federal legislation;
  - (f) to another health information custodian for the purpose of ensuring quality or standards of care including providing for use or disclosure for risk management purposes, for quality of care committee or similar bodies or for the purpose of ensuring quality or standards of care within the health information custodian organization;
  - (g) to another health information custodian for the purpose of planning, monitoring, evaluation, audit, resource allocation or monitoring or preventing fraud against programs or services that the health information custodian delivers or funds in whole or in part;
  - (h) to another health information custodian for monitoring prescriptions for certain drugs;
  - (i) to an officer of the Legislature if the information about the individual is necessary for the performance of the officer's duties;
  - (j) if the disclosure is authorized by a federal, provincial or territorial treaty, agreement or arrangement made pursuant to legislation.
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#### **Tell us what you think**

- Q18 Are the circumstances outlined in the proposed provision appropriate for disclosure without an individual's consent? If not, what should be amended?
- Q19 Are there additional circumstances when personal health information should be disclosed without an individual's consent? What are they?
- Q20 Should there be a requirement that all disclosures without consent are documented?

#### **c. Disclosure of personal health information without consent unless the individual objects**

In other circumstances, it may be reasonable for the health information custodian to be permitted to disclose information without the individual's consent unless the health information custodian knows that the disclosure would be against the express wishes of the individual. Again, the circumstances under which this would be appropriate would be exceptional and would be required to be outlined in legislation

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## PROPOSED PROVISION

1. A health information custodian has the discretion to disclose personal health information about an individual to family members of the individual or to another person with whom the individual is believed to have a close personal relationship if the information is given in general terms and concerns the presence, location, condition, diagnosis, progress and prognosis of the individual on the day on which the information is disclosed and the disclosure is not contrary to the express request of the individual.
  2. A health information custodian may disclose personal health information about an individual who is deceased, or is believed to be deceased:
    - (a) for the purpose of identifying the individual;
    - (b) for the purpose of informing any person whom it is reasonable to inform, the circumstances that the individual is deceased or believed to be deceased;
    - (c) to the spouse, partner, sibling or child of the individual if the recipients of the information reasonably require the information to make decisions about their own health care or their children's health care, having regard to any views that the individual previously expressed that are known to the health information custodian; and
    - (d) for carrying out the deceased person's wishes for the purpose of tissue or organ donation.
  3. Where an individual is deceased, health information may be disclosed to family members of the individual or to another person with whom the individual is believed to have had a close personal relationship, if the information relates to circumstances surrounding the death of the individual or to health services recently received by the individual and the disclosure is not contrary to the express request of the individual.
  4. A health information custodian may disclose personal health information about an individual to a successor where the health information custodian is transferring its records to the successor as a result of the health information custodian ceasing to be a health information custodian and the successor is the health information custodian.
  5. When transferring its records to a successor, the health information custodian shall make reasonable efforts to give notice to the individual before transferring the records, or if that is not possible, as soon as possible after transferring the records.
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### Tell us what you think

- Q21 Are the circumstances outlined in the Proposed Provision appropriate for disclosure without an individual's consent unless the individual objects? If not, what should be amended?
- Q22 Are there additional circumstances when personal health information could be disclosed without an individual's consent unless the individual objects? What are they?

### 3.9 Disclosure outside Nova Scotia

In certain circumstances, disclosure of personal health information outside of Nova Scotia may be necessary to support the provision of health care to an individual, or for another authorized purpose. The proposed provision outlines recommendations for permitted disclosure to another province or territory in Canada.

Disclosure outside Canada is governed by the Nova Scotia *Personal Information International Disclosure Protection Act*, which prohibits the disclosure of personal information outside the country. Exceptions are outlined in that legislation.

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#### PROPOSED PROVISION

1. A custodian may disclose personal health information about an individual collected in the province to a person outside the province but only where:
  - (a) the individual who is the subject of the information consents to the disclosure;
  - (b) the disclosure is permitted by this Act or the regulations;
  - (c) the person receiving the information performs functions similar to the functions performed by a person to whom this Act would permit the custodian to disclose the information in the province;
  - (d) the following conditions are met:
    - i. the disclosure is for the purpose of health planning or health administration;
    - ii. the information relates to health care provided in the province to a person who is a resident of another province or territory of Canada; and
    - iii. the disclosure is made to the government of that other province or territory of Canada;
  - (e) the disclosure is reasonably necessary for the provision of health care to the individual and the individual has not expressly instructed the custodian not to make the disclosure in its entirety; or
  - (f) the disclosure is reasonably necessary for the administration of payments in connection with the provision of health care to the individual or for contractual or legal requirements in that connection.
2. Where a custodian discloses personal health information about an individual under paragraph (1)(e) and an express request of the individual who is the subject of the information prevents the custodian from disclosing all the personal health information that the custodian considers reasonably necessary to disclose for the provision of health care to the individual, the custodian shall notify the person to whom it makes disclosure of that fact.

### **Maintaining disclosure information**

3. (1) Except as otherwise provided under subsection (2) or [*the provision permitting disclosure without consent*], a custodian that discloses personal health information shall make a note of the following:

- (a) the name of the person to whom the custodian discloses the information;
- (b) the date and purpose of the disclosure; and
- (c) a description of the information disclosed.

(2) Subsection (1) does not apply where a custodian discloses personal health information by permitting access to the information stored in the information system of the custodian, provided that when the information is accessed, the database automatically keeps an electronic log of the following information:

- (a) the user identification of the person that accesses the information;
- (b) the date and time the information is accessed; and
- (c) a description of the information that is accessed or that could have been accessed.

### **Limitations on disclosure**

4. (1) The disclosure of personal health information by a custodian shall be limited to the minimum amount of information necessary to accomplish the purpose for which it is used.

(2) This section does not apply to personal health information that a custodian is required by law to disclose.

### **Disclosure does not make recipient a custodian**

5. A person who is not a health information custodian is authorized to collect the personal health information that a custodian may disclose to it, but that person does not become a custodian merely by virtue of its collection of the personal health information that the custodian has disclosed to it.

### **Disclosure outside Canada**

6. (1) Sections 1-5 do not apply to disclosure of personal health information outside of Canada.

(2) Disclosure of personal health information outside of Canada is governed by the *Personal Information International Disclosure Protection Act*

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#### **Tell us what you think**

Q23 Are the proposed provisions appropriate for disclosure outside of Nova Scotia? Why or why not?

### **3.10 Retention, destruction and disposal**

Although collection, use and disclosure are the most common components of information management, more attention is being paid to the importance of appropriate retention periods, and methods of secure destruction and disposal. The limits on

retention of personal information is one of the 10 Fair Information Practices (Principle 4.5 – see Appendix B).

Appropriate retention schedules are particularly important with the development of electronic health records. With paper records, retention schedules would be adhered to out of a need to free up storage space. This is not as significant a factor with electronic health records, so it is important to ensure that the principles are clearly defined.

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## PROPOSED PROVISION

### General

1. Health information custodians must take appropriate measures for the retention, secure destruction and proper disposal of personal health information to prevent any reasonably anticipated unauthorized use or disclosure of the personal health information or unauthorized access following its disposal.

### Retention

2. Every health information custodian shall have a retention schedule for personal health information.
3. Personal health information shall be retained only as long as is necessary for the fulfillment of the identified purposes for which it was collected.
4. Notwithstanding section 3, if a public body uses an individual's personal health information to make a decision that directly affects the individual, the public body shall retain that information for at least one year after using it so that the individual has a reasonable opportunity to obtain access to it.

### Destruction, Disposal and De-identification

5. Personal information that is no longer required to fulfill the identified purposes should be securely destroyed, erased, or de-identified.
6. For the purposes of sections 1 and 3, "secure destruction" and "securely destroyed" means the destruction of a record in such a manner that reconstruction of the record is not reasonable foreseeable in the circumstances.
7. Personal health information may be de-identified and retained for purposes other than the original purposes for which it was collected.

