

# Personal Health Information in New Brunswick:



## *Balancing Privacy Rights and Access Requirements*

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Report of the New Brunswick Task Force  
on Personal Health Information

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## **Acknowledgement**

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## **List of Acronyms**

EHR- Electronic Health Record

GDP- Gross Domestic Product

iEHR- Interoperable Electronic Health Record

IPC- Information and Privacy Commissioner

PHI- Personal Health Information

PHIPA- Personal Health Information Protection Act (Ontario)

PIA- Privacy Impact Assessment

PIPEDA- Personal Information Protection and Electronic Documents Act (Canada)

PMP- Prescription Drug Monitoring Program

POPIA- Protection of Personal Information Act (New Brunswick)

RCPSC- Royal College of Physicians and Surgeons of Canada

RHAs- Regional Health Authorities

## Section 1: Introduction and Overview of Report

### 1.1 Mandate

On May 23, 2007 the Honorable Michael Murphy, Minister of Health for New Brunswick, announced the creation of a Personal Health Information Task Force (the **Task Force**) dealing with access to and protection of personal health information (PHI). The under-signed were appointed as co-chairs.

The mandate of the **Task Force** was to consult with New Brunswickers and provide recommendations to the Minister of Health on new legislation to govern the collection, use and disclosure of PHI in the province.

In making the announcement of the **Task Force**, the Minister noted the rapidly developing capacity to share personal health information through technological advancements and emphasized the “...*obligation to properly use and protect information.*” The Minister also indicated that the “*government plans to introduce legislation that is specific to the use and protection of personal health information as part of the **Charter for Change** commitment to modernize privacy and right to information laws in New Brunswick and further protect an individual's personal information from misuse.*”<sup>1</sup>

This **Task Force** deals with issues pertaining to the collection, use and protection of personal health information. While related, the work of this **Task Force** is separate from the independent review of the existing **Right to Information Act** and **Protection of Personal Information Act** conducted under the chairmanship of Donald Savoie of the Université de Moncton.

Much like consultations that examined this subject in other Canadian provinces, the New Brunswick **Task Force** focuses on privacy and confidentiality in the management of PHI. It is particularly interested in how better management of PHI may advance the quality of care to individuals

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<sup>1</sup> *The Honourable Michael Murphy, Minister of Health of New Brunswick, statement announcing the creation of the New Brunswick Task Force on Personal Health Information, May 23, 2007.*

and lead to improvements in the organization of the health care system itself. Some envision a future where an electronic health record (EHR) infrastructure will make access to PHI much easier both for the purpose of providing care to individuals and for system planning and management.

## **1.2 Process**

Information on New Brunswick's **Task Force**'s coordinates, its mandate and details of the consultation timetable were publicized through the Minister's announcement, a press release and a dedicated website. A Background Paper and a Consultation Guide was posted on the **Task Force** website prior to the beginning of consultations. In a letter sent on May 18, 2007 in anticipation of the Minister's announcement, the co-chairs invited more than 100 stakeholders and interest groups to participate in the consultation process.

The general public, government ministries and agencies, and interested parties were provided various opportunities to make their views known to the **Task Force**. Public hearings, with simultaneous interpretation, were held in seven communities across the province (Saint John, Moncton, Fredericton, Edmundston, Campbellton, Bathurst and Miramichi). Individuals and stakeholders were invited to prepare written submissions or offer comments through regular mail or by using our website. Some exercised their option of making their views public by accepting posting on the **Task Force** website. A number of groups met with the **Task Force** in private.

Approximately 40 written briefs were received (see Appendix 2) and upwards of 15 stakeholders were engaged in extended discussions of PHI issues.

The **Task Force** met with affected government departments and agencies collectively to hear their interests and concerns. It also met with selected departments and agencies for a more in-depth exploration of the issues. In addition, departments and agencies were asked to submit a written description of their current use of PHI and to indicate how they might be impacted by the new legislation contemplated in this area. Separate meetings were held with the New Brunswick Ombudsman, Mr. Bernard Richard, in his capacity as Privacy Commissioner for the province and with Mr. Donald Savoie as chair of the provincial government's **Task Force on the Right to**

**Information and Protection of Personal Information.** Meetings were also held with representatives of physicians and pharmacists in New Brunswick.

Finally, the **Task Force** studied the PHI legislation of other Canadian jurisdictions and consulted with certain experts and officials in other provinces to learn firsthand about their experience in developing PHI legislation and its implementation. It also took good note of the excellent work done in this area under the aegis of the Federal-Provincial-Territorial Conference of Deputy Ministers of Health and contained in the **Pan Canadian Health Information Privacy and Confidentiality Framework** (the Pan Canadian Framework).<sup>2</sup>

The steps and process chosen by New Brunswick in preparation for the adoption of legislation for the protection of PHI differ from those followed in most other Canadian jurisdictions. This province has chosen to seek public input in determining the content of such legislation while most other jurisdictions consulted the public on draft legislation. This, however, does not preclude further consultations at the drafting or legislative stage, if deemed necessary.

This report and its recommendations are shaped by: i.) what the **Task Force** heard in New Brunswick from those who presented their views, ii.) the experience and best practices in other jurisdictions, and iii.) what the co-chairs believe will work best in New Brunswick.

### **1.3 Overview and Context of the Report**

We believe that there ought to be several objectives for PHI legislation in New Brunswick. While the reasoning for each objective will be set out over the course of the report, there is value in consolidating and listing these objectives at the beginning of this report:

- One set of rules for all custodians of PHI in New Brunswick.
- A balance between the privacy and access rights of the individual patient on the one hand and the access requirements of health system managers and health service providers on the other hand.

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<sup>2</sup> Conference of Federal-Provincial-Territorial Deputy Ministers of Health, **Pan Canadian Health Information Privacy and Confidentiality Framework**, January, 2005

- A scope of application for PHI legislation that is practical in terms of enforcement.
- An independent privacy oversight and review body that has both “hard” and “soft” powers.
- Implementation of the legislation only after appropriate education and training of PHI custodians and only after a privacy commissioner’s office has been established with resources that are commensurate to the task.

In the course of 16 short sections, this report reviews and gives advice on the principal policy and legislative issues related to protecting privacy and providing appropriate access to PHI. The principal issues correspond to the section headings in this report. These issues have been thoroughly examined in most other Canadian jurisdictions and this report does not, by and large, break new ground.

However, three points are addressed in this report which, as far as we know, have not been reviewed or considered in similar studies. First, we are mindful of the significant implementation challenges associated with PHI legislation and although it is not explicitly in our mandate, we offer advice on implementation. Second, unlike work on PHI legislation in other provinces, this report is being drafted at a time when interest and investment in an interoperable electronic health record (iEHR) is growing quickly. Because of this, the **Task Force** cannot ignore the privacy implications of an iEHR. We are aware of the opinion that an iEHR cannot be created in a timely way without legislative authority to require the disclosure of PHI by data custodians to the Minister of Health or to an arms length entity charged with the creation and maintenance of an iEHR. Readers will find reference to a precedent for such authority at various points in the report. The third unique aspect to the report derives from the previous point and that is the requirement for certain data custodians (pharmacists in particular) to disclose specific PHI to the Minister of Health in order for the Minister to implement an effective Prescription Drug Monitoring Program (PMP) as promised in the **Charter for Change**. Therefore, the **Task Force** believes it is obliged to address the privacy implications of the proposed PMP.

Two key terms are at the heart of the report: privacy and confidentiality. These terms are essentially two sides of the same coin. In the words of the

Pan Canadian Framework, privacy in relation to information, “*involves the right of individuals to determine when, how and to what extent they share information about themselves with others*” ... [and] ... “*confidentiality is the obligation of an organization or custodian to protect the information entrusted to it and not misuse or wrongfully disclose it.*”<sup>3</sup> That said, we caution readers that neither the right of privacy nor the obligation of confidentiality are absolute but are situated within a legal context that recognizes that there will be occasions when a patient’s right to privacy is qualified by circumstances (see Sections 6, 7, 8, 10 and 11) and when a data custodian’s obligation to protect the privacy of an individual’s information is qualified by a larger public interest (see Section 11 in particular).

The consultation paper issued by the **Task Force** stated that “*There is no information more sensitive and in need of protection than personal health information, the information about the state of our bodies and minds.*”<sup>4</sup> We are confident that every privacy commissioner in Canada would agree with this statement. In fact, on this point, the introduction to the submission received from the New Brunswick Ombudsman quoted a decision of the Supreme Court of Canada written by Mr. Justice Gerard Laforest (as he then was) in *R. v. Dyment* (1988) as follows: “*... privacy is essential for the well-being of the individual. For this reason alone, it is worthy of constitutional protection ... Recent trends in health care exacerbate the problems relating to privacy in the medical context ... The dehumanization that can result has led some hospitals in the United States to appoint an ombudsman for patients.*”<sup>5</sup> Recognizing these threats, jurisdictions across North America have made important strides in protecting privacy rights over the last 20 years.

## **Section 2: Characteristics of the Canadian Health Care Sector**

In Canada, health care constitutes one of the largest industries with spending of over \$148 billion (combining both the public and private sectors) in 2006 and employing over 1 million individuals. It represents approximately 10% of our Gross Domestic Product (GDP). It is also very complex, highly specialized and information intensive. Its workforce is among the most

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<sup>3</sup> **Ibid**, p. 28.

<sup>4</sup> Personal Health Information Task Force, **Personal Health Information Access and Privacy: Background Paper**, May 2007, p.3.

