**Nova Scotia Advisory Commission on AIDS**
**Commission consultative de la Nouvelle Écosse sur le sida**

# BRIEF TO THE LAW AMENDMENTS COMMITTEE
# BILL #89, PERSONAL HEALTH INFORMATION ACT
# November 24, 2010, Nova Scotia Advisory Commission on AIDS

First, I wish to thank the Law Amendments Committee for the opportunity to present some important issues around this proposed legislation. My name is Larry Baxter, Chairman of the NS Advisory Commission on AIDS (the Commission). With me today representing the Commission are Mary Hart-Baker, Commissioner, and Michelle Proctor-Simms, Director. By provincial statute, the Commission is an arms length advisory body to the Minister of Health and other Ministers on matters relating to HIV and AIDS.

The Commission supports the need for and intent of the proposed legislation to strengthen protection of personal health information in Nova Scotia. We know some persons living with HIV/AIDS (PHAs) have experienced stigma and discrimination as a result of unauthorized disclosure of their HIV status to third parties without their consent. Their experiences serve as a cautionary tale for what can happen not only to PHAs, but also to any person whose personal information has been improperly shared and/or breached especially if it relates to a stigmatized health condition. Inadequate protection of personal health information is particularly frightening and could have serious consequences for people living with stigmatized health conditions. Therefore, we believe

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that PHAs and Nova Scotians in general require greater protection of their personal health information than what would be provided in the Act as currently proposed.

After reading the bill a few times, attending presentations on its contents and discussing its implications numerous times, one is left with a bit of disconnect. While titled Personal Health Information, the focus of the bill is not entirely patient or individual focused. If one takes the term personal health information at full face value, one would come up with several characteristics or principles; such as:

- Ownership of its contents;
- Control over its contents;
- Access to its contents;
- Confidentiality of the contents; and
- Consent for who else sees it.

So when one rereads and reviews the proposed legislation with this more personalized lens, one finds the legislation lacking in many ways. Recognizing that ownership of one's own personal health information record may not be achievable during this round of legislative review; we must then look even more carefully at the other characteristics as a way to compensate for this lack of ownership. We must ensure that these other principles are as strong as possible to counteract the lack of ownership. For instance, should consent be more than knowledgeable implied consent? Making the baseline as knowledgeable explicit and specific consent could help counterbalance the lack of ownership.

To address some of the other characteristics of personal health, we chose to address them through scenarios to see how the legislation would potentially handle certain circumstances. After Bill 64 was withdrawn, we provided the Minister with these scenarios. It does not seem that the revised version as Bill 89 has adequately addressed our concerns. So we ask that the Law Amendments Committee apply these scenarios and their questions to this proposed legislation to see if it is strong and clear enough to protect these other principles of personal health information. If not, then a strong message needs to be given to the crafters of the companion regulations to ensure that the Act is implemented in a very patient centered manner.

Specifically, there are <u>three issues</u> that should be addressed to further protect PHAs and all Nova Scotians from unauthorized disclosure of personal health information regarding:

1. The ability to limit or "lock-out" certain individuals from accessing one's personal health information contained in a record either in whole or in part;
2. The assessment of potential harm or embarrassment to an individual in the event of a privacy breach, including whether the individual should be notified of the breach; and, although, beyond the scope of this legislation
3. The need to ensure that non-regulated health care providers, as well as other individuals and commercial enterprises who provide various services and collect personal health information are aware of and are in compliance with other privacy legislation, whether federal and provincial, and that the public be made aware of their legislated privacy rights.