### Policies, Guidelines and Procedures

8. Organizations shall develop policies, guidelines and implement procedures to govern the retention, secure destruction and proper disposal of personal health information.
9. This section does not override or modify any requirement in an enactment of Nova Scotia or Canada concerning the retention or destruction of records maintained by public bodies.
10. Sections 1 – 9 apply to personal health information in both paper and electronic format.

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### Tell us what you think

- Q24 Are the proposed provisions appropriate for the protection of personal health information? Why or why not?

### 3.11 Research

As discussed in the Purpose section (see Part 3.1 *Purpose of the legislation*), personal health information legislation balances two interests: the interests served by protection of privacy, and the interests served by appropriate use of personal health information.

One important use of personal health information is to support health research. Information about individuals is one of the basic resources used by researchers in Nova Scotia. When health information is available for analysis by health researchers, it can benefit Nova Scotians by supporting research which may:

- monitor the health of the population;
- identify populations at high risk of disease;
- determine the effectiveness of treatment;
- quantify prognosis and survival;
- assess the usefulness of preventive strategies, diagnostic tests and screening programs;
- inform health policy through studies on cost-effectiveness;
- support administrative functions; and
- monitor the adequacy of care.<sup>6</sup>

#### Identifiable vs. de-identified information

The information required by researchers does not always have to be identifiable. In many cases, de-identified information may still allow the researchers to meet their research objectives. In other cases, some identifiers are required in order to fulfill the objectives of the research.

#### Consent for use of information for research

Another key issue around research is consent. Because research is usually a *secondary* use of the personal health information (e.g. the information was collected from the individual for another *primary* purpose, like treatment), consent should be obtained from the individual for use of the information for research. However, there will be circumstances where information may be used without the individuals' consent. To ensure protection of privacy to the fullest extent possible, there must be criteria for when this will be permitted.

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## PROPOSED PROVISION

### Definitions

1. **Data Matching** is the creation of individually identifying health information by combining individually identifying or non-identifying health information or other information from two or more databases without the consent of the individuals who are the subjects of the information.
2. **De-identified information** is information which has had all identifiers removed that:
  - (a) identify the individual; or

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<sup>6</sup> Adapted from Secondary Use of Personal Information in Health Research: Case Studies November 2002 (Canadian Institutes of Health Research), at page 5

- (b) that it is reasonably foreseeable in the circumstances could be utilized, either alone or with other information, to identify the individual.
- 3. **Impracticable** means a degree of difficulty higher than inconvenience or impracticality but lower than impossibility.
- 4. **Planning and management of the health system** is the analysis or compiling of statistical information solely with respect to:
  - (a) the management, evaluation or monitoring of;
  - (b) the allocation of resources to; or
  - (c) planning for all or part of
 the health system, including the delivery of services.
- 5. (1) **Research** is a systematic investigation designed to develop or establish principles, facts or generalizable knowledge, or any combination of them, and includes the development, testing and evaluation of research.
 

(2) Planning and management of the health system does not constitute research.
- 6. **Research Ethics Board** means any Research Ethics Boards established and operating in conformity with the Tri-Council Policy Statement.
- 7. **Tri-Council Policy Statement** means the Tri-Council Policy Statement "Ethical Conduct for Research Involving Humans" adopted in August 1998 by the Medical Research Council of Canada, the Natural Sciences and Engineering Research Council of Canada and the Social Sciences and Humanities Research Council of Canada, and includes amendments to the statement and any other statement of principles and guidelines respecting ethical conduct for research involving humans adopted by those councils in substitution for the Tri-Council Policy Statement.

**Application**

- 8. Sections 9 - 15 do not apply to research which exclusively uses statistical, aggregate or de-identified information.

**Limitation on use and disclosure**

- 9. The use and disclosure of personal health information by a custodian shall be limited to the minimum amount of information necessary to accomplish the research purposes for which it is to be used or disclosed.

**Use by custodian of personal health information for research**

- 10. A custodian may use personal health information for research, provided that the custodian meets the following requirements prior to commencing the research:
  - (a) prepares a research plan that meets the requirements in sections 14-16;
  - (b) submits the research plan to a Research Ethics Board;
  - (c) receives the approval of the Research Ethics Board; and
  - (d) prior to the commencement of research meets any conditions imposed by the Research Ethics Board.

### **Requirements for disclosure of personal health information for research**

11. A health information custodian may disclose personal health information about an individual to a researcher if the researcher:

- (a) submits to the custodian,
  - i. an application in writing,
  - ii. a research plan that meets the requirements of sections 14-16; and
  - iii. a copy of the submission to and decision of a research ethics board that approves the research plan; and
- (b) enters into the agreement required by section 18.

### **Requirements for disclosure of personal health information for research without consent**

12. A health information custodian may disclose personal health information about an individual to a researcher without the consent of the subject individual if:

- (a) the researcher has met the requirements in section 10;
- (b) the Research Ethics Board has determined that the consent of the subject individuals is not required; and
- (c) the custodian is satisfied that:
  - i. the research cannot be conducted without using the personal health information;
  - ii. the personal health information is limited to that necessary to accomplish the purpose of the research;
  - iii. the personal health information is in the most de-identified form possible for the conduct of the research;
  - iv. the personal health information will be used in a manner that will ensure its confidentiality and
  - v. it is impracticable to obtain consent; and
- (d) the custodian informs the privacy oversight body.

### **Forms**

13. A custodian may prescribe forms for use by researchers for:

- (a) an application under s. 11(a)(i);
- (b) a research plan under s. 14; and
- (c) a disclosure agreement under s. 18.

### **Research plan**

14. Prior to commencing research, a researcher seeking to conduct research utilizing personal health information shall submit a research plan to a Research Ethics Board.

15. The research plan shall be in writing.
16. In order to meet the requirements for a custodian under this Act, the research plan shall include:
- (a) a description of the research proposed to be conducted;
  - (b) a statement regarding the duration of the research;
  - (c) a description of the personal health information required and the potential sources of the information;
  - (d) a description as to how the personal information will be used in the research;
  - (e) if the personal health information will be linked to other information, a description of the other information as well as how the linkage will be conducted;
  - (f) if the researcher is conducting the research on behalf of or with the support of a person or organization, the name of the person or organization;
  - (g) the nature and objectives of the research and the public or scientific benefit anticipated as a result of the research;
  - (h) if consent is not being sought, an explanation as to why seeking consent is impracticable;
  - (i) an explanation as to why the research cannot reasonably be accomplished without the use of personal health information;
  - (j) if there is to be data matching, an explanation of why data matching is required;
  - (k) a description of the reasonably foreseeable risks arising from the use of personal health information and how those risks are to be mitigated;
  - (l) a statement that the personal health information is to be used in the most de-identified form possible for the conduct of the research;
  - (m) a description of all individuals who will have access to the information, and
    - i why their access is necessary;
    - ii their roles in relation to the research; and
    - iii their qualifications;
  - (n) a description of the safeguards that the researcher will impose to protect the confidentiality and security of the personal health information;
  - (o) information as to how and when the personal health information will be destroyed or returned to the custodian;
  - (p) the funding source of the research;
  - (q) whether the researcher has applied for the approval of another Research Ethics Board and, if so, the response to or status of the application; and

- (r) whether the researcher’s interest in the disclosure of the personal health information or the conduct of the research would potentially result in an actual or perceived conflict of interest on the part of the researcher.

**Discretion to disclose**

17. The custodian is not required to disclose personal health information.

**Research agreement**

18. If the custodian discloses personal health information to a researcher, the researcher shall enter into an agreement with the custodian to adhere to the requirements in section 19.