<sup>5</sup> The New Brunswick Ombudsman, **Submission to the New Brunswick Task Force on Personal Health Information**, [http://www.gnb.ca/0051/personal\\_health\\_information/submissions-e.asp](http://www.gnb.ca/0051/personal_health_information/submissions-e.asp), p. 2.

diversified. In medicine alone, the Royal College of Physicians and Surgeons of Canada (RCPSC) now recognize 38 different specialties and subspecialties<sup>6</sup>. The industry also counts on several other professionals spread in multiple workplaces, both public and private. One national newspaper, the **Globe and Mail**, lists no less than 130 different job titles in its health career advertisement section. Several of the professions involved rely on their own code of ethics as it relates to the handling of PHI.

Every minute, the Canadian “health care system” generates over 2,000 transactions involving an exchange of information. This is comparable to the volume of transactions found in the country’s banking institutions. Annually, Canadians make more than 322 millions visits to the doctor (94% results in handwritten paper records), have over 382 million drug prescriptions filled on their behalf, cause 440 million laboratory tests to be performed and use imaging procedures on more than 35 million occasions.<sup>7</sup> In New Brunswick, community pharmacies filled more than 9 million drug prescriptions in 2006-07. In the same fiscal year, approximately 5 million Medicare payment transactions took place in the province. Each of these transactions requires documentation and information exchange.

In New Brunswick, the public component of the health care industry alone has over 18,000 employees (excluding fee for service physicians). This is close to 40% of all (46,732) provincial public sector employees. Service management and delivery is highly decentralized through 8 semi-autonomous Regional Health Authorities (RHAs), each with their own administration and support systems, including separate patient records. In addition, numerous specialized and disease specific organizations play a role in health care planning and delivery across the province. Most of them have developed and use their own data sets that are generally not interconnected and often overlap with one another.

The health care sector, although highly dependent on information to conduct its business, makes relatively limited use of information technology (IT). Investments in IT lag behind most other industries. Surveys conducted in the United States and Britain in the late 1990s show that health care ranked 38<sup>th</sup>

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<sup>6</sup> See Preston Smith, MD., “Too many sub-specialists in health care”, **Times & Transcript**, Moncton, NB, July 18, 2007.

<sup>7</sup> See the Health Council of Canada, **Health Care Renewal in Canada. Clearing the Road to Quality**, Annual Report to Canadians 2005, February 2006. These figures were for calendar year 2005.

out of 53 industries in term of its expenditure on IT per employee.<sup>8</sup> The banking sector spent nine times as much on IT per employee as in the health sector.

This relative lack of investments in IT also holds true in Canada's health care industry. It manifests itself in several ways. According to a recent study by The Conference Board of Canada, in a seven-country comparison (Netherlands, New Zealand, U.K., Australia, Germany, United States, Canada) "*Canada reported the lowest capability among its primary care physicians for accessing and sharing medical records. Only 8 % of them routinely order tests electronically, 11% routinely prescribe medication electronically, 27% routinely access patient test results electronically, and only 15 % routinely access patient hospital records electronically*"<sup>9</sup>. In other words, notes on patients are often still held on paper.<sup>10</sup> Where it exists, electronic information is fragmented in locally based systems. A great deal of duplication can be found and health care organizations still operate as separate "silos". Hospitals and physicians often act without the benefit of complete information about the patient's condition, medical history, services provided in other settings, or medications prescribed by other clinicians.

In the Canadian institutional setting (hospitals and other establishments) a large quantity of data is still handled manually. In 2004, it was estimated that less than 30% of all hospitals kept an electronic record of drugs prescribed to patients. Only about 20% did computerized management of medical imaging. And a mere 36% had developed and made use of one form or another of patient electronic records.

Canada and New Brunswick are still several years away from having a comprehensive patient electronic record (containing information on the entire continuum of care: hospitals, doctors' offices, community pharmacies, Public Health offices and chronic care facilities). Progress on the development of the iEHR is slow and uneven across the country. However, the iEHR is now universally recognized as a way of achieving better, more integrated health care, and of improving health care planning and management. Information technology provides a means to avoid many

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<sup>8</sup> See "The health of nations. A survey of health-care finance". *The Economist*, July 17, 2004.

<sup>9</sup>The Conference Board of Canada, **Exploring Technological Innovation in Health Systems**, Report, August 2007, p. 35

<sup>10</sup> In 2004, the U.K. spent the equivalent of \$300 per person to implement electronic health records. In 2007, Canada is spending approximately \$40 per person for the same purpose. Estimates indicate that implementing an electronic health record for all Canadians will require \$350 per person.

medical errors: computerized systems, including electronic patient cards, would allow checks on the accuracy of doses and improve patient safety by telling doctors about other drugs that patients may be taking. An iEHR would also make it easier to integrate medical services between primary care providers and hospitals.

Consumers' penchant for DVDs, digital cameras, high-speed Internet and cell phones is also changing the way people think and behave. As electronic devices and information technology achieve greater penetration in Canadian households, patients are expecting that more communications with health care providers take place via the Internet. The most recent statistics indicate that 72% of the Canadian population now regularly uses the Internet.<sup>11</sup> It has become an indispensable medium of information and communication. Canada ranks second, just behind the United States, as the most connected country in the world. Consumers of health services expect to be able to communicate with the health care system in the same way that they do with their financial institutions or their travel agents, that is via electronic means. In the United States, 25% of physicians report communicating with their patients via e-mail. They use the Internet to transmit test and diagnostic results, to arrange appointments or to help them manage their conditions.

Technical factors and cost go some distance in explaining the slow progress in implementing an iEHR system in Canada. In preliminary estimates, Canada Health Infoway has pegged the cost of implementation of the iEHR at approximately \$10 billion for 100% of Canadians. However, worries about patient privacy and confidentiality have also slowed movement toward an iEHR. This is why governments across Canada are working to establish legal frameworks that will protect confidentiality of patient information while allowing appropriate access to that information for purposes of providing health care.

### **Section 3: One Set of Rules for New Brunswick**

As mentioned in Section 2, the health sector is information intensive. It is also true to say that this sector requires the unfettered flow of accurate information between health service providers within the circle of care as one of the conditions for the successful diagnosis, treatment and care of patients. In New Brunswick, there are two legal regimes that have a bearing on the

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<sup>11</sup> Mario Girard, "Les Canadiens champions d'Internet", *La Presse*, Montreal, Octobre 11, 2005.

management of (PHI). The **Protection of Personal Information Act (POPIA)** governs the management of PHI within the provincial public sector RHAs, hospitals, nursing homes, the Department of Health, etc. and the **Personal Information Protection and Electronic Documents Act (PIPEDA)**, which governs the management of PHI within the private sector (physicians' offices, community pharmacies, physiotherapy clinics, etc). The **Task Force** has heard expressions of concern about the lack of rule clarity regarding the management of PHI within each sector and this lack of clarity is reinforced by uncertainties about which privacy rules apply when PHI is exchanged across this boundary. In our research into the circumstances that caused other provinces to seek one legal regime to govern the management of PHI, a "patchwork of rules" was the most frequently cited factor. We accept the view that one set of rules and one arbiter (a Privacy Commissioner) would best serve the privacy interests of New Brunswickers as well as better serve their health care needs.

*"...it is our position that there is a need for common rules across sectors, and that any proposed law extend to custodians of health information in both the public and private sectors and be broad enough to capture entities such as private laboratories and diagnostic imaging facilities..."* **Canada Health Infoway**

Under the federal privacy legislation (**PIPEDA**) it is possible for a province that enacts comprehensive privacy legislation or comprehensive sector-specific privacy legislation (ex. personal health information), to seek a federal declaration that the provincial legislation is "substantially similar." If the federal Privacy Commissioner agrees that the provincial legislation is substantially similar, then the federal Privacy Commissioner will recommend to the federal Industry Minister (under whose authority **PIPEDA** resides) that the Minister seek a Governor-in-Council declaration that the provincial legislation is substantially similar. When such a declaration is made, all private sector custodians that possess PHI will fall under the provincial legislation for purposes of enforcement. As of this writing, three provinces have such a declaration for purposes of PHI: British Columbia, Ontario and Quebec.<sup>12</sup> In Ontario, there is stand alone PHI legislation, as there is in Alberta, Saskatchewan and Manitoba. In Quebec and British Columbia, there is provincial legislation that applies to all privacy issues in the public and private sectors.

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<sup>12</sup> See **Website of Federal Privacy Commissioner**:[http://www.privcom.gc.ca/legislation/ss\\_index\\_e.asp](http://www.privcom.gc.ca/legislation/ss_index_e.asp).

Many lawyers and health professionals see merit in establishing harmonious PHI statutes across the country. Were this to happen, it would not only mean that a single set of rules governed the management of PHI in each province but it would mean there was sufficient similarity across the country that PHI could be exchanged inter-jurisdictionally. Essentially there would be the same privacy and access rules for all Canadians. To make such a development more likely, the federal, provincial and territorial governments (via their Departments of Health) have consulted with stakeholders and developed what has come to be known as the Pan Canadian Framework. The Pan Canadian Framework is a set of guidelines for provinces that wish to develop PHI legislation that will have a high probability of being declared as substantially similar to **PIPEDA**. Among other things, the Pan Canadian Framework is consistent with Schedule 1 of **PIPEDA** which sets out 10 principles (along with their interpretation) that must guide the legislative drafting process for a privacy statute.