When the Committee considers revision to the proposed legislation, we draw your attention to these concerns with specific clauses:

1. **The ability of an individual to limit or "lock-out" specific individual(s) from accessing one's personal health information**: In the section under "Consent," there is a clause [S 17(1, 2)] stating that *"an individual may limit or revoke his or her consent to the collection of personal health information or to the use or disclosure of personal health information in the custody or control of the custodian by notice to the custodian."* Under another clause related to "Practices to Protect Personal Health Information"[S 62 (1)], custodians are required "*to implement, maintain, and comply with information practices to ensure that personal health information in the custodian's custody or under its control is protected against, among other things, unauthorized access to or use"* [S 62 (1c)]. Another clause (S 65) states that *"a custodian who maintains an electronic information system shall implement any additional safeguards for such information required by the regulations"*.

   Finally, we note that subsequent clauses [S 67(1f) and S68(a) respectively] require custodians to facilitate communication and training of staff about the custodian's policies and procedures to protect personal health information and the Act; and to make available to the public a written statement that provides a general description of the custodian's information practices.

The protections outlined in these clauses represent important and needed innovations, but are not sufficient to protect personal health information from unauthorized access. Fundamental to the principle of informed consent - whether express or implied for the collection, use, and disclosure of personal health information -- is that it be given with full knowledge of the primary and any secondary purpose(s), and the potential benefits and consequences. This includes being informed of *who would (or could) access the information* (and/or to what specific parts) and, what the privacy safeguards are in place, as well as the ability to control or limit, or revoke who can access the information. To be able to limit or revoke access, individuals must be aware of this right and the process in which to exercise it.

To illustrate these points, please consider the following scenario:

> *A PHA was referred by her GP to a specialist. Both her GP and the specialist use an electronic health record system accessible to all health care custodians in the Nova Scotia network. Thus, the specialist and other health professionals working in the same office and involved in her case would have access to health information entered into the system, including results of blood and other diagnostic tests. After accepting the appointment, the PHA finds out that a nurse who works with the specialist is a tenant living in her apartment building. She's very concerned that this nurse would have access to her health information, particularly information related to her HIV diagnosis and care. She wishes to*

> *"lock-out" the nurse from accessing her record or, at least any information related to her HIV status.*

We ask the Committee to examine whether the Bill and any anticipated regulations would be strong enough to:

- Allow the patient in this scenario to lock out the nurse from her electronic health record, or at least that sensitive part of the health record related to HIV.
- Allow the patient in this scenario to lock out the nurse *if the record was paper-based, rather than electronic,* where the potential for unauthorized access (whether unintended or deliberate) could be greater.
- Allow the patient in this scenario to lock out a *non-professional staff member,* such as a receptionist, from either her paper <u>or</u> electronic record. While non-professional staff are unlikely to be involved in patient care and/or have "a need" to access personal health information, such individuals can and often do become privy to patients' personal information and/or would have the means/opportunity to access it (whether inadvertent or otherwise) .
- Ensure this patient is aware of her right to limit or revoke access, and the process in which to do so prior to giving consent. If so, we ask if the onus would be on the health care provider to inform the patient of this specific right (as part of the initial assessment or consultation

process), or on the patient to inquire about this right after exposure to a general public awareness initiative (by the health care system) or through general patient education practices of individual custodians?

- In the case of electronic records, ensure that the patient is informed of other potential health care settings beyond the specialist's office, such as a hospital emergency room, where the information contained in the record could potentially be accessed and/or used.
- Particularly for paper records, ensure that the right to lockout or limit access applies to the flow of any new and/or sensitive information into the record (e.g., lab results) that might indicate the nature of the patient's health condition.

To address these concerns, the Commission advises that the proposed Bill or subsequent regulations be enhanced by:

- Indicating that patients/clients have the right to lock-out both health-care and non-professional staff/agents of the custodian from accessing their personal health record either in paper or electronic form -- in its entirety or specific parts -- without having to explain the reason.
- Requiring custodians to develop educational materials and practices to inform patients/clients of this right and how they may exercise it. This may include the development of a patient counselling guidelines and protocol for health care professionals to use as part of the initial intake or consultation process with each new patient.