19. An agreement referred to in section 18 shall include the following commitments by the researcher:

- (a) to comply with any terms and conditions imposed by the Research Ethics Board;
- (b) to comply with any terms and conditions imposed by the custodian;
- (c) to use the information only for the purposes outlined in the research plan as approved by the Research Ethics Board;
- (d) not to publish the information in a form where it is reasonably foreseeable in the circumstances that it could be utilized, either alone or with other information, to identify an individual;
- (e) to allow the custodian to access or inspect the researcher’s premises to confirm that the researcher is complying with the terms and conditions of this statute and of the agreement between the custodian and the researcher;
- (f) to notify the custodian immediately and in writing if the personal health information is stolen, lost, or subject to unauthorized access, use, disclosure, copying or modification;
- (g) to notify the custodian immediately and in writing of any known or suspected breach of the agreement between the custodian and the researcher; and
- (h) not to attempt to identify or contact the individuals unless the custodian or researcher has obtained prior consent by the individuals.

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**Tell us what you think**

Q25 Are the proposed provisions appropriate for research? Why or why not?

**3.12 Practices to protect personal health information**

Health information custodians should have the responsibility of implementing policies, practices and other safeguards to protect personal health information. These protections help ensure that personal health information in all forms is not subject to loss, theft, or unauthorized access and disclosure.

These safeguards can be:

- administrative (e.g. policies, training, Conditions of Appropriate Use agreements),
- technical (e.g. encryption, password protection); or
- physical (e.g. locked offices, secured shredding bins).

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## **PROPOSED PROVISION**

### **Practices to Protect Personal Health Information**

1. A health information custodian shall protect the confidentiality of personal health information that is in its custody or under its control and the privacy of the individual who is the subject of that information.
2. A health information custodian shall implement and maintain administrative, technical and physical safeguards that are reasonable in the circumstances to ensure that personal health information in the health information custodian's custody or under its control is protected against:
  - (a) theft or loss of the information; and
  - (b) unauthorized access to or use, disclosure, copying or modification of the information.
3. A health information custodian shall restrict access to an individual's personal health information by an employee, agent, contractor or volunteer of the custodian or by a health care professional who has the right to treat persons at a health care facility operated by the custodian to only that information that the employee, agent, contractor, volunteer or health care professional requires to carry out their duties and responsibilities.

### **Record of User Activity**

4. (1) A custodian shall create and maintain, or have created and maintained, a record of user activity for any electronic information system it uses to maintain personal health information.
  - (2) A record of user activity may be generated manually or electronically.
  - (3) Subject to administrative requirements set out in the regulations, a record of user activity related to an individual's personal health information shall be available to that individual upon request.
  - (4) A custodian shall not charge a fee to an individual for a record of user activity.

### **Additional safeguards for electronic health records**

5. A health information custodian who maintains personal health information in electronic form shall implement any additional safeguards for such information required by the regulations.

### **Privacy Impact Assessments**

6. A custodian may complete a privacy impact assessment to identify, assess and mitigate potential risks associated with the new collection, use, disclosure and retention of personal health information, or when creating or modifying electronic personal health information systems and communication technologies.

### **Protection of personal health information disclosed by custodian**

7. When disclosing personal health information, a custodian may make the disclosure subject to any restrictions or conditions that the disclosing custodian considers advisable to protect the information.

### **Contact Person**

8. A health information custodian shall have in place and comply with information practices, policies and procedures that meet the requirements of this Act.
9. A health information custodian shall designate one or more individuals as a contact person.
10. The contact person is an agent of the health information custodian and is authorized on behalf of the health information custodian to:
  - (a) facilitate the health information custodian's compliance with this Act;
  - (b) ensure that all agents of the health information custodian are appropriately informed of their duties under the Act;
  - (c) respond to inquiries about the health information custodian's information practices;
  - (d) respond to requests for access to and correction of records;
  - (e) receive complaints;
  - (f) facilitate the communications to and the training of the health information custodian's staff about the health information custodian's policies and procedures and about this Act; and
  - (g) developing information to explain the organization's policies and procedures.

### **If no contact person**

11. A health information custodian that is a natural person and that does not designate a contact person under section 9 shall perform on his or her own the functions described in section 10.

### **Written public statement**

12. A health information custodian shall, in a manner that is practical in the circumstances, make available to the public a written statement that:
  - (a) provides a general description of the health information custodian's information practices;
  - (b) describes how to contact:
    - (i) the contact person described in section 9 if the health information custodian has one, or
    - (ii) the health information custodian, if the health information custodian does not have that contact person;
  - (c) describes how an individual may obtain access to or request correction of a record of personal health information about the individual that is in the custody or control of the health information custodian; and
  - (d) describes how to make a complaint to the health information custodian and to the [oversight body] under this Act.

### Tell us what you think

- Q26 Are the proposed provisions appropriate? Why or why not?
- Q27 When determining what safeguards are “reasonable in the circumstances” in section 2 (above), should the health information custodian take into account the type of personal health information which is being protected? Should some personal health information be given more protection than other personal health information?
- Q28 Should any additional safeguards be required for electronic health records?

### 3.13 Reporting of a privacy breach

As long as personal health information is in the hands of individuals, it is inevitable that there will be privacy breaches of this information. Some breaches are due to the mistakes of custodians (e.g. lost files and laptop computers, sending e-mail to the wrong address) and some are deliberate breaches (e.g. looking at the health record of a friend, family member or celebrity out of curiosity). Both types of breaches may result in the personal health information of Nova Scotians falling into the wrong hands, and possibly made public, with implications that range from embarrassment to identity theft.

#### Notification

Currently, breaches may take place and the individual whose information was breached is never informed. Although breach policies are increasingly providing for notification of the individual, there is no requirement in Nova Scotia that individuals be told that their personal health information has been lost, stolen or accessed improperly.

A recent survey commissioned by the Federal Privacy Commissioner and Canada Health Infoway (Electronic Health Information and Privacy Survey: What Canadians Think) showed that 70% of Canadians surveyed indicated that being informed of privacy breaches would make them more comfortable with electronic health records.

The Privacy Commissioner of Canada’s privacy breach guidelines<sup>7</sup> introduced in 2007 state that “notification can be an important mitigation strategy that has the potential to benefit both the organization and the individuals affected by a breach”.

The Privacy Commissioner Guidelines suggest that notification be considered on a case-by-case, taking into account the risk of harm to the individual. This is similar to the approach taken by the Nova Scotia Departments of Health/ Health Promotion and Protection breach policy, which requires that:

*“Individuals should be informed of a privacy breach and the specific information that was the subject of the breach if there is a risk of: a) harm or embarrassment*

<sup>7</sup> Key Steps for Organizations in responding to Privacy Breaches  
[http://www.privcom.gc.ca/information/guide/index\\_e.asp](http://www.privcom.gc.ca/information/guide/index_e.asp)

*to the individual; b) public disclosure of the personal information; or c) malicious use of the personal information.*<sup>8</sup>

#### When is notification necessary?

There are four potential approaches to breach notification:

1. Mandatory notification of all breaches. This requires notifying individuals that a theft or loss of their information has occurred even if it was confirmed that the information was not viewed by any other person (e.g. a file was lost, and later recovered in a locked trunk where no other person could have accessed it). It would also require notification when an individual accessed information by accident (e.g. a nurse calls up an electronic record of the wrong patient by accident, and the audit log confirms that the record was only viewed for a few seconds).
2. Mandatory notification of breaches only when it has been confirmed that the information could have been viewed by another person (e.g. a laptop is lost and never recovered) or was intentionally accessed in an unauthorized way (e.g. a doctor views a record of a patient who is not in her care for several minutes).
3. Notification on a case-by-case basis, where there has been a breach (as outlined in number #2 above) with the decision made based on the risk of harm or embarrassment to the individual
4. No notification.