Ontario is the most recent province to enact PHI privacy legislation and the Ontario legislation has been declared substantially similar to **PIPEDA**. This **Task Force** regards the **Personal Health Information Privacy Act** of Ontario (**PHIPA**) as the “gold standard” among PHI privacy statutes in Canada because: i.) it is the most recent (up-to-date) enactment among the provinces, ii.) it is stand alone legislation, iii.) it has been declared substantially similar by the federal Minister responsible for privacy, iv.) it has a progressive, open and transparent regulation-making process and v.) it provides for “data institutes” as a method of de-identifying or anonymizing PHI so that this information can be used for purposes such as program evaluation, resource allocation, system planning and health research.

### *Recommendation(s)*

Taking all of this into consideration, this **Task Force** makes the following recommendations:

1. That New Brunswick enact PHI legislation that regulates the collection, use and disclosure of PHI in the public and private sectors and that the drafting of this legislation be guided principally by the Pan Canadian Framework, **PIPEDA** and Ontario’s **PHIPA**.
2. That in order to reduce legal uncertainty arising from the current application of federal and provincial privacy statutes to the

management of PHI in New Brunswick, the New Brunswick provincial government should seek, at the earliest practical opportunity, a federal declaration that New Brunswick's PHI legislation is substantially similar to the federal legislation (**PIPEDA**)

## **Section 4: Purposes of an Act and Definition of Personal Health Information**

### **4.1 Purposes**

To repeat the assertion in the Consultation Paper, there is no information that is more sensitive and in need of protection than PHI. Therefore, the importance of establishing and maintaining the strongest possible legal regime for the protection of that information, consistent with enabling health care providers to give the best possible care, cannot be overstated. Technology makes gathering, compiling, storing, retrieving and exchanging such information much easier. It also facilitates the use of the same information in the delivery of health care to individuals as well as in the planning and management of the health care system. There is a general consensus across the country that this new found capacity to collect, use and disclose information needs to be exercised with privacy rights in mind. This is why New Brunswick, like most other Canadian provinces, wants to move to strengthen the legal regime for the protection of PHI.

**POPIA** and **PIPEDA** are laws of general application. They have not been designed to deal specifically with PHI issues. It is our view that they are not adequate to address emerging issues regarding access to and confidentiality of such information. As stated in Section 3, they do not promote a consistent treatment of PHI across the public sector, or between the public and the private sectors. In New Brunswick, over 20 laws have elements bearing on the collection, use and disclosure of PHI. Even acts solely under the responsibility of the Department of Health do not take a consistent approach in this area.

Faced with similar circumstances, four provinces (Alberta, Saskatchewan, Manitoba and Ontario) have opted to enact dedicated legislation to govern all aspects of PHI. A fifth province, Newfoundland and Labrador, is currently in the process of developing similar legislation. A dedicated PHI

act is also the preferred option of most of those who presented their views to the **Task Force**. They emphasized the need for a single provincial regime across the private and public sectors.

### *Recommendation(s)*

In view of the above, it is, therefore, recommended that:

3. The purposes of new PHI legislation should:

- a) establish rules for the collection, use and disclosure of PHI that balance the privacy rights of individuals with the access requirements of health service professionals, health system managers and other legitimate users of PHI;
- b) confirm the right of individuals to request access to their PHI, to ask for correction(s) to their PHI and to have any changes recorded;
- c) provide for independent review of the application of the act and for resolution of complaints;
- d) provide for effective remedies in the event of contraventions.

One brief submitted to the **Task Force** recommended that the PHI act have a preamble to convey the rationale and spirit of the act. However, in our view, a strong and clear statement of purposes at the beginning of the act will serve the same purpose.

## **4.2 Definition of Personal Health Information**

In order for PHI legislation to work effectively, it will be necessary to adopt a definition of what constitutes PHI. The **Pan Canadian Health Information Privacy and Confidentiality Framework** and each of the provincial PHI statutes offer similar definitions of PHI. Those who presented to the **Task Force** during the consultation process, however, did not have a common understanding of what constitutes PHI. Some had a less comprehensive definition in that it excluded unrecorded information and information held by employers.

The various sources identified above offer core elements that could guide New Brunswick in formulating a definition of PHI for the purpose of the act. In most provinces' legislation, PHI means information that can be linked to a specific person and that relates to:

- that person's health or health care history, including genetic information;
- the provision of health care to that person; and
- payment for health care provided to that person.

It also includes general information about a person (such as name, address, gender and date of birth) if that information is collected during provision of a health service or if it is used to administer payment for a health care service. However, it excludes statistical or anonymous information that cannot be linked to a person. This definition applies in all Canadian jurisdictions.

Canadian provincial jurisdictions are inconsistent in their treatment of recorded and unrecorded PHI. The Pan Canadian Framework does not establish a distinction between recorded and unrecorded information. Nor does Ontario legislation where PHI means identifying information about an individual in oral or recorded form. In Alberta, on the other hand, only PHI that is in written form, photographed, recorded or stored in some manner in a record is included. Newfoundland is taking a similar approach by proposing that only recorded information be included.

As a matter of principle, the privacy of unrecorded PHI is deserving of no less protection than that which is recorded. This said, a number of those who presented to the **Task Force** raised the potential difficulties that the inclusion of unrecorded information would create. In the opinion of the Canadian Bar Association, New Brunswick Branch, it would pose "*potentially unworkable challenges*".<sup>13</sup> And, as observed by other presenters to the **Task Force**, it is important to recognize that professional codes and other safeguards exist to ensure patient confidentiality is maintained by those who provide health care services.

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<sup>13</sup> The Health Law Section of the New Brunswick Branch of the Canadian Bar Association, **Submission to the New Brunswick Task Force on Personal Health Information**, July 2007, p. 6.

The New Brunswick Pharmaceutical Society held a similar view and went so far as to suggest that “...neither clients, nor data custodians, should be permitted to provide waivers whereby certain information would not be recorded.”<sup>14</sup>

It is our view that the exclusion of unrecorded information would only marginally affect the completeness of an individual’s health record while considerably simplifying the implementation of PHI legislation. Including unrecorded information would probably present problems of “lost memory” and interpretation. Furthermore, inclusion of unrecorded information in the definition of PHI would likely discourage proper documentation of decisions, diagnoses and treatments.

#### *Recommendation(s)*

4. It is recommended that, for the purpose of its PHI legislation, New Brunswick adopt a definition of PHI similar to that proposed in the Pan Canadian Framework and **PHIPA**. We recommend, however, that New Brunswick’s definition exclude unrecorded information.

## **Section 5: Scope and Application of the Act**

### *Policy Considerations and Inter-jurisdictional Context*

There are two key policy issues that need to be addressed under “scope and application.” One is the type of PHI the legislation should cover. We have addressed this question in the previous section. The other issue is to whom the legislation should apply. Should it regulate all holders of any PHI in the public sector as well as in the private sector; including employers, private health care facilities and employees/health professionals working therein? And a related question is whether it should impose the same obligations on all holders of PHI regardless of their role in the health care sector? While in theory, one might argue that the scope of application of such legislation should be as broad as possible, it is reasonable to ask what is most practical and what added value a “blanket application” would bring?

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<sup>14</sup> New Brunswick Pharmaceutical Society, **Submission to the New Brunswick Task Force on Personal Health Information**, July 2007, p. 1.

Provinces with health information legislation have addressed this question by imposing varying obligations on holders of PHI depending on their role in the health care sector and the use they make of the information.

*“Legislation should apply to all people, agencies or organizations who hold, contribute to, or require access to an individual’s personal health information.”* **River Valley Health Presentation**

Therefore, not all entities possessing PHI are included under the legislation. Only those that are defined as “health information custodians” or “health information trustees” per the act are included. Provinces with PHI legislation adhere relatively closely to the definition of custodian offered in the Pan Canadian Framework which is “...*an individual or organization that collects, uses, or discloses personal health information for the purposes of care and treatment, planning and management of the health system or health research*”.<sup>15</sup> Typically, provincial legislation also lists categories of health information “custodians” or “trustees” and only those persons or organizations captured by one of those categories fall within the scope of the act. “Custodians” or “trustees” may include persons (health care professionals) or organizations, thus allowing coverage of a broad spectrum both in the public and private sectors. In Ontario, for example, entities listed as “custodians” include organizations and persons such as health care facilities, clinics, pharmacies, laboratories, doctors and other health care practitioners, and the Ministry of Health and Long Term Care.

The list of non-custodian entities includes professional governing bodies, such as the College of Physicians and Surgeons of Ontario, insurance companies, children’s aid societies and hospital foundations. In most provinces, employers possessing PHI are considered outside the ambit of the act. While employers may hold PHI, the vast majority are not, either directly or indirectly, in the health care business and do not use the information they hold for the purpose of delivering care. Furthermore, practical limits must be recognized to ensure that the new legislation is enforceable and that non-health care employers and organizations are not paralyzed by an overly complicated and stringent legislative framework.

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<sup>15</sup> See the **Pan Canadian Health Information Privacy and Confidentiality Framework**, op.cit., p.3.

In certain defined circumstances, a number of holders of PHI may, however, be held as “agents” or “affiliates” of custodians. PHIPA defines agent(s) broadly as “...a person(s) or entity(ies) who act for and on behalf of a custodian in respect of PHI for the purposes of the custodian.”<sup>16</sup> They, therefore, carry out functions with PHI on behalf of the custodians. Their obligations are derived from the authority and responsibility of the custodians.

Although not directly involved in the provision of care, persons or organizations who maintain and administer an electronic (EHR) system, because of the role that they play and because of the potential inadvertent disclosure, should, in our view, be listed as custodians in the PHI legislation.

A major consideration is that the scope of the legislation be broad enough to capture all holders of PHI who collect, use and disclose such information for the purpose of providing health care regardless of whether they are in the public or private sectors, whether they act independently or not and whether they are in the profit or not-for-profit sectors. Certified and registered health care practitioners are custodians for the purpose of the act in most provinces. Alberta stands apart as its health information legislation regulates only publicly funded entities and those providing care that is paid for by Alberta’s public insurance health plan.

