

## 1 Introduction

In this discussion, the Newfoundland and Labrador Health Boards Association (NLHBA) is taking the opportunity to build on our presentation to the Freedom of Information Review Committee (“the Committee”) on principles for protection of personal health information in order to support the Committee’s recommendation for separate health information legislation.

Based on their review of the NLHBA presentation, *Freedom of Information and Privacy in the Health System*, and the presentation by the Newfoundland and Labrador Centre for Health Information (NLCHI), amongst others, the Committee recommended:

*That government enact separate health information legislation to apply to all health organizations; and until that time, personal health information remain subject to the jurisdiction of the proposed Freedom of Information and Protection of Privacy Act. (Recommendation 9)*

The NLHBA is in full support of this recommendation, and is presenting this discussion paper to underline the importance of this proposed legislative initiative for the health system to move confidently into the future with an appropriate regime for personal health information in place, with, as the Committee stated, “an appropriate balance . . . between an individual’s right to privacy and society’s needs [which] should be dealt with in legislation specifically designed for the purpose.” A legislative and regulatory framework for access to information and protection for personal health information will assist in the accountability of Government to its citizens, protect the privacy of individuals and the confidentiality of their personal health information and facilitate the improvement and development of the health system in the province. This presentation will address the need for specific health information legislation, covering both an individual’s legitimate need for protection of personal privacy and confidentiality of personal health information, held both privately and publicly, and the collective need and requirements of society for limited disclosure of personal health information.

## **2 What is Health Information and Where is it?**

In the absence of a piece of legislation specifically for the collection, use and disclosure of health information, the portion of the publicly-funded health system that is governed by Health Boards will fall under the broad umbrella of the new *Access to Information and Protection of Privacy Act* (to be proclaimed). This will replace a mixture of separate pieces of legislation, the *Freedom of Information Act*, the *Hospitals Act* and other legislation such as the *Child, Youth and Family Services Act* and the *Adoption Act*.

However, in today's health system individual health information is held not only by Government and its agencies, including Memorial University, but also by various private bodies, such as physicians' offices and private clinics, private research companies and other private health organizations, both large and small. Health services are delivered in a number of different types of locations, such as institutions, clinics, communities and private residences. The integration of community services into the health system has broadened the definition of health and the services that can be included as health services. Some health services are delivered privately, such as physiotherapy or optometry, and a number of alternative health disciplines are increasingly often linked to the health system, such as chiropractic, massage therapy or acupuncture. We know little about the level of security for individuals' health information held outside the public system, and security for health information held within the public system is strained by the pace of change and economic constraints.

Continuing technological advances allow health information to be collected and held in a number of different ways, offering both enhanced security and new risks of unauthorized access and use that were not envisaged by current legislation. On the one hand, the newly paperless Saint-Eustache Hospital north of Montreal was judged by the Quebec privacy commission to be more secure than a similar institution with paper records. On the other hand, the linkage of information from, for example, private insurance companies with employee records and linkage of employment insurance records with customs records has caused serious privacy concerns that will need to be addressed in the health context.

At the same time, the huge numbers of existing conventional paper and film records in health and community services in both public and private locations are the focus of access requests for reasons secondary to the original purpose for collection. Storage is becoming a problem and there are no province-wide policies to regulate the preservation, security and/or destruction of health records. Collections of human tissue that offer new sources of personal health data offer a new area of health information that will need to be addressed. In the health research setting as well as the delivery of health services it is crucial to get this right so that safeguards are in place for protection of personal health information that enable appropriate secondary access for research purposes, both biomedical and health systems.

We are requesting Government to undertake public consultations with health stakeholders in order to develop a separate piece of legislation governing health information. A key factor in the proposed health information legislation will be the development of a clear definition of health information, which is broad enough to incorporate health information collected in all types of public and private organizations and which sets out obligations and penalties for public and private individuals and organizations. Legislation that applies to all types of personal information in all public settings will not provide the kind of focussed framework that is required for the health system.

### **3 The Newfoundland and Labrador Centre for Health Information**

The NLHBA have had the opportunity to review the NLCHI documentation presented in November, 2002 to the Minister of Health and Community Services supporting their position on the need for separate legislation to govern the protection of personal health information.