When assessing the alternatives, it important to consider the following:

- a) **What is an “unauthorized access”?** Many people may think that the greatest risk of exposure of information comes from people outside the health care system, including laptop thieves and hackers. But many breaches can occur within the system, with healthcare providers who have access to records looking at the records of patients, clients or residents not in their care.

Access to information cannot always be refined to the point that only your care provider and the specific individuals who support your care are the only ones who have access. For example, if you are admitted to a floor of a hospital, most people who provide care to that floor have access to your record, but only those who are directly involved in providing or supporting your care are “authorized” to view your record. People who are merely curious about your record would be committing a privacy breach if they looked at your information.

- b) **What is “harm”?** News articles on privacy breaches have often raised the fear of identity theft. But harm comes in many forms, including the embarrassment caused by others knowing your health information, or a potential risk to your employment, financial status or social relationships if friends, family or your employer were aware of your health status. Even the loss of trust that you have in your health care providers can be “harm”.

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<sup>8</sup> Preventing and Managing an Information Breach (October 1, 2007)

- c) **What form should notification take?** In some cases, individual phone calls or letters may be appropriate. Where large numbers of individuals are affected, a public notice circulated via the local media may be appropriate.

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## PROPOSED PROVISION

### Notification of breach

1. Subject to the exceptions and additional requirements, if any, that are prescribed, a health information custodian that has custody or control of personal health information about an individual shall notify the individual at the first reasonable opportunity if the information is stolen, lost, or subject to unauthorized access, use, disclosure, copying or modification.

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### Tell us what you think

- Q29 Is the proposed provision appropriate? Why or why not?
- Q30 Specifically, do you think individuals should be notified when their privacy is breached?
- Q31 Should every loss, theft or unauthorized access be reported to the individual, or should there be criteria for determining when notice is required?
- Q32 What factors should a health information custodian consider when deciding whether to notify an individual of a breach?
- Q33 Should there be an independent review of all breaches, regardless of whether the individual has been notified?

### 3.14 Privacy rights of deceased individuals

Individuals in Nova Scotia continue to have certain protections for their personal information after they have died. This has been confirmed in decisions by the *Freedom of Information and Protection of Privacy Act* Review Officer.

To be consistent with this, the proposed definition of “*personal health information*” refers to information about an individual “*whether living or deceased*” (see Part 3.2 (b)).

However, it has also been stated that the rights of the deceased diminish over time, and personal health information Acts have also provided for this by setting a time at which information is no longer protected. Currently the *Freedom of Information and Protection of Privacy Act* allows personal information held in the Public Archives or the archives of a public body to be released if an individual has been dead for twenty (20) years or more.

Provincial personal health information Acts also provide for personal health information (e.g. hospital records) to be disclosed without consent after a specific period of time has passed. The length of time ranges from 20-50 years after the individual has died, or 100-120 years after the record was created.

When considering this issue, it is also important to note that health care custodians are required to have retention and destruction schedules, which would require the destruction or de-identification of personal health information after a specified period of time. It would be rare that a retention period would be more than 20 years.

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## PROPOSED PROVISION

### Disclosure of record of deceased

1. A health information custodian may disclose personal health information without the knowledge or consent of the individual if the disclosure is made after the earlier of:
  - (a) one hundred and twenty years after the record containing the information was created; and
  - (b) fifty years after the death of the individual to whom the personal health information relates.

### Retention and destruction schedule

2. Prior to release of personal health information to the archives of a public body or to the Public Archives the health information custodian shall ensure that the health information custodian's retention and destruction schedules have been followed.

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### Tell us what you think

- Q34 Do you think that the period proposed for disclosure of information related to deceased persons or older records without consent is appropriate? Why or why not?

## 3.15 Access to your personal health information

Legislation and case law in Canada provides for an individual to have full access to his/her own personal health records with very limited exceptions. In Nova Scotia, the *Freedom of Information and Protection of Privacy Act* and the *Hospitals Act* also provide for this access, as does the Federal *Personal Information Protection and Electronic Documents Act*.

It makes sense that personal health information would continue this right. In fact, the right to request access to your personal health information is a fundamental component of all provincial health information legislation.

Working with that assumption, there are specific details that require further consideration:

### a. Exceptions to access

The right to access your personal health information is not absolute. There may be some limited exceptions to this right. If the access is denied to all or part of the record, the onus falls on the health information custodian to justify the denial.

These exceptions may be to protect the individual or another person. For example, a daughter may provide information to her mother's physician that the mother has had violent outbursts. If the information about the daughter's statement was given to the mother it may result in a risk to the safety of the daughter. The physician would have to make a judgment about whether to release this information to the mother.

In making this type of judgment, it may be appropriate for a health information custodian to consult with a health care professional involved in the individual's care.

Other exceptions may relate to information that is subject to legal privilege (e.g. solicitor-client privilege), and information that was collected in the course of an investigation or primarily for use in a legal proceeding.

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### PROPOSED PROVISION

1. Subject to this Part, an individual has a right of access to a record of personal health information about the individual that is in the custody or under the control of a health information custodian
2. Notwithstanding Section 1, a custodian may refuse to grant access to personal health information about the individual if it is reasonable to believe that:
  - (a) the record or the information in the record is subject to a legal privilege that restricts disclosure of the record or the information, as the case may be, to the individual;
  - (b) another Act, an Act of Canada or a court order prohibits disclosure to the individual of the record or the information in the record in the circumstances;
  - (c) the information in the record was collected or created primarily in anticipation of or use in a proceeding, and the proceeding, together with all appeals or processes resulting from it, have not been concluded;
  - (d) the following conditions are met:
    - i. the information was collected or created in the course of an inspection, investigation or similar procedure authorized by law, or undertaken for the purpose of the detection, monitoring or prevention of a person's receiving or attempting to receive a service or benefit, to which the person is not entitled under an Act or a program operated by the Minister, or a payment for such a service or benefit, and
    - ii. the inspection, investigation, or similar procedure, together with all proceedings, appeals or processes resulting from them, have not been concluded;
  - (e) granting the access could reasonably be expected to:
    - i. result in a risk of serious harm to the treatment or recovery of the individual or a risk of serious harm to the mental and physical health of the individual or another person,
    - ii. lead to the identification of a person who was required by law to provide information in the record to the custodian, or

- iii. lead to the identification of a person who provided information in the record to the custodian explicitly or implicitly in confidence if the custodian considers it appropriate in the circumstances that the name of the person be kept confidential.
3. Notwithstanding Section 2, an individual has a right of access to that part of a record of personal health information about the individual that can reasonably be severed from the part of the record to which the individual does not have a right of access as a result of clauses (2) (a) to (e).
4. Despite Section 3, if a record is not a record dedicated primarily to personal health information about the individual requesting access, the individual has a right of access only to the portion of personal health information about the individual in the record that can reasonably be severed from the record for the purpose of providing access.

#### **Consultation regarding harm**

5. Before deciding to refuse to grant an individual access to a record of personal health information under Section 2(e)(i), a health information custodian may consult with a health care professional who has been involved in the individual's care, or another appropriate health care professional.

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#### **Tell us what you think**

Q35 Are the proposed provisions appropriate? Why or why not?

Q36 Are there any other exceptions which could be included in the legislation?

#### **b. Process for requesting access**

Most health information custodians have a process for patients to follow when requesting a copy of their health record. This may include a form, a time during which the record will be provided, and a fee (if applicable).

#### **c. Making the request**

Most applications for access to a health record are made in writing. This allows the individual to provide all the information necessary for the health information custodian to review the request and locate the record. It also provides a record for both the health information custodian and the individual of what was requested.