The establishment of a uniform and consistent set of rules for the management of PHI across the entire health sector requires that, in the event of conflict between dedicated PHI legislation and any other statute, the former prevails. Rules dealing with PHI found in statutes other than in dedicated PHI legislation are generally removed or made consistent with the provisions of dedicated health information legislation. In our opinion, where this is not possible and where there is an intention to preserve existing special rules within the health sector, the exceptions should be made explicit.

### *Pan Canadian Framework*

The Pan Canadian Framework espouses the concept of custodians as referred to and described above. It provides a sample list of entities that should be considered as custodians, including classes of health professionals.

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<sup>16</sup> See Halyna Perun, Michael Orr and Fannie Dimitriadis, **Guide to the Ontario Personal Health Information Protection Act**, Irwin Law, Toronto, Ontario, 2005, p. 53.

It does not distinguish between the private and the public health sector. Nor does it take a position on whether or not employers should be included.

The Pan Canadian Framework also introduces agents/affiliates as holders of health information, but acting on behalf and within the authority and obligations of custodians.

### *Oral and written briefs*

Most briefs favored a broad scope for PHI legislation and they advocated the same set of rules for the private and public sectors. They also supported defining health care professionals, regardless of where they practice, as custodians. They were divided, however, on whether or not PHI held by employers should fall under the authority of the new act.

### *Recommendation(s)*

5. The following is recommended with regard to the scope of application of new PHI legislation:
  - a) that a custodian of PHI be defined as an individual or organization that collects, uses, or discloses PHI for the purposes of care and treatment, for planning and management of the health system, for health research and health education;
  - b) that the obligations imposed on custodians of PHI be based on the role they play in the health care system and on the use they make of PHI rather than on where they work and how they are remunerated;
  - c) that the definition of custodian apply uniformly in both the private and public sectors;
  - d) that the legislation make provision for the Minister of Health to identify and list, by regulation, entities and classes of health care professionals that will be considered as custodians;
  - e) that the legislation specifically identify persons or organizations who contribute to, maintain and administer electronic health record (EHR) systems as custodians;
  - f) that PHI held by employers continue to be regulated by PIPEDA or POPIA, as the case may be;

- g) that rules dealing with PHI in existing health-related legislation be removed or made consistent with the provisions of PHI legislation wherever possible, and that in the event of conflict between PHI legislation and any other legislation, the former should prevail.

Guidance in drafting the “scope of application” provisions of the New Brunswick legislation can be found specifically in the Pan Canadian Framework’s “Core Concepts” and under Sections 3, 7, 8 and 9 of Ontario’s **PHIPA**.

## **Section 6: Right of Access to Personal Health Information**

### *Policy Considerations and Inter-jurisdictional Context*

Perhaps the most fundamental manifestation of a privacy right in relation to (PHI) is the right to know what is contained in your medical or patient records. This right is grounded in the common law and in the Charter of Rights and Freedoms. That said, operationalizing the right can pose practical challenges. An individual living in New Brunswick has PHI distributed over many sites: one or more hospitals, one or more physician offices, one or more pharmacies, perhaps also a physiotherapy clinic or an allergy clinic and so on. If the individual has received health care outside New Brunswick, the fragmentation of his/her health records will be greater still.

*“Access to one’s own personal information with the option to obtain additional explanations is a basic right that should be denied only under highly specific circumstances, such as when the disclosure of personal information poses a hazard to the individual or society”* **Regional Health Authority 4**

As explained in the introduction to this report, the current legal landscape complicates the assembly and review of these records. Partly as a result of this complex legal landscape, there is no single standard in New Brunswick in relation to how requests are made to access one’s PHI, how entitlement to one’s PHI is explained by the custodian, how access is granted, how and when fees are charged, how corrections are made and so on. A single legislative enactment for PHI would potentially remedy this situation by creating the legal authority to develop and apply a single set of rules and procedures.

It is common practice for Regional Health Authorities (RHAs) holding PHI to have a privacy officer who is responsible for overseeing the handling of access requests, inquiries and complaints. These privacy officers, with the support of their organizations, are expected to act in good faith when handling inquiries and complaints and to do so in a timely fashion. When an individual is dissatisfied with the response or the refusal to respond on the part of an organization possessing their PHI, they may refer their complaint to the Privacy Commissioner (presently the Ombudsman in New Brunswick) who acts in an independent oversight and review capacity.<sup>17</sup>

The Commissioner of Official Languages for New Brunswick has submitted a brief that poses a number of questions related to the mandate of this **Task Force**, all of which pivot around the translation of patient records. In the words of the Commissioner: “... *the Official Languages Act provides that every health establishment must serve the members of the public in the official language of choice. The ... question is whether the provision of medical records is in fact a ‘service’* ”.<sup>18</sup>

Some might argue that the constitutional right (in New Brunswick) to receive services in the official language of choice requires translation of the record if it is not in the official language of the patient. However, the **Task Force** accepts the view that patient records are not services to patients; rather, they are working tools of health service providers. Therefore, as long as patients are personally served in the official language of their choice, we believe the constitutional right has been satisfied. It is our understanding that the objective of RHAs is to supplement the constitutional right with a practice of accommodation, namely, when the patient wants to see his/her record, to provide a physician to assist the patient in interpreting his/her record. Similarly, RHAs strive to accommodate the language needs of unilingual physicians by translating a patient record if it is in an official language the physician cannot understand. This accommodation is provided with the understanding that the official patient record is the one in the language used to create the record and with the further understanding that the technical nature of many records means the translated version may not

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<sup>17</sup> A total of 38 privacy complaints were received by the Ombudsman in 2005-06. See the Ombudsman of New Brunswick, **Annual Report 2005 – 2006**, p.41. A follow-up inquiry with the Ombudsman’s office revealed that approximately one third of the privacy complaints were health-related.

<sup>18</sup> See Commissioner of Official Languages of New Brunswick, **Letter to the New Brunswick Personal Health Information Task Force**, June 12, 2007, p.2.

accurately capture the full meaning of the official record. The key in the effort to accommodate is that the accommodation not produce an undue delay in the treatment and care of the patient and that the wait times for francophone and anglophone patients are approximately equal.

### *Pan Canadian Framework*

Subject to limited and defined exceptions such as the unavoidable disclosure of information about an identifiable third party, the Pan Canadian Framework recommends that the right of access to one's own health information be understood to include the entitlement "*to examine, receive a copy of and request a correction to the information.*" The Pan Canadian Framework also anticipates that custodians will "*designate a contact person to help ensure compliance with the legislation*". In this regard, see also **PIPEDA**, Schedule 1, Principle 1.

### *Oral and Written Briefs*

There was a general consensus that the right of access for each patient should be, more or less, as defined in the Pan Canadian Framework. Of the briefs received, the greatest interest in a patient right of access was expressed by the RHAs, arguably the institutions having the most experience with the exercise of this right. For the sake of consistency and fairness, the RHAs recommended a single regime that all RHAs would be obliged to follow. There was general agreement that the Pan Canadian Framework should be the principal source of guidance in drafting a legislative provision on this point.

### *Recommendation(s)*

6. It is recommended that the legislative provisions of a new act dealing with individual access to PHI should confirm, subject to exceptions where access would cause harm to the individual or someone else or where access would reveal information about a third party:
  - a) the right to view one's own PHI in a timely way including the right to know who has accessed the record;
  - b) the right to receive copies;
  - c) the right to challenge the accuracy of the record, and to have the health record corrected or, in the event that a correction

is refused, to appeal the refusal to an independent Privacy Commissioner; and

- d) the obligation of the custodian to record the correction and to notify other custodians (who have recently accessed the record) of the correction or, if there is an irreconcilable disagreement between the custodian and the patient, to affix a statement of the disagreement to the patient's record and to notify other custodians (who have recently accessed the record) of the patient's disagreement.

## Section 7: Models of Consent

### *Policy Issues and Inter-jurisdictional Context*

Consent is a difficult concept: philosophically, practically and legally. Nonetheless, giving legislative expression to the most relevant forms of consent is necessary if there is to be an appropriate balance struck between the privacy rights of patients and the valid PHI access requirements of health service providers and health system managers.

In its Health Information Privacy Code, the Canadian Medical Association defines “consent” and “implied consent” in the following words:

*“Consent means a patient’s informed and voluntary agreement to confide or permit access to or the collection, use and disclosure of his or her health information for specific purposes ... [and] ... [i]mplied consent arises where agreement may be reasonably inferred from the action or inaction of the individual and there is good reason to believe that the patient has knowledge relevant to this agreement and would give express consent if it were sought.”*<sup>19</sup>

Ontario’s **Personal Health Information Protection Act** allows health information custodians (health professionals) within the “circle of care”<sup>20</sup> to rely on *implied consent* wherever it is reasonable to do so; in other words, when it is reasonable to believe that the patient understands the purposes for

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<sup>19</sup> Canadian Medical Association, **Health Information Privacy Code**, 2007, page 3.

<sup>20</sup> “Circle of care” is a somewhat elastic term that is usually intended to include those health service providers who are required to treat and care for a patient. See Perun et al, **op.cit.**, pp. 216-17.

which the information is being collected, used and disclosed.<sup>21</sup> Implied consent is also sometimes known as *deemed consent*.<sup>22</sup>

A more rigorous or demanding approach to consent is known as *knowledgeable consent*. This model requires a health care provider “to post or make readily available a notice” that explains in lay terminology the purposes and possible consequences of collecting, using and disclosing a patient’s PHI<sup>23</sup> both within and outside the circle of care. This model is also referred to as the *implied knowledgeable consent* model.