The NLHBA supports the NLCHI position on the impact of the federal *Personal Information Protection and Electronic Documents Act* (PIPEDA) and the need for a

collection, use and disclosure framework which specifically addresses issues in the health system. The NLHBA feels that the complexities of health systems, as opposed to other sectors that are privy to personal information, are not addressed within PIPEDA, leading to undefined terms and statements on “commercial” activity and “consent” and contradictory interpretations on its application to settings such as physicians, hospitals, long term care, home-based care and so on within a health system.

This paper is intended as a companion piece to the NLCHI focus to highlight the views of the health system on the need to address in separate legislation the many ethical, legal, legislative and regulatory issues related to the protection of personal health information.

#### **4 Who should have Access and under What Conditions?**

It has been clearly established in the *Hospitals Act* that the record compiled in a hospital on an individual is the property of that hospital authority. However the individuals in question have the right to expect protection of their personal privacy and confidentiality of their information, with certain clearly-defined exceptions, statutory and otherwise. A defining characteristic of the health system is the physician/patient expectation of confidentiality over the extremely sensitive personal information that is contained in patient files. Individuals have the right to full access to their own health records, to challenge accuracy and completeness of the information, and to have it amended where appropriate. As far as access by individuals is concerned, however, most people do not know how to seek access to their health records and would find it difficult to identify where those records might be located. Access privileges for others must be strictly regulated on a “need to know” basis according to the health professional’s requirements for the individual’s care.

On the other hand, there are clear benefits to society from limited disclosure for secondary use of personal health information for public health purposes, health research studies, quality assurance, program planning and so on. The challenge lies in securing the management, integration and evolution of the health system, while respecting the legitimate demands of individuals for the protection of their personal health information.

Care will be needed in order to avoid either an overly-restrictive regime that may significantly impede valuable health research and improvements to the health system, or inappropriately free access by third parties to sensitive personal health information. How can appropriate circumstances be determined for loss of individual control over access and use of personal health information?

This question can be addressed by defining secondary access from the outset as an infringement on privacy, as exceptions to be authorized on a strictly limited basis using open and agreed-upon standards to determine whether the infringement can be justified and regulate the proposed activity. Health information is initially collected in the course of the diagnosis, management and treatment of the individual. Any secondary use of the data needs clear disclosure rules and limits to access, in which the applicant would be required to identify:

- the purpose for use of the data
- proposed safeguards against unauthorized access, security, integrity and confidentiality of the health information in question
- proposed methods of protecting individual privacy.

Legislation regulating health information should also offer a clear regime regarding consent which is appropriate to the health sector, recognizes the complexities of consent in the health field and deploys the full scope of means for protecting privacy (encoding, stripping or encrypting of data, confidentiality agreements, review and oversight by independent body, etc.). For accountability purposes, legislation should also require an electronic access tracking system to keep track of access to records and reasons for access requests, and set out a regime for the validation and conversion of health records to electronic formats.

The standards developed by the Newfoundland and Labrador Centre for Health Information and the Canadian Centre for Health Information, based on the Canadian Standards Association CSA Standards, provide an excellent starting point for discussions

on overall policy for health information legislation governing privacy and access to health information in our province.

## **5 Who should Review the Process?**

Newfoundland and Labrador needs an Information or Privacy Commissioner or Commission Office with the responsibility of:

- overseeing and monitoring the consistent province-wide application of privacy and freedom of access legislation,
- ensuring compliance both by Government and the private sector,
- participating on the provincial research ethics board, which reviews health research with human participants in the province,
- and investigating complaints.

It is possible that this role may be given to the newly-established Ombudsman office, although the complexity and breadth of the issues involved may require a separate organization dedicated to information and privacy issues.

## **6 Conclusion**

The health system in Newfoundland and Labrador has changed significantly over the past few decades. It was clearly envisaged at the time of developing the *Hospitals Act* that the health system would require special attention with regard to privacy and access to the particularly sensitive personal health information in hospital health records. This legislative decision, which dealt with the health system as it then was, now needs to be revisited in the context of today's health system. Legislation for health information needs to meet the challenges of the expanded mandate of the health system with its existing records in many locations and of the rapidly-evolving technological potential for collecting and storing health information. This merits a separate comprehensive piece of health information legislation, developed through broad consultation with all stakeholders in the health system, to address the complex issues in the most effective manner.