Individuals making the request should be as specific as possible about the information they are requesting. Any information that can help the health information custodian locate the record will not only make the process more efficient, but it may significantly reduce the fee (where applicable).

However, some individuals may not be able to request the record in writing, due to literacy or language barriers. In order to be true to the concept of "right to request access", the health information custodian could be required to assist the individual in making the request. This could involve the health information custodian filling out the

form, or allowing the individual to take the form and have it completed by someone else who could assist them.

Individuals have the right to request their health information for any reason they wish. Individuals do not need to tell the health information custodian why they are requesting the information.

There may be circumstances when the health information custodian is comfortable allowing access to health information without a formal request. For example, in the course of a health care visit, a physiotherapist may be willing to allow the patient to review the record and be provided with a copy of test results. The requirement for a process should not prevent informal communications between the health information custodian and the individual.

The individual may also decide that they only want to view the record without receiving a copy of it. This should also be accommodated by the health information custodian.

Finally, to protect themselves and the privacy of the individual, the health information custodian should make a reasonable effort to ensure that the person making the request is the individual or their substitute decision-maker.

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## PROPOSED PROVISION

### Request for access

1. A person may obtain access to a record by:
  - (a) making a request in writing to the health information custodian that has the custody or control of the record;
  - (b) specifying the subject-matter of the record requested with sufficient particulars to enable the health information custodian to identify and locate the record; and
  - (c) paying any fees required by the health information custodian.
2. The applicant may ask to examine the record or ask for a copy of the record or both.

### Assistance

3. If the request does not contain sufficient detail to enable the health information custodian to identify and locate the record with reasonable efforts, the health information custodian shall offer assistance to the person requesting access in reformulating the request to comply with section 1.
4. A health information custodian may waive the requirement to make the request in writing if the individual making the request:
  - (a) has a limited ability to read or write English; or
  - (b) has a disability or condition that impairs the individual's ability to make a request in writing.
5. An individual does not have to provide the reasons or purposes for which they are requesting the information.

### **Identity of individual**

6. A health information custodian shall not make a record of personal health information or a part of it available to an individual under this Part or provide a copy of it to an individual without first taking reasonable steps to be satisfied as to the individual's identity and the authority to access the information.

### **Informal access**

7. Nothing in this Act prevents a health information custodian from,
- (a) granting an individual access to a record of personal health information, to which the individual has a right of access, if the individual makes an oral request for access or does not make any request for access under section 1; or
  - (b) with respect to a record of personal health information to which an individual has a right of access, communicating with the individual or his or her substitute decision-maker who is authorized to consent on behalf of the individual to the collection, use or disclosure of personal health information about the individual.
8. The health information custodian has the discretion to determine whether to grant informal access.

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#### **Tell us what you think**

- Q37 Are the proposed provisions appropriate? Why or why not?
- Q38 Should individuals be required to put all requests for information in writing?
- Q39 What is a reasonable requirement for a health information custodian to assist an individual in making a request?

#### **d. Frivolous or vexatious requests**

The vast majority of individuals request their information in a responsible manner. Occasionally, there are individuals who request their information for no reason except to obstruct the operations of a health information custodian. For example, an individual could make weekly requests for information, even though the information has been provided and has not been updated. In these cases, it may be appropriate to allow the health information custodian to refuse the request. As is the case with most refusals of a right, the onus would be on the health information custodian to justify the refusal.

Some individuals may be concerned that their reasons for requesting the information may be considered to be frivolous, and would be worried that the request could be refused based on the health information custodian's opinion of their request. However if the individual is not required to provide reasons for their request (see above) there would be little opportunity for the health information custodian to refuse because s/he felt that the request was frivolous based on the reason for the request.

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## PROPOSED PROVISION

### Frivolous or vexatious requests

1. A health information custodian who believes on reasonable grounds that a request for access:

- (a) is frivolous or vexatious;
- (b) amounts to an abuse of the right of access;
- (c) is made for a purpose other than to obtain access; or
- (d) would interfere in the custodian's operations

may refuse to grant the request.

2. When a refusal is made under section 1, the health information custodian shall provide the individual with a notice that sets out the reasons for the refusal and that states that the individual is entitled to make a complaint about the refusal.

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### Tell us what you think

Q40 Is the proposed provision appropriate? Why or why not?

### e. Fees

Health information legislation in other provinces allows health information custodians to charge reasonable fees for providing a copy of an individual's health information records. Reasonable fees may include the actual costs associated with copying and preparing the records or the cost may be capped at a maximum amount.

Current fees for copies of hospital records are found in the regulations to the *Hospitals Act* and include both administrative and reproduction fees. The *Personal Information Protection and Electronic Documents Act*, states that access should be provided at "minimal or no cost to the individual". This Act governs many commercial health care providers in private practice including doctors, physiotherapists, and dentists, and for-profit organizations like nursing homes and home care agencies.

In some cases, the health information custodian may decide to waive the fee after consideration of the actual time and effort involved, or the financial situation of the individual.

Under the *Freedom of Information and Protection of Privacy Act*, public bodies do not charge individuals any fee for access to their own information. For example, individuals are entitled to receive a copy of information related to their application for nursing home placement at no charge.

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## PROPOSED PROVISION

### Fee for access

1. A health information custodian that makes a record of personal health information or a part of it available to an individual under this Part or provides a copy of it to an individual may charge the individual a fee for that purpose if the health information custodian first gives the individual an estimate of the fee.

### Amount of fee

2. The amount of the fee shall not exceed the prescribed amount or the amount of reasonable cost recovery, if no amount is prescribed.

### Waiver of fee

3. A health information custodian mentioned in section 1 may waive the payment of all or any part of the fee that an individual is required to pay under that subsection if, in the health information custodian's opinion, it is fair and equitable to do so.
  4. The health information custodian has the discretion to determine whether to grant a fee waiver.
- 

### Tell us what you think

Q41 Is the proposed provision appropriate? Why or why not?

## 3.16 Correction of your health information

Another right available to individuals under various privacy Acts includes the right to request a correction of your health information. In some cases, the correction you wish to make may be a factual error (e.g. wrong date of birth). In other cases, an individual may wish to dispute an assessment or diagnosis on the record.

Professional standards for health records would not always allow a record to be changed. However, a health information custodian may place a notation on the record that the information has been verified and outlining the correct information. The health information custodian could also place a statement of disagreement on the record outlining the individual's disagreement with the information.

It is common for health information to be used for reasons other than care and treatment. For example, health information may be required for employment reasons, to satisfy requirements for adoption, or to qualify for a benefit. In those cases, the information would be viewed by the individual as needing to be correct not only for the health information custodian's use but for any other potential uses.

As with requests for access, there may be circumstances when a health information custodian considers a request or requests for correction to be frivolous or vexatious. In these cases, it could be appropriate to allow the health information custodian to refuse the request.

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## PROPOSED PROVISION

### Correction

1. If a health information custodian has granted an individual access to a record of his or her personal health information and if the individual believes that the record is not accurate, complete or up-to-date, the individual may request in writing that the health information custodian correct the record.

### Informal request

2. If the individual makes an oral request that the health information custodian correct the record, nothing in this Part prevents the health information custodian from making the requested correction.

### Duty to correct

3. The health information custodian shall grant a request for a correction under section 1 if the individual demonstrates, to the satisfaction of the health information custodian, that the record is not complete, accurate or up-to-date and gives the health information custodian the information necessary to enable the health information custodian to correct the record.
4. Despite section 1, a health information custodian is not required to correct a record of personal health information if,
  - (a) it consists of a record that was not originally created by the health information custodian and the health information custodian does not have sufficient knowledge, expertise and authority to correct the record; or
  - (b) it consists of a professional opinion or observation that a health information custodian has made in good faith about the individual.