“After consulting with other Privacy Commissioners, I have determined that implied knowledgeable consent is the best option. Without provisions requiring implied knowledgeable consent the legislation would most likely not be considered “substantially similar” to PIPEDA and then both pieces of legislation would apply and paramouncy issues would result. “ **Ombudsman**

More rigorous still is the *informed consent* approach that requires health care professionals “to provide to the patient details about the foreseeable consequences of [a] decision ...” regarding the collection, use and disclosure of PHI.<sup>24</sup> This approach or model contemplates the active exchange of information, questions and answers between the health service provider/health information custodian and a patient.

The highest and most rigorous form of consent is *express consent*. Once again, drawing on the CMA Health Information Privacy Code, “(e)xpress consent is given explicitly, either orally or in writing. Express consent is unequivocal and does not require any inference on the part of the provider seeking consent”. Express consent is the standard among Canadian jurisdictions when PHI is collected, used or disclosed outside the circle of care.”<sup>25</sup>

Within the circle of care, the standard for consent among Canadian jurisdictions is implied knowledgeable consent; this form of consent requires the use of notices, pamphlets and/or posters as methods of making patients aware of their privacy rights. In this model, health care providers may infer the consent of patients from the circumstances.

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<sup>21</sup> **Ibid.**, p. 201.

<sup>22</sup> See **The Health Information Protection Act**, subsection 27 (2); Chapter H-0.021 of the Statutes of Saskatchewan, 1999.

<sup>23</sup> Perun et al, **op.cit.**, p. 199.

<sup>24</sup> **Ibid.**, p.198.

<sup>25</sup> See Canadian Medical Association, **Health Information Privacy Code**, **op.cit.**, p.3.

The use of the implied knowledgeable consent model within the circle of care predominates for reasons of logic and practicality. If, for example, an individual presents himself in a physician's office or in an emergency room and medical personnel collect health information about the individual for purposes of addressing the individual's symptoms, it is widely accepted that an individual "with capacity" would understand and accept that his PHI will be used and disclosed, as necessary, to other health service providers for purposes of diagnosis, treatment and care. An express consent model would be onerous and impractical in such circumstances (i.e. within the circle of care).

*"...subject to certain exceptions, physicians should be able to rely upon implied consent for the collection, use, and disclosure of personal health information for the provision of health care to the individual. In many health care settings, it is far too onerous to require a physician to obtain explicit patient consent for every collection, use and disclosure of personal health information..."* **Canadian Medical Protective Association**

Ideally, health care professionals would periodically explain the law and the practice regarding consent and disclosure to their patients, particularly the frequent need to disclose PHI within the circle of care so as to ensure a correct diagnosis and appropriate treatment. However, the implied knowledgeable consent model is satisfied by posted notices and reasonable inferences as explained above.

Most jurisdictions and most professional health service provider organizations accept the principle that the collection, use and disclosure of PHI for reasons other than care and treatment, are secondary purposes and, as such, require the express consent of the individual. That said, it has become commonplace in the enactment of PHI privacy laws to set out a long list of exceptions to the requirement for express consent for secondary uses of PHI. Such exceptions to the express consent rule include determination of patient eligibility for service, payment of service, health system planning, medical research, peer review, quality assurance, the protection of public health, and compliance with a court order. Collectively, such exceptions might be considered as "public interest exceptions". (There is additional discussion of PHI disclosure without consent in Section 11.) The importance of such exceptions is eloquently stated by The Honourable Horace Krever; *"(c)ritical as the right of privacy is, like every other right, it is not absolute and where it conflicts with other interests deemed more important it must yield to them, **provided the resulting impairment is as small as possible.**"*

*(Emphasis added) Societal recognition must be given to such essential interests as health research, health-insurance administration, and public health. To minimize the importance of these interests to all of us, who are after all patients, would be a disservice.*”<sup>26</sup>

There are several other issues in relation to consent that warrant attention. Sometimes an individual lacks the mental capacity to make decisions about medical treatment and about the collection, use and disclosure of their PHI. A procedure for determining who is a substitute decision-maker in such circumstances and the criteria to guide them can be found in the PHI legislation of other jurisdictions. Similarly, when minors clearly have the capacity to make medical decisions about themselves, the PHI legislation of other provinces provide for their consent in relation to the collection, use and disclosure of PHI.

There is also an issue regarding the time limit on an individual’s oral or written statement of express consent in relation to disclosure of PHI. An appropriate time limit will vary with the circumstances and the circumstances are varied. At one end of the continuum, the time limit on express consent involving insurers may be measured in days or weeks. At the other end of the continuum, the time limit on consent for Medicare purposes is measured in years. In our view, the establishment of time limits for consent should be addressed on an incremental basis through regulation as requirements become apparent.

### *Pan Canadian Framework*

In relation to the collection, use and disclosure of PHI, the Pan Canadian Framework; i) accepts the prevailing models of implied knowledgeable consent within the circle of care and express consent outside the circle of care, and ii) accepts a long list of public interest exceptions to the requirement for express consent for disclosure of PHI outside the circle of care. The Pan Canadian Framework also requires express consent for the disclosure of PHI by custodians to other custodians for purposes other than the provision of health care and for disclosure of PHI to third parties such as insurers, lawyers, the media, fund raisers and marketers. Finally, the Pan Canadian Framework also contemplates circumstances in which minors have sufficient capacity to make decisions about their PHI.

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<sup>26</sup> From the Forward of Perun et al, *op cit.* , p. xxxv.

### *Oral and Written Briefs*

A substantial majority of briefs submitted to this **Task Force** support the prevailing approaches to determining individual consent for the collection, use and disclosure of PHI. Some of the concerns expressed in briefs to the **Task Force** regarding the protection of PHI against inappropriate use and disclosure can be addressed through what is referred to as a “lock box,” which is to say, a provision that allows an individual to withhold or withdraw consent in relation to the uses and/or disclosure of his/her PHI (see following Section). No advice was received by the **Task Force** on consent issues related to incapacity and time limits. However, two briefs urged the **Task Force** to make a clear recommendation on the rights of minors.<sup>27</sup> In this regard, minors who are 16 years of age or older may give or withhold their consent in Ontario.<sup>28</sup>

### *Recommendation(s)*

7. It is recommended that new provincial PHI legislation adopt *implied knowledgeable consent* as the consent standard within the circle of care and *express consent* as the standard outside the circle of care including the exceptions set out in the Pan Canadian Framework. It is also recommended that capacity to consent or object to the collection, use and disclosure of PHI ought to be presumed for any person of 16 years of age or older unless circumstances indicate otherwise to the custodian. And it is recommended that time limits on express consent ought to vary by circumstance and be established in regulations that are made when the requirement is apparent.
8. When an individual lacks the capacity to make decisions about his/her PHI and where there is no substitute decision-maker, it is recommended that new personal health information legislation establish procedures for determining a substitute decision-maker

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<sup>27</sup> Oral recommendation made by the New Brunswick Pharmaceutical Society during the presentation of a brief on June 27, 2007 and New Brunswick Pharmacists Association, **Submission to the New Brunswick Task Force on Personal Health Information**, July 2007, p.6.

<sup>28</sup> See **PHIPA**, subsection 23(1).

9. It is recommended that the disclosure of PHI to the media, to fund-raisers and to hospital visitors (including clergy) require the express consent of the patient or of the substitute decision-maker.
10. It is also recommended that the proclamation of PHI legislation be preceded by a public education campaign led by the Minister of Health with the objective of raising awareness and understanding of PHI privacy and consent issues.

## **Section 8: Withholding and Withdrawing Consent**

### *Policy Issues and Inter-jurisdictional Context*

A number of jurisdictions with PHI legislation provide for individuals to withhold and withdraw consent regarding the disclosure of their PHI (see in particular, Ontario, Manitoba and Saskatchewan). A provision that affirms an individual's right to withhold or withdraw is sometimes known as a "lock box". Given the widening of the "circle of care" in which PHI is typically used and disclosed, and given the numerous exceptions to the express consent rule that typically apply outside the circle of care, it is important that PHI legislation provide for the withholding and withdrawal of consent by patients respecting their PHI.

During debate on Ontario's PHI legislation, the Minister responsible said; *"If we have a health care system that is patient-centered, the patient, at the end of the day, has the right to determine how and when and ... if their personal health information will ever or should ever be disclosed."*<sup>29</sup> To give this provision meaning without simultaneously complicating diagnosis and treatment within the circle of care, it is important that there be patient education about the right to withhold and withdraw consent and about the potential consequences for diagnosis, treatment and care if the right to withhold and withdraw consent is exercised. In the same vein, if a custodian who discloses partial PHI (at the direction of the patient) believes that all information necessary for the provision of health care has not been disclosed, the custodian must notify the recipient that the PHI being disclosed is incomplete. The Ontario College of Physicians and Surgeons has expressed concern about the operation of this provision. *"Although the*

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<sup>29</sup> Quoted in Perun et al, *op.cit*, p. 284.

*College ... expects physicians to respect patients' wishes, the College notes that a lack of patient information could jeopardize patient safety. In non-emergency situations, the College stipulates that physicians are not obliged to accept or treat a patient about whom they have insufficient information.*"<sup>30</sup>

It is important to note that an individual's right to withhold and/or withdraw consent for the disclosure of some or all of their PHI would not override all exemptions to the requirement to obtain express patient consent for the disclosure of PHI. For example, a court order or a significant risk to public health could override a patient's lock box directive. Nor would this provision, release a professional health care provider from the obligation to enter and retain PHI on a patient file if required to do so by law or by established standards of professional practice.