- Requiring the Provincial Government to implement a public education initiative to inform Nova Scotians of all their privacy rights covered by PHIA and other related privacy legislation (e.g., PIPEDA). This would be in addition to any educational materials and practices developed by individual custodians. The "average" member of the public would probably not distinguish between the various pieces of legislation and see all such privacy rights applying in any service setting, whether or not it was for a health care purpose. This point is further expanded upon later in point 3 of this submission.
- Ensuring that specific practices and procedures are outlined in the regulations to implement and support the legislation, including the means to reasonably sever parts of the record from the whole record. We understand the means to "reasonably sever" a part(s) of the record from the whole record are being examined; we strongly encourage that these be pursued.

2. **The assessment of potential harm or embarrassment and/or notifying of a privacy breach:** In the section, "Reporting of a Privacy Breach" [S 69], it is stated that a custodian shall notify the individual at the first reasonable opportunity if the custodian believes on a reasonable basis that personal health information has been "stolen, lost or subject to unauthorized access, use, disclosure, copying or modification" [S69(a)], and, as a result, there is

"potential for harm or embarrassment to the individual" [S69(b)]. A subsequent clause [S70(2)], indicates that the custodian shall notify the Privacy Review Officer (PRO) as soon as possible when a custodian determines that personal health information may have or has been subjected to one of the aforementioned events and decides "there is no potential for harm or embarrassment to the individual as a result" [S70(b)], and, this notification to the individual is not required."

These provisions and clauses offer reasonable and prudent "checks and balances" to protect individuals from undue concern and anxiety about a possible breach of confidentiality, but lack sufficient detail on what types of policies and procedures a custodian would apply in assessing both whether a breach had or may have occurred and if there is potential for harm or embarrassment. Furthermore, the assessment of "potential harm or embarrassment" is a highly subjective process; it will vary depending on who is undertaking the assessment, what type of personal health information has been and how it was breached, and who may have accessed the information.

Please consider this scenario to further illustrate this concern:

> *A woman with a history of depression has given birth to her first child at a regional hospital (outside the Halifax Regional Municipality). On a Friday afternoon, a Public Health Nurse visits her before she and the baby are discharged from the hospital*

> *to assess post-natal support needs. Some of the questions relate to past episodes of depression and the woman discloses her history. After completing the assessment, the Public Health Nurse leaves her room and stops at the nurses' station. She places the woman's file on the desk while re-arranging paperwork in her briefcase. While doing so, she engages in conversation with a colleague at the desk. Distracted, she forgets to retrieve the woman's file from the desk and leaves the hospital. She discovers the file missing Monday morning when she gets back to her office and remembers leaving it at the nurses' station. She immediately informs the charge nurse of this oversight. She hopes that the file is found, and that no one opened and/or looked at the file, but cannot be sure.*

Given the stigma related to some mental health conditions like depression (as well as other conditions, including HIV/ AIDS) any potential or actual breach of personal health information could be cause for significant concern and/or fear. Therefore, we ask the Committee to consider whether the legislation and/or regulations would provide an appropriate and consistent process to ensure the incident in this case (and other actual or suspected breaches):

- Follows rigorous and comprehensive procedures to determine if a breach had actually occurred;
- Uses appropriate criteria and procedures for assessing the potential for harm or embarrassment to the patient;

- Follows clear and consistent guidelines for decisions about whether to inform the patient of this potential breach of her personal information. For instance, would the decision to inform the patient be based on the degree of sensitivity of the information; length of time the file was missing; and/or whether the file had not been located?

To address this concern, the Commission advises that the legislation and/or subsequent regulations be enhanced by:

- Requiring that a standard provincial protocol be developed for assessing possible privacy breaches; and where it has been determined that a beach has or has likely occurred, for assessing potential harm or embarrassment to an individual.
- Detailing the specific policies and procedures for these assessments in the regulations. The regulations themselves could define a highly rigorous and comprehensive process. Alternatively, the regulations could empower patients to identify information <u>they perceive or experience</u> as sensitive in advance whether they would want to be advised of any general or specific breach, and the nature of the breach including specific individuals involved.