### Duties upon correction

5. Upon granting a request for a correction, the health information custodian shall:
  - (a) make the requested correction by:
    - i. recording the correct information in the record and,
      - (A) striking out the incorrect information in a manner that does not obliterate the record, or
      - (B) if that is not possible, labeling the information as incorrect, severing the incorrect information from the record, storing it separately from the record and maintaining a link in the record that enables a person to trace the incorrect information, or
    - ii. if it is not possible to record the correct information in the record, ensuring that there is a practical system in place to inform a person who accesses the record that the information in the record is incorrect and to direct the person to the correct information;
  - (b) give notice to the individual of what it has done under subsection (a);
  - (c) at the request of the individual, give written notice of the requested correction, to the extent reasonably possible, to the persons to whom the health information custodian has disclosed the information with respect to which the individual requested the

correction of the record, except if the correction cannot reasonably be expected to have an effect on the ongoing provision of health care or other benefits to the individual.

#### **Frivolous or vexatious requests**

6. A health information custodian that believes on reasonable grounds that a request for a correction:

- (a) is frivolous or vexatious;
- (b) amounts to an abuse of the right of correction;
- (c) is made for a purpose other than to obtain a correction; or
- (d) would interfere in the custodian's operations

may refuse to grant the request.

7. When a refusal is made under section 6, the health information custodian shall provide the individual with a notice that sets out the reasons for the refusal and that states that the individual is entitled to make a complaint about the refusal.

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#### **Tell us what you think**

Q42 Are the proposed provisions appropriate? Why or why not?

Q43 Are there circumstances when a health information custodian should not have to make a correction to the record? If so, can you provide examples of the circumstances?

### **3.17 Collection and use of health card numbers**

The Health Card Number is a 10-digit unique number assigned to each permanent resident of Nova Scotia who applies for and receives medical service insurance through the Department of Health. The Nova Scotia Health Card is proof of this insurance, and the health card number is used to uniquely identify individuals in the health care system.

Some organizations outside the health care system have requested that Nova Scotians provide the health card number as identification or a way to identify the person for non-health care purposes. In some cases this collection may be authorized by the Department of Health. Other purposes may be well outside of what the Department would consider reasonable.

Currently, no legislation gives the authority to the Department of Health to control who may collect the health card number. A provision in health information legislation would allow such control to protect the health card number as proof of medical services insurance and to uniquely identify the individual in the health care system.

Current uses outside the health care system may be continued by regulation. For example, the Department of Justice uses the health card number and the corresponding database to select jurors for trials in Nova Scotia.

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### PROPOSED PROVISION

1. Only the following have the right to require an individual to provide the individual's health card number or collect or use an individual's health card number:
  - (a) a health information custodian; or
  - (b) persons authorized by the regulations to do so.
2. When requesting a health card number from an individual, the person referred to in subsection (1) must advise the individual of the person's authority under subsection (1).
3. An individual may refuse to provide the individual's health card number where the person requesting it is not a person referred to in subsection (1)

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### Tell us what you think

Q44 Are the proposed provisions appropriate? Why or why not?

### 3.18 Privacy review and oversight

Independent privacy oversight is a critical component of an effective privacy framework. The individual or office charged with oversight is responsible for overseeing the health information custodian's compliance with privacy legislation and policy.

The Pan-Canadian Framework outlined other potential responsibilities for an independent privacy oversight body:

- monitoring how the Act is administered and conducting reviews;
- initiating investigations of privacy compliance;
- resolution and mediation of privacy complaints;
- providing oversight and review of privacy impact assessments;
- undertaking research matters relating to privacy legislation;
- developing public education programs;
- promoting best practice; and
- providing advice and comments to health information custodians.

#### Current status in Nova Scotia

Currently Nova Scotia is the only jurisdiction in Canada with no individual organization that has the legal authority to provide oversight for privacy issues and complaints. The federal government and the other provinces and territories have a blend of Ombudsman

offices and Privacy Commissioners, with a mix of order-making powers and bodies who make recommendations.

### “Substantially Similar” and independent oversight

In order for the *Personal Health Information Act* to be declared “substantially similar” with the *Personal Information Protection and Electronic Documents Act* (see Part 4 for further information on “substantially similar”), the federal department of Industry Canada requires that legislation have the following oversight:

“...an independent and effective oversight and redress mechanism with powers to investigate. The effective enforcement of privacy protection and recourse for individuals who believe that their personal information has been misused are both essential to sound privacy legislation.”

### Oversight review

The Nova Scotia Department of Justice has undertaken a review of the privacy oversight function with the objective of the assessment of and recommendation for potential oversight models. In anticipation of this review, no provisions have been recommended in this Discussion Paper, but your comments on this function are very important.

#### **Tell us what you think**

- Q45 Is independent privacy oversight an important component of health information legislation? Why or why not?
- Q46 Which of the potential responsibilities outlined in the Pan-Canadian Framework are appropriate? (see list above)
- Q47 Are there additional responsibilities for which an independent privacy oversight body should be responsible?
- Q48 What do you think should be the priorities for the responsibilities assigned to an independent privacy oversight body?

### **3.19 Offences and penalties**

In order to make the protections in personal health information legislation meaningful, they must be enforceable and carry with them the potential for reasonable fines and penalties.

In other jurisdictions, fines and penalties provisions have set out:

- a. the activities considered an offence under the Act and its regulations; and
- b. the corresponding penalties.

Rather than review a proposed provision, you are asked to review the following potential offences, and the range of fines and penalties, and comment on their appropriateness.

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## **Potential Offences**

### **1. Collection, Use, Disclosure, Retention and Destruction**

- (a) To collect, use, or disclose health information in contravention of this Act and its regulations.
- (b) To gain or attempt to gain access to health information in contravention of this Act and its regulations.
- (c) To obtain or attempt to obtain another individual's personal health information by falsely representing that the person is entitled to the information.
- (d) To fail to protect personal health information in a secure manner as required by this Act.
- (e) In connection with the collection, use or disclosure of personal health information or access to a record of personal health information, makes an assertion, knowing that it is untrue, to the effect that the person is a person who is entitled to consent on behalf of another individual.
- (f) To willfully dispose of a record of personal health information in contravention of requirements for protection of personal health information required in this Act or its regulations.

### **2. Health Numbers**

- (a) To require production of or collects or uses another person's health card number in contravention of this Act and its regulations

### **3. Access to records**

- (a) To alter, falsify, conceal, destroy or erase any record, or direct another person to do so, with the intent to evade a request for access to the record.
- (b) To make a request under this Act, under false pretences, for access to or correction of a record of personal health information.

### **4. Hindering investigations**

- (a) To obstruct, make a false statement to, or mislead or attempt to mislead the privacy oversight body or another person in the performance of the duties, powers or functions of the privacy oversight body under this Act,
- (b) To obstruct, make a false statement to, or mislead or attempt to mislead another individual or organization in the performance of the duties, powers or functions of that individual or organization under this Act.

### **5. Commercial use**

- (a) To use individually identifying health information to market any service for a commercial purpose or to solicit money unless the individual who is the subject of the health information has expressly consented to its use for that purpose.

- (b) To disclose personal health information contrary to this Act with the intent to obtain a monetary or other material benefit or to confer such a benefit on another person,

## 6. Agreements

- (a) To knowingly breach the terms and conditions of an agreement entered into with a custodian under this Act.

### Tell us what you think

- Q49 Are the proposed provisions appropriate? Why or why not?
- Q50 Are there other potential offences which should be added?
- Q51 Should due diligence (e.g. the care that a reasonable person exercises under the circumstances to avoid harm) be a possible defence to these offences? Why or why not?

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### Range of fines and penalties

In other Canadian jurisdiction, fine and penalties range from a maximum of \$10,000 – \$50,000 for an individual, and \$10,000 – \$250,000 for an organization or corporation.