### *Pan Canadian Framework*

The Pan Canadian Framework calls for the inclusion in legislation of a patient's right to withhold and withdraw consent and recommends that the "*custodian must inform the individual of the consequences of any such restriction*".<sup>31</sup>

### *Oral and Written Briefs*

The **Task Force** received two briefs that addressed issues related to the need for a lock box provision in PHI legislation.<sup>32</sup> These briefs noted the sometimes precarious situations in which women find themselves when dealing with the health system, particularly women who have been victims of violence. These briefs emphasized the importance of women having confidence that their information will be held in strict confidence, otherwise, they may not seek the care and attention they need. The lock box provision is meant to help with such situations. Education about this right and the potential consequences of exercising it is important.

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<sup>30</sup> **Ibid**, p. 289.

<sup>31</sup> **Pan Canadian Health Information Privacy and Confidentiality Framework**, op. cit, p. 7.

<sup>32</sup> See the Fredericton Sexual Assault Crisis Centre and the New Brunswick Advisory Council on the Status of Women, **Submissions to the New Brunswick Task Force on Personal Health Information**, ([http://www.gnb.ca/0051/personal\\_health\\_information/submissions-e.asp](http://www.gnb.ca/0051/personal_health_information/submissions-e.asp)).

*“...We also have questions about whether all information on a patient is made available to all persons with access to health care data and would prefer a system where various levels of clearance would be used, based on the need to know...”* **Rosella Melanson, Executive Director, New Brunswick Advisory Council on the Status of Women**

### *Recommendation(s)*

11. It is recommended that PHI legislation provide for the withholding and withdrawal of individual consent in relation to the use and disclosure of PHI.
12. It is also recommended that, notwithstanding an individual’s directive to withhold or withdraw consent, the legislation contain overrides to such a directive provided the overrides are modeled on the exceptions to express consent in the Pan Canadian Framework. An override to the directive should also be provided for purposes of establishing and operating a Prescription Drug Monitoring Program. However, it is recommended that there be no exception or override to an individual’s directive to withhold or withdraw consent in relation to the creation of an EHR.

In framing the legislative provision(s), drafters are encouraged to review the relevant provisions of the Pan Canadian Framework and Schedule 1, Principle 4.3.8 of **PIPEDA** as well as Section 19 of Ontario’s **Personal Health Information Protection Act (PHIPA)**.

## **Section 9: Collection of Personal Health Information**

### *Policy Considerations and Inter-jurisdictional Context*

The construction of an individual or patient health record begins with the process of collection of personal health data. The conditions under which PHI is collected will influence how health information is managed. Defining the purposes for which the information is collected is a first step from which decisions on use and disclosure are based. Multiple and vague collection purposes will make rules around use and disclosure more difficult to establish and will more easily lead to breaches of confidentiality and trust. Clearly defined purposes of collection help the organization by assisting in

judging the inherent relevance of the data that it proposes to collect as well as for data that it may already have in its possession.

Currently, in New Brunswick, there is no uniform set of rules concerning the collection of personal health data. The rules that apply differ depending on the health care setting. They may vary depending on whether you are in a hospital, a doctor's office, a private laboratory or a community pharmacy. Furthermore, it is not always clear who may collect such data and what are their obligations. In other provinces, the introduction of PHI legislation has helped address these issues. Such legislation has contributed to the creation of a common legal environment for the collection of personal health data.

Perhaps the greatest benefit of PHI legislation is to establish why personal health data are collected in the first place. The key principles underpinning Canadian health information legislation are that; i.) collection of PHI is carried out in the most limited manner possible, ii.) it is shared on a need-to-know basis and iii.) it is collected with the highest degree of anonymity possible.

The health information legislation of other provinces also calls for the collection of PHI directly from the person the information is about unless other means of collection are expressly authorized by legislation, such as when authorized or required by a court order or a law of the province or of Canada. Circumstances where indirect collection is permitted are generally well spelled out in legislation, for example,

- when information collected from the individual might be reasonably expected to be inaccurate, and
- when direct collection from the individual may be expected to endanger the health of that individual or another person, and
- when collection is in the individual's best interest but time and circumstances do not permit direct collection.

Issues of consent associated with collection are significant but are discussed under the "Models of Consent" Section of this report.

Federal privacy legislation (**PIPEDA**) deals explicitly with the use of electronic means in the collection of personal information. It provides for the use of electronic alternatives where laws contemplate the use of paper records. Most provincial health information legislation also contains provisions to that effect but offer less guidance than PIPEDA. Since PHI

will be collected increasingly through electronic means and since the development and maintenance of a patient electronic health record is heavily dependent on the use of information technology, it is essential that PHI legislation legitimize the practice of electronic collection of PHI if New Brunswick's **Electronic Transactions Act** does not already provide the required legal underpinning.

### *Pan Canadian Framework*

The Pan Canadian Framework deals with issues of collection of health information at the level of principle. It embraces the concept that PHI should be collected in the most limited manner and for identified purposes. It provides further advice in its Appendix A- "Ancillary Provisions" under Section 3. The content of this Section is strikingly similar to collection provisions found in legislation in several Canadian provinces.

### *Oral and written briefs*

Representatives of Regional Health Authorities (RHAs) told us of the impact that the introduction of **POPIA** had on their approach to collection of health information. It caused them to review the rationale for their longstanding data collection practices. As a result, they discontinued collection of certain data. They foresaw potential similar "sobering" effects following the introduction of PHI legislation in New Brunswick. Collectively, they were supportive of the idea of providing, in law, a clear statement of purpose for the collection of PHI.

### *Recommendation(s)*

13. It is recommended that new PHI legislation recognize that the primary purpose of the collection of PHI is for the diagnosis, treatment and care of the patient.
14. It is further recommended that new PHI legislation:
  - a) Establish rules to govern the collection of PHI for purposes other than diagnosis, treatment and care;
  - b) Establish rules for the indirect collection of PHI;
  - c) Provide for the collection of PHI by electronic means.

In developing the collection provisions of the legislation, it is suggested that drafters be guided by the relevant principles outlined in the Pan Canadian Framework's Overview and by **PIPEDA**'s Schedule 1- Principle 2 "Identifying Purposes". Valuable application considerations are contained in Section 3 of the Pan Canadian Framework's Appendix A "Ancillary Provisions", in **PIPEDA**'s "Electronic Alternatives" Sections 33 to 36 and in Ontario's **PHIPA** Sections 29, 30 and 31.

## **Section 10: Use of Personal Health Information**

### *Policy Considerations and Inter-jurisdictional Context*

"Use" and "disclosure", while closely interconnected, are different concepts in the context of health information legislation. "Use" generally applies to PHI in the custody or control of a health information custodian and is generally defined to mean "*to handle or deal with [such] information and includes reproducing the information but does not include disclosing the information.*"<sup>33</sup> The introduction of statutory authority regarding "use" affects traditional holders of PHI in a significant way. Currently, in New Brunswick, as was the case in other provinces before the advent of health information legislation, there are only minimal requirements concerning the use of PHI in health settings. Plus, these requirements are not uniform across all health settings.

As is the case for collection, PHI legislation in other provinces impose limitations on the use of PHI. A general policy principle here is that PHI must not be used for purposes other than the one(s) for which it was collected in the first place. PHI legislation, therefore, permits use for the same lawful purposes that govern collection. And while it is true that PHI legislation permits use primarily for the purpose of providing care to individuals, it is worth noting that it often authorizes "other uses" without express consent<sup>34</sup>.

It is important to underline that PHI legislation in other Canadian provinces does not specifically contemplate or authorize the use of PHI for the purpose of creating a patient electronic health record (EHR). Our interpretation is that the constitution of a patient electronic health record would arguably fall

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<sup>33</sup>See the **Pan Canadian Health Information Privacy and Confidentiality Framework**, op.cit., p. 4.

<sup>34</sup>See Section 7 of this report "Models of Consent".

in the broad category of “system planning and management” that is found in the PHI legislation of other provinces and would, therefore, be permitted. One could also argue that the gathering and assembling of PHI for the constitution of an EHR amounts to use for a “primary purpose” since it serves in the provision of care and treatment as much as for system planning and management. Given the significance an EHR can play in the provision of care and in health system management, as well as its potentially far reaching implications for privacy, we advise that New Brunswick’s health information legislation expressly authorize the collection, use and disclosure of PHI for the purpose of the creation and maintenance of an EHR.

*“NANB supports the use of an implied knowledgeable consent model for the collection, use and disclosure of personal health information within the circle of care. Unless otherwise stated in legislation, the individual’s consent must be obtained for any collection, use and disclosure of personal health information. Express consent should be obtained for purposes outside the circle of care, except as specifically otherwise provided by legislation.”* **Nurses Association of New Brunswick**

Because of the sensitivity surrounding the uses to which PHI may be put and because there are so many valid public interest exceptions to the use of PHI outside the circle of care (see Section 7), we take the view that, in the interest of education and public policy debate, there ought to be a policy or background paper accompanying the introduction of PHI legislation that explains the rationale for each exception to the express consent requirement including an exception for a Prescription Drug Monitoring Program.