3. **Ensure that non-regulated health care providers and other individuals and commercial enterprises (who do not provide health care services) are aware of and in compliance with relevant federal and provincial privacy legislation.** The Commission has become aware through anecdotal reports that some health spas and hair salons are requesting new clients to complete health-related questionnaires, including questions related to HIV and other blood-borne pathogens. We are not aware of how widespread the use of such questionnaires has been in Nova Scotia, but it raises serious concerns about awareness and compliance among this sector – including non-regulated health care providers (e.g., massage therapists) – with the federal *Personal Information Protection and Electronics Documents Act* (PIPEDA) and other relevant federal and provincial privacy laws. While beyond the scope of the proposed Bill, we raise this as a potential gap in either the legislative framework and/or the implementation governing the protection of personal information in this province.

To illustrate this concern, please consider this scenario:

> *A PHA is applying for a membership at a local fitness centre and is asked to complete a health questionnaire. One question asks if you have ever tested positively for HIV. The PHA does not want to disclose his HIV status. He wonders why the fitness centre would "need to know" a person's HIV status to obtain a membership and if all such centres ask for this information. He decides not to*

*apply for a membership and returns the uncompleted questionnaire to the front desk person.*

Except in rare circumstances, a person's HIV status would not be relevant to this service or most commercial services available to the public. Therefore, we ask the Committee to consider:

- How could the <u>public,</u> especially those with sensitive or stigmatized health conditions, be better informed of their privacy rights generally, and, specifically, when accessing a particular service, including awareness of the right to refuse to give out personal information and still receive service in some situations?
- How are service providers and commercial organizations being made aware of their responsibilities under existing privacy laws? What could be done to ensure these organizations are better informed of their rights and responsible under existing privacy laws? How are they being enforced?

Such service providers must adhere to the **Canadian Standards Association Model Code for Protection of Personal Information** based on the 10 fundamental privacy principles used in existing legislation and the basis of the proposed Bill to limit the potential for PHAs and others to be harmed as a result of the disclosure of health information. These standards include communicating to clients what personal information is being collected and of its relevance to the service to be provided, and the policies and practices to safeguard their personal information (e.g., security measures; retention schedules).

To address this and the aforementioned concerns, the Commission advises that a **province-wide communication strategy** be developed and implemented on the existing provincial and federal privacy legislation when the PHIA is proclaimed into law. The communication strategy should be tailored to the relevant information and/or training needs and concerns of three target audiences: the public; regulated health care professionals and custodians, and non-regulated health care and non-health service providers and organizations. As part of this strategy, we recommend that:

- Regulated health care professionals, custodians, and regulatory bodies be informed of their rights and obligations under PHIA and the regulations governing these (e.g., staff orientation and training), and related applicable laws
- Non-regulated health care and non-health service providers and commercial organizations are made aware of the relevant privacy legislation, and their rights and obligations and the regulations governing these. Service providers and organization that are not in compliance should work with the appropriate provincial and/or federal body to ensure establishment of the necessary policies and practices (including staff orientation and training).
- As indicated previously, the public be educated about all their privacy rights under the various pieces legislation governing and protecting these rights,

distinguishing between the different legislation and to the types of services each would apply. Key messages would include how information is currently being protected; how new and recent legislation has improved the security of their personal information; how to learn information about privacy laws; and how to raise concerns about the new legislation or make a complaint.

- For PHAs and other people living with a stigmatized health condition, more specific information and communication measures should be developed in consultation with relevant health care providers and/or community-based organizations; advocacy groups; and members of affected populations

Again, we thank the members of committee for your time and attention in hearing these concerns and our suggestions and recommendations regarding Bill 89. If desired, the Commission would be pleased to discuss or assist with any further examination of these concerns.