Penalties for similar regulatory acts in Nova Scotia have fines with ranges from \$2,000 – \$25,000 for an individual and 2,000 - \$500,000 for an organization. Some Acts (including the *Freedom of Information and Protection of Privacy Act*) also carry the potential for an individual to be subject to up to six months imprisonment in place of or in addition to the fine.

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An individual who is guilty of an offence under this Act or its regulations is liable to the following:

1. in the case of an individual, to a fine of not more than \$10,000, or imprisonment for six months, or both; and
2. in the case of a corporation, to a fine of not more than \$50,000.

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### Tell us what you think

- Q52 Are the ranges of fines and penalties appropriate? Why or why not?

## 3.20 Review of legislation

It is not uncommon for provincial health information legislation to contain a mandatory review clause which requires government to review the legislation within a specific

period of time. Alberta, British Columbia, Manitoba and Saskatchewan health information laws all contain a provision which requires a review: Manitoba must review the Act within five (5) years of it coming into force, and the other jurisdictions review within three (3) years of coming into force.

The benefit of a mandatory review is that it requires government to evaluate whether legislation is working, and ensures an opportunity for consultation on any issues or required changes.

The challenge with a mandatory review is that the timing is arbitrary; the timeline is determined at the time the legislation is implemented and a review may not fit in with other priorities in health care or on the public agenda.

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### **PROPOSED PROVISION**

#### **Review of this Act**

1. Within three years after this Act comes into force, the minister shall
  - (a) undertake a comprehensive review of the operation of the Act that involves public input; and
  - (b) within one year after the review is undertaken or within such further time as the House of Assembly may allow, submit a report on the review to the Assembly.

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#### **Tell us what you think**

- Q53 Is mandatory review a good idea?
- Q54 If so, what would be an appropriate time period for a review and a review report?
- Q55 If you don't support a mandatory review, would you have any recommendation for an ongoing review process?

## **PART 4. “SUBSTANTIALLY SIMILAR”**

In 2004, the federal *Personal Information Protection and Electronic Documents Act* (PIPEDA) came into effect for many commercial activities, including some activities in health care. Under this federal law, all health care sector individuals and organizations who engage in “*commercial activity*” are covered by *PIPEDA* when they collect, use, disclose and retain personal information.

Included under *PIPEDA* are physicians, dentists, pharmacists and pharmacies, optometrists, and any other provider who is determined to be “*commercial*”.

Provincial health departments raised concerns about the application of this legislation to health care, as it was developed by Industry Canada for application to the commercial sector which did not have any privacy regulation (e.g. retail). Despite the concerns, *PIPEDA* has applied to commercial aspects of health care since 2004.

Under *PIPEDA*, provinces have the option of developing privacy legislation which may be deemed to be “*substantially similar*” to *PIPEDA*. In 2002, Industry Canada published the criteria used to determine whether provincial or territorial legislation would be considered to be “*substantially similar*” to *PIPEDA*.

Under the policy, privacy laws are “*substantially similar*” if they:

- incorporate the ten principles in the National Standard of Canada entitled *Model Code for the Protection of Personal Information* (see Appendix B) with special emphasis on the principles of consent, access and correction rights;
- provide for an independent and effective oversight and redress mechanism with powers to investigate; and
- restrict the collection, use and disclosure of personal information to purposes that are appropriate or legitimate

If a personal health information Act is deemed to be “*substantially similar*” by the Federal department of Industry Canada, the province will receive an Order so declaring from the Governor in Council.

This will result in all commercial health care providers included as “health information custodians” in the *Personal Health Information Act* being removed from the jurisdiction of *PIPEDA*; they will be fully and solely under the jurisdiction of the provincial health information legislation. If the legislation is not deemed to be substantially similar, commercial healthcare providers will be under two comprehensive pieces of privacy legislation.

Currently, four pieces of information privacy legislation, including one health information Act, has been determined to be “*substantially similar*”. They are:

Quebec - *An Act Respecting the Protection of Personal Information in the Private Sector*

British Columbia - *Personal Information Protection Act*

Alberta - *Personal Information Protection Act*

Ontario - *Personal Health Information Protection Act*

**Tell us what you think**

Q56 Should the legislation be developed to aim for substantial similarity with the *Personal Information Protection and Electronic Documents Act*? Why or why not?

## APPENDIX A: Privacy legislation in Canada

### **Federal**

*The Privacy Act*

*Personal Information Protection and Electronic Documents Act*

### **Alberta**

*Freedom of Information and Protection of Privacy Act*

*Health Information Act*

*Personal Information Protection Act*

### **British Columbia**

*Freedom of Information and Protection of Privacy Act*

*Personal Information Protection Act*

### **Manitoba**

*Freedom of Information and Protection of Privacy Act*

*Personal Health Information Act (PHIA)*

### **New Brunswick**

*Protection of Personal Information Act*

### **Newfoundland and Labrador**

*Access to Information and Protection of Privacy Act*

*The Personal Health Information Act (not yet in force)*

### **Northwest Territories**

*Access to Information and Protection of Privacy Act*

### **Nova Scotia**

*Freedom of Information and Protection of Privacy Act*

*Personal Information International Disclosure Protection Act*

### **Nunavut**

*Access to Information and Protection of Privacy Act*

### **Ontario**

*Freedom of Information and Protection of Privacy Act*

*Municipal Freedom of Information and Protection of Privacy Act*

*Personal Health Information Protection Act, 2004*

### **Prince Edward Island**

*Freedom of Information and Protection of Privacy Act*

**Quebec**

*Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information*

*Act Respecting the Protection of Personal Information in the Private Sector*

**Saskatchewan**

*Freedom of Information and Protection of Privacy Act*

*Local Freedom of Information and Protection of Privacy Act*

*Health Information Protection Act*

**Yukon**

*Access to Information and Protection of Privacy Act*

## APPENDIX B: 10 Fair Information Principles

### PRINCIPLES SET OUT IN THE NATIONAL STANDARD OF CANADA ENTITLED MODEL CODE FOR THE PROTECTION OF PERSONAL INFORMATION, CAN/CSA-Q830-96

The 10 Principles are outlined below. For the full Model Code, please see Schedule 1 to the *Personal Information Protection and Electronic Documents Act* at the Department of Justice Canada site: <http://laws.justice.gc.ca/en/P-8.6>

#### **4.1 Principle 1 — Accountability**

An organization is responsible for personal information under its control and shall designate an individual or individuals who are accountable for the organization's compliance with the following principles.

#### **4.2 Principle 2 — Identifying Purposes**

The purposes for which personal information is collected shall be identified by the organization at or before the time the information is collected.

Persons collecting personal information should be able to explain to individuals the purposes for which the information is being collected.

#### **4.3 Principle 3 — Consent**

The knowledge and consent of the individual are required for the collection, use, or disclosure of personal information, except where inappropriate.

Note: In certain circumstances personal information can be collected, used, or disclosed without the knowledge and consent of the individual. For example, legal, medical, or security reasons may make it impossible or impractical to seek consent. When information is being collected for the detection and prevention of fraud or for law enforcement, seeking the consent of the individual might defeat the purpose of collecting the information. Seeking consent may be impossible or inappropriate when the individual is a minor, seriously ill, or mentally incapacitated. In addition, organizations that do not have a direct relationship with the individual may not always be able to seek consent. For example, seeking consent may be impractical for a charity or a direct-marketing firm that wishes to acquire a mailing list from another organization. In such cases, the organization providing the list would be expected to obtain consent before disclosing personal information.

#### **4.4 Principle 4 — Limiting Collection**

The collection of personal information shall be limited to that which is necessary for the purposes identified by the organization. Information shall be collected by fair and lawful means.