### *Pan Canadian Framework*

Although the Pan Canadian Framework recognizes that the use of PHI is to be carried out “...*in the most limited manner, on a need-to know basis and with the greatest degree of anonymity possible in the circumstance*”, it also proposes that it be done in a way that is “...*enable[es] the flow of information where appropriate to support effective care delivery, the management of the health system and an interoperable health record*”.<sup>35</sup>

### *Oral and written briefs*

The vast majority of those who appeared before the **Task Force** or presented their views in writing were in agreement that PHI should be used primarily

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<sup>35</sup>Pan Canadian Health Information Privacy and Confidentiality Framework, op.cit., p.2.

for the purpose of providing care to the individual. PHI was seen as a tool that supports the seamless delivery of service to the patient. No brief expressed concerns with the use of PHI within the circle of care. Also, all favored applying the implied knowledgeable consent model for use of PHI within the circle of care.

However, there was much less consensus on when and how “use” should be permitted outside the circle of care and for what purposes. Some of the presenters interested in the use of PHI for the purpose of research favored a review of the ethics of each research proposal and an evaluation mechanism such as that found **PHIPA**. This was the position of Canadian Medical Association in its Health Information Privacy Code, as well as the Dalhousie University Pediatrics and Community Health and Epidemiology Department. One other brief from the research community, namely from the Populomix Cancer Research Institute of the University of New Brunswick, took the view that the Province of New Brunswick “... *should encourage PHI research within existing and future databases in so long as the databases can be sufficiently encrypted and secure*”.<sup>36</sup> In the opinion of this Institute, most researchers do not need identifiable PHI in order to conduct their research.

One brief in particular, from Canada’s Health Informatics Association, was noteworthy for its strict approach to the use of PHI for the purpose of health system management and for research. It suggests that a key criterion in determining other uses should be for the “*benefit of the individual*” and where “*that connection lessens*” health information privacy legislation adopt “... *stronger control, and more use of de-identified or anonymous information*”.<sup>37</sup> The brief goes further in advocating that such legislation reflect a “*NO use of identifiable information unless required*” philosophy. It points out that although that might have been the intention of existing health information legislation, “...*the message doesn’t come across strongly enough to have organizations make the shift from broadening the legislated use of identifiable information rather than creating systems which use, link and analyze de-identified information*”. As a result, the brief remarks that,

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<sup>36</sup>Populomix: Cancer Research Institute/Institut de recherche sur le cancer, **Submission to the New Brunswick Task Force on Personal Health Information**, Fredericton, NB, June 28, 2007., p. 2.

<sup>37</sup>COACH: Canada’s Health Informatics Association, **Submission to the New Brunswick Task Force on Personal Health Information**, June 15, 2007, p. 3.

*“...the tendency seems to be to write more and more legislative exceptions”.*<sup>38</sup>

Overall, presenters expressed a preference that PHI be rendered anonymous when used for purposes such as system management or research.

There was support, among the briefs presented, for the use of PHI for the purpose of constituting a comprehensive patient electronic health record. The proposal to use PHI for the purpose of having a prescription drug monitoring program for narcotics as contemplated by the New Brunswick Minister of Health was also received positively by several presenters. Both the New Brunswick Pharmaceutical Society and the New Brunswick Pharmacists Association, two organizations which would be directly involved in such a program, expressed support for such an initiative and *“..... encourage(d) government to empower such program to be able to interact in a meaningful way with law enforcement officials and with Regulatory bodies of both prescribers and dispensers of prescription drugs”.*<sup>39/40</sup> The New Brunswick Ombudsman, however, in his brief, urged that in instituting such a program, privacy considerations *“not take a back seat”.*<sup>41</sup>

*“We are also in support of the use of personal health information for the purposes of having a Prescription Drug Monitoring Program. We need clear legislation to health professionals that enables them to work with law enforcement officials and with Regulatory bodies.”* **New Brunswick Pharmacists’ Association**

### *Recommendation(s)*

15. It is recommended that new PHI legislation set conditions for use of PHI that are consistent with the purpose for which such information was collected. Use of PHI for “other purposes” should be provided for in law.

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<sup>38</sup> *Ibid.*, p. 4.

<sup>39</sup> New Brunswick Pharmaceutical Society, *op.cit.*, p. 3.

<sup>40</sup> The Task Force did not solicit opinions on the institution of a general prescription drug monitoring program by the Ministry of Health. And it did not receive views on the subject. The support expressed was in relation to a specific initiative, namely the monitoring of narcotics. Whether a comprehensive drug monitoring program would be understood as primarily to enhance treatment/care or as for “other purposes” would very much depend on the nature and characteristics of the program. This cannot be determined in abstract.

<sup>41</sup> Bernard Richard, Ombudsman and Child & Youth Advocate, **Submission to the New Brunswick Task Force on Personal Health Information**, July 4, 2007, p. 8.

16. It is further recommended that new PHI legislation:

- a) provide that, wherever possible, PHI collected for the purpose of the provision of care be rendered anonymous when used for purposes such as system management, program evaluation or research;
- b) authorize the use of PHI for the purpose of constituting and maintaining a comprehensive patient electronic health record system; and
- c) authorize the use of PHI for the purpose of drug monitoring programs as may be required to address the misuse of certain prescription drugs.

In developing the “use” provisions of its health information legislation, drafters are encouraged to follow the general direction provided in **PIPEDA** (Schedule 1, Principle 5- “Limiting Use, Disclosure and Retention”) and in the Pan Canadian Framework’s Overview section. More detailed guidance will also be found in the Pan Canadian Framework’s Appendix A “Ancillary Provisions” Section 8, and in Ontario’s **PHIPA**’s Section 37 on “Permitted Use.”

## **Section 11: Disclosure of Personal Health Information**

### *Policy Considerations and Inter-jurisdictional Context*

Policy considerations regarding the disclosure of PHI are closely associated with those relating to collection and use. The general principle is that the information can be disclosed only to the extent the recipient needs to know the information.

As is the case with collection and use of PHI, there are exceptions. Such exceptions vary from province to province and tend to fall into three broad categories.<sup>42</sup> The first category includes situations that can be considered as an extension of the provision of care to the individual (ex: where disclosure is necessary to prevent or lessen a serious or immediate threat to the health of the individual, or to inform a relative or any other person in the event of the individual’s death). In the second category are those instances where disclosure takes place in the interest of quality of care and health system

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<sup>42</sup> This is an elaboration on the “public interest exceptions” list presented in Section 7 of this report.

management (ex: disclosure for the purpose of peer review). In the third category are instances where disclosure is unrelated to health care but is for a greater public good (ex: to comply with the law or for investigations).

It is important to note that where PHI legislation permits disclosure without express consent, generally it does not usually require the custodian to make a disclosure. In other words, custodians may exercise their discretion in disclosing PHI in most instances. And even where legislation allows disclosure without consent, custodians may still choose to seek the patient's consent. The exceptions to a custodian's discretion to disclose arise with a court order, a search warrant or when a statute such as the Family Services Act requires disclosure.

### *Pan Canadian Framework*

The Pan Canadian Framework envisages disclosure of PHI according to the same general principle that governs collection and use, namely, "*in the most limited manner, on a need-to-know basis and with the highest degree of anonymity possible in the circumstances*". The Framework offers guidance as to when and how disclosure may take place in Appendix A "Ancillary Provisions."

### *Oral and written briefs*

Of all the issues related to PHI, disclosure is the one that has attracted the greatest interest among those who presented to the **Task Force**. There is genuine concern that the personal and therapeutic relationship between the patient and the health care professional might be eroded by fear that PHI could be released improperly to other parties without consent. This was a recurring theme in the various presentations.

While most briefs recognized that there might be legitimate reasons to release or disclose information for purposes other than the provision of care, there was a general view that relatively strict rules should apply for disclosure to third parties.

There was general consensus that instances of release without express consent outside the circle of care need to be expressly authorized and provided for in law. For COACH, Canada's Health Informatics Association, "... release of personal health information to government administration should be very closely watched, and the purposes very clearly defined ... such as fraud prevention but not as broad as system efficiency."<sup>43</sup> There appears to be more openness to disclosure to third parties without express consent where the focus for the use of the information is clearly to the benefit of the individual rather than to the "system." Such is the case, for example, where custodians disclose to non-custodians for purposes of payment in the context of electronic submission of information. Representatives of the health insurers were of the view that the proposed New Brunswick legislation should authorize such disclosure so that consumers can continue to take advantage of the efficiency and effectiveness of pay direct drug card transactions.

Disclosure of PHI for the purpose of law enforcement generated considerable discussion during our hearings. Hospital authorities, doctors and pharmacists expressed concern about the uncertainty that currently exists in this area. They are looking to the proposed PHI legislation to clarify when and how PHI must be released to law enforcement officers. They would like clear requirements stipulated in law. Doctors, as represented by their provider of medical-legal assistance (the Canadian Medical Protective Association-CMPA), have expressed concern that an "open flow" of information between physicians and police services has the potential to discourage individuals from seeking treatment. They oppose the creation of new mandatory disclosure requirements beyond those already in existing laws such as child abuse or fitness to drive.

The brief from the CMPA also reminds us of the mostly "permissive" (as opposed to mandatory) nature of PHI legislation in other provinces.<sup>44</sup> It observes that in every jurisdiction such legislation authorizes or permits disclosure in certain delineated circumstances but generally does not mandate the custodian to disclose. Typically, requirements to disclose, where they exist, are addressed in other legislation.

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<sup>43</sup>COACH: Canada's Health Informatics Association, *op. cit.*, p. 2.

<sup>44</sup>Canadian Medical Protective Association (CMPA), **Submission to the New Brunswick Task Force on Personal Health Information**, June 18, 2007.