#### **4.5 Principle 5 — Limiting Use, Disclosure, and Retention**

Personal information shall not be used or disclosed for purposes other than those for which it was collected, except with the consent of the individual or as required by law. Personal information shall be retained only as long as necessary for the fulfilment of those purposes.

**4.6 Principle 6 — Accuracy**

Personal information shall be as accurate, complete, and up-to-date as is necessary for the purposes for which it is to be used.

**4.7 Principle 7 — Safeguards**

Personal information shall be protected by security safeguards appropriate to the sensitivity of the information.

**4.8 Principle 8 — Openness**

An organization shall make readily available to individuals specific information about its policies and practices relating to the management of personal information.

The information made available shall include

**4.9 Principle 9 — Individual Access**

Upon request, an individual shall be informed of the existence, use, and disclosure of his or her personal information and shall be given access to that information. An individual shall be able to challenge the accuracy and completeness of the information and have it amended as appropriate.

Note: In certain situations, an organization may not be able to provide access to all the personal information it holds about an individual. Exceptions to the access requirement should be limited and specific. The reasons for denying access should be provided to the individual upon request. Exceptions may include information that is prohibitively costly to provide, information that contains references to other individuals, information that cannot be disclosed for legal, security, or commercial proprietary reasons, and information that is subject to solicitor-client or litigation privilege.

**4.10 Principle 10 — Challenging Compliance**

An individual shall be able to address a challenge concerning compliance with the above principles to the designated individual or individuals accountable for the organization's compliance.

# Personal Health Information Legislation for Nova Scotia

## Discussion Document - Questions

**Please note: Responses due by November 1, 2008.**

**An electronic version of the Questions document is available by contacting the Personal Health Information Project at 902.424.7058 or by e-mail at [phia@gov.ns.ca](mailto:phia@gov.ns.ca)**

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### **Purpose of the legislation**

Q1 Is this an appropriate statement of the purpose of the legislation? Why or why not?

### **Scope of the legislation**

#### **“Who” - health information custodians**

Q2 Is the provision describing “health information custodians” appropriate? Why or why not?

Q3 Are there other person or organizations who provide health care who should be considered as health information custodians under this Act?

#### **“What” - definition of personal health information**

Q4 Is the proposed provision appropriate? Why or why not?

Q5 Specifically, should both recorded and unrecorded information be covered, or should the legislation only apply to information that is recorded?

**“What” - definition of health care**

Q6 Is the proposed provision appropriate? Why or why not?

Q7 Specifically, are there any health care services that are not captured in the proposed provision that should be covered by personal health information legislation?

**Consent for collection, use and disclosure of personal health information**

Q8 Are the proposed provisions appropriate? Why or why not?

Q9 Specifically, do you think that the definition of what is “knowledgeable” outlined in section 5 is reasonable?

**Mature minors and consent**

Q10 Are the proposed provisions appropriate? Why or why not?

Q11 Specifically, is it appropriate to continue the current approach that leaves it to the health information custodian to decide the minor’s ability to consent in the circumstances?

Q12 Should there be an exact age stated in the legislation at which minors can be considered to have the ability to consent to the collection, use and disclosure of their personal health information? If so, what would be an appropriate age?

Q13 If this approach were implemented, what would be appropriate factors for health information custodian to consider when determining when minors can consent to the collection, use and disclosure of their personal health information?

**Substitute decision-maker**

Q14 Are the proposed provisions appropriate? Why or why not?

**Collection of personal health information**

Q15 Are the proposed provisions appropriate for the protection of privacy in limiting collection of personal health information? Why or why not?

**Use of personal health information**

Q16 Do you agree with the proposed provisions? Why or why not?

**Disclosure**

**General**

Q17 Are the proposed provisions appropriate? Why or why not?

**Disclosure of personal health information without consent**

Q18 Are the circumstances outlined in the proposed provision appropriate for disclosure without an individual's consent? If not, what should be amended?

Q19 Are there additional circumstances when personal health information should be disclosed without an individual's consent? What are they?

Q20 Should there be a requirement that all disclosures without consent are documented?

**Disclosure of personal health information without consent unless the individual objects**

Q21 Are the circumstances outlined in the Proposed Provision appropriate for disclosure without an individual's consent unless the individual objects? If not, what should be amended?

Q22 Are there additional circumstances when personal health information could be disclosed without an individual's consent unless the individual objects? What are they?

**Disclosure outside Nova Scotia**

Q23 Are the proposed provisions appropriate for disclosure outside of Nova Scotia? Why or why not?

**Retention, destruction and disposal**

Q24 Are the proposed provisions appropriate for the protection of personal health information? Why or why not?

**Research**

Q25 Are the proposed provisions appropriate for research? Why or why not?

### **Practices to protect personal health information**

- Q26 Are the proposed provisions appropriate? Why or why not?
- Q27 When determining what safeguards are “*reasonable in the circumstances*”, should the health information custodian take into account the type of personal health information which is being protected? Should some personal health information be given more protection than other personal health information?
- Q28 Should any additional safeguards be required for electronic health records?

### **Reporting of a privacy breach**

- Q29 Are the proposed provisions appropriate? Why or why not?
- Q30 Specifically, do you think individuals should be notified when their privacy is breached?
- Q31 Should every loss, theft or unauthorized access be reported to the individual, or should there be criteria for determining when notice is required?
- Q32 What factors should a health information custodian consider when deciding whether to notify an individual of a breach?
- Q33 Should there be an independent review of all breaches, regardless of whether the individual has been notified?

### **Privacy rights of deceased individuals**

Q34 Do you think that the period proposed for disclosure of information related to deceased persons or older records without consent is appropriate? Why or why not?

### **Access to your personal health information**

#### **Exceptions to access**

Q35 Are the proposed provisions appropriate? Why or why not?

Q36 Are there any other exceptions which could be included in the legislation?

#### **Process for requesting access**

Q37 Are the proposed provisions appropriate? Why or why not?

Q38 Should individuals be required to put all requests for information in writing?

Q39 What is a reasonable requirement for a health information custodian to assist an individual in making a request?

#### **Frivolous or vexatious requests**

Q40 Is the proposed provision appropriate? Why or why not?

## **Fees**

Q41 Is the proposed provision appropriate? Why or why not?

## **Correction of your health information**

Q42 Are the proposed provisions appropriate? Why or why not?

Q43 Are there circumstances when a health information custodian should not have to make a correction to the record? If so, can you provide examples of the circumstances?

## **Collection and use of health card numbers**

Q44 Are the proposed provisions appropriate? Why or why not?

## **Privacy review and oversight**

Q45 Is independent privacy oversight an important component of health information legislation? Why or why not?

Q46 Which of the potential responsibilities outlined in the Pan-Canadian Framework are appropriate for the oversight body?

Q47 Are there additional responsibilities for which an independent privacy oversight body should be responsible?

Q48 What do you think should be the priorities for the responsibilities assigned to an independent privacy oversight body?

### **Offences and penalties**

- Q49 Are the proposed provisions appropriate? Why or why not?
- Q50 Are there other potential offences which should be added?
- Q51 Should due diligence (e.g. the the care that a reasonable person exercises under the circumstances to avoid harm) be a possible defense to these offences? Why or why not?
- Q52 Are the ranges of fines and penalties appropriate? Why or why not?

### **Review of legislation**

- Q53 Is mandatory review a good idea?
- Q54 If so, what would be an appropriate time period for a review and a review report?
- Q55 If you don't support a mandatory review, would you have any recommendation for an ongoing review process?

**“SUBSTANTIALLY SIMILAR”**

- Q56 Should the legislation be developed to aim for substantial similarity with *Personal Information Protection and Electronic Documents Act*? Why or why not?

**Additional Comments**

- Q57 Are there any additional comments or questions related to the collection, use, disclosure, retention and destruction of personal health information or the content of this discussion paper?