While none of the presenters to the **Task Force** have proposed that New Brunswick adopt “mandatory” rather than “permissive” health information legislation, a few opined that the ability to develop and maintain a comprehensive patient electronic health record may be dependent on, among others things, the Minister having the authority to compel disclosure. Voluntary disclosure, most agreed, would likely result in incomplete patient health records. Nonetheless, they were reluctant to support directed disclosure. They were more open to compulsory disclosure to an independent third party. Ontario’s **PHIPA** provides such a model of disclosure. Under Section 47(2) of the Act, custodians can be directed by the Minister to disclose PHI, without the consent of the patient to whom the information relates, to data institutes (essentially independent third parties) if the Privacy Commissioner approves. The Minister can, in turn, require disclosure of PHI from such an institute upon satisfying the Privacy Commissioner that the disclosure is reasonably required in the public interest and that de-identified information is insufficient.<sup>45</sup>

Taking this into consideration, we believe that the Minister of Health in New Brunswick should be authorized to create an arms length data institute for the primary purpose of establishing and operation an iEHR.

Recently, health care delivery has been strengthened through the use of province-wide health registries. For example, registries are being used in several provinces to reduce wait times in priority areas such as cancer treatment, cardiac care, diagnostic imaging, joint replacements, sight restoration and organ transplants. Such registries of PHI can play a vital role in improving access to health care by connecting patients in need of care to health care providers. While the **Task Force** heard no opposition to the use of such instruments, a number of presenters underlined the need to clarify the rules governing disclosure to provincial registries. We support the approach taken by Ontario’s **PHIPA** where health information custodians are permitted to disclose PHI about a patient without the consent of the patient to a prescribed (determined by regulation) health registry, that is a person or an organization who compiles or maintains a registry of PHI for the purposes of facilitating or improving the provision of care or for a purpose relating to the storage or donation of body parts or bodily substances.<sup>46</sup>

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<sup>45</sup> See Halyna Perun et al, **op. cit.**, Chapter 11, p.478.

<sup>46</sup> **PHIPA**, Section. 39 (1) (c).

The **Task Force** is also aware of requests, in New Brunswick, to disclose demographic information collected in the health sector (namely the Medicare number) to non-custodians for use outside the health care system. While demographic information may not reveal an individual's health conditions and status, the fact remains that such information has been collected in the context of and for the purpose of providing care, or for the payment of such care on behalf of an individual. Therefore, such demographic information should be treated as personal information and be cared for in the same manner as other personal information. We believe that, here too, clearer disclosure rules need to be established. Disclosure of health numbers to non-custodians for use outside the health care system should occur only with express consent, except where otherwise authorized by legislation. For example, the disclosure of information from the New Brunswick Medicare database for the purpose of updating the Register of Electors should occur only with the express consent of individuals. This is the practice at the federal level where the tax return database serves to update and maintain the federal voting list but only with an individual's express consent that the information can be disclosed for that purpose. Individuals know that by refusing consent they may not be registered on the voters list and may, therefore, be denied the right to vote.

On the other hand, the disclosure of demographic information from the Medicare system without consent for the constitution of jury lists, which has been the practice for some time in New Brunswick, is reasonably justifiable in our view. There is sufficient "public interest" to warrant such a legislative exception since the constitution of juries is an essential element of a well functioning justice system and of democracy more broadly. While individuals are free to decide to vote or not, they do not have the same discretion with respect to membership on a jury. They must serve unless exempted.

*Recommendation(s)*

17. It is recommended that new PHI legislation make provisions for disclosure of PHI without express consent.

18. It is further recommended that new PHI legislation:

- a) provide for the creation, by the Minister of Health, of a health data institute (an independent third party) eligible to receive disclosures of PHI from health information custodians for the primary purpose of establishing and operating an EHR;
- b) contain a provision allowing the Minister of Health to compel a custodian to disclose PHI to the data institute;
- c) permit the disclosure by custodians of PHI without express consent to provincial health registries that may be established by the Minister of Health;
- d) set the conditions under which demographic information from the Medicare system may be disclosed without an individual's express consent for use outside the health care system;
- e) permit the disclosure, without an individual's express consent, of demographic information from the New Brunswick Medicare system for the purpose of constituting jury lists;
- f) permit the disclosure, with an individual's express consent, of demographic information from the New Brunswick Medicare system for the purpose of maintaining a permanent Register of Electors in New Brunswick.

In drafting the disclosure provisions of its new health information legislation, we recommend that New Brunswick adopt a model based on the Pan Canadian Framework's "Core Provisions" 5, 6, 7 and 9 to 14, as well on **PIPEDA** (Schedule 1, Principle 5- "Limiting Use, Disclosure and Retention") and **PHIPA**'s Section 47 dealing with data de-linking and data institutes, and Section 39 on health registries.

## **Section 12: Obligations and Powers of Data Custodians**

### *Policy Considerations and Inter-jurisdictional Context*

PHI legislation imposes obligations on health information custodians. They are basic requirements aimed at ensuring health information custodians are accountable and open about their information management practices.

Custodians are required to implement practices that promote patient awareness of the rules regarding collection, use and disclosure, as well as avenues for redressing problems. **PIPEDA** and provincial PHI legislation require that information management policies of custodians be made readily available.

Provincial health information laws include an obligation on the part of the custodian to notify both the patient and the Privacy Commissioner of a breach of confidentiality. Custodians also have the responsibility to ensure the accuracy and security of the PHI in their custody or control. This extends to proper methods of disposing of records.

Typically, PHI legislation also requires that privacy impact assessments (PIAs) be conducted to determine how proposed changes in information management policy or practices or systems may affect the confidentiality of the PHI they hold.

Obligations imposed on custodians by health information legislation are similar across Canadian jurisdictions. For the most part, the legislation embodies the principles set out in the Canadian Standards Association Privacy Code in matters of accountability, accuracy, safeguard and openness. The meeting of such requirements is important as it creates transparency and reliability, thus fostering public trust in health care providers and in the health care system overall. Where PHI legislation does not specify processes or actions for PHI custodians to follow, it typically requires them to act “reasonably.” For example, the Manitoba act stipulates that when allowing PHI to be examined or copied, the trustee must be reasonably satisfied of the identity of the person making the request. In Ontario, the custodian shall take reasonable steps to ensure that PHI is protected against theft, loss and unauthorized use or disclosure and that records are protected against unauthorized copying, modification or disposal. In Alberta, custodians must protect against any reasonably anticipated threat or hazard to security or integrity or loss of PHI, or unauthorized use, disclosure, modification, or access to the same.

*“New Brunswick’s new health privacy legislation should place the onus on the health data custodian to prove its compliance with applicable privacy and security standards and other requirements. Each HDC should be required to conduct self-audits and produce annual compliance reports.”* **David A. Townsend, Faculty of Law UNB and Kevin R. Motley, Student at Law UNB**

Although New Brunswick does not yet have dedicated PHI legislation, the key holders of PHI have devoted considerable time and effort developing sound information management practices. Many, like hospital authorities and regulated health professions, have a long history of practices that respect the privacy and confidentiality of PHI and will be able to draw on such experience in the context of the proposed new legislation. More recently, in New Brunswick, these same organizations have taken steps to comply with federal (**PIPEDA**) and provincial (**POPIA**) privacy legislation. As a result, they are considerably better prepared in the general management of PHI. For example, all have now designated a contact person for PHI and most have embarked on staff training. To the extent that organizations do not already have such policies in place, or where there are gaps, they will need to review and adapt their existing practices to comply with the requirements of any new health information legislation. Based on presentations made by the New Brunswick Regional Health Authorities, the systematic documentation of information management practices and policies in writing is likely where the bulk of the additional work lies.

The delivery and administration of modern health care create new challenges in the area of health information management. These are worthy of special attention. As more components of health care delivery and health care management are being sub-contracted or contracted-out, custodians may employ or retain agents to assist with certain functions. They may permit an agent to collect, use or disclose PHI on their behalf where they (the custodians) themselves are allowed to do so. However, health information legislation is generally quite clear that the custodian retains responsibility for the information in the hands of the agent. As observed in one of the briefs we received, “*custodians must understand that while they can outsource services, they cannot outsource accountability*”.<sup>47</sup> Formal written agreements between the custodian and the agents are highly recommended in such circumstances. This also significantly increases the number of organizations and persons that need to be aware of the requirements of health information legislation and trained in the management of PHI.

Because a large amount of care is now delivered in the patient’s own home, provincial legislation recognizes the practice of keeping a record of PHI in the patient’s home. **PHIPA**, for example, permits a health information

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<sup>47</sup>Professor David A Townsend and Kevin R. Motley, **Submission to the New Brunswick Task Force on Personal Health Information**, Faculty of Law, University of New Brunswick, July 6, 2007, p. 16.

custodian to keep a record of PHI about a patient in the patient's home in any reasonable manner to which the patient consents.

The expanding utilization of information technologies in the health care milieu generally and in the collection and management of health information in particular calls for the implementation of "technical safeguards". They consist in the application of a series of techniques (from encryption, to unique user identifier, to passwords, to automatic logoff, to firewalls) that contribute to a health information custodian's protection of the integrity and confidentiality of the PHI database.

PHI legislation also requires that privacy impact assessments be conducted to determine how proposed changes in information management policy or practices or systems may affect the confidentiality of the PHI they hold.

PHI legislation also typically confers certain powers on custodians to facilitate the discharge of their obligations and responsibilities. The two most commonly conferred powers deal with agreements and fees. Custodians or trustees who entrust PHI to an information manager are required, prior to such action, to enter into an agreement to establish appropriate safeguards for the information to be provided.

Fees are also allowed to be charged to recover part or all of the costs associated with certain aspects of the management of health information. Charging fees in certain circumstances can also serve to discourage frivolous uses or requests. Provincial health information legislation generally does not impose standard charges. Staff from the Ontario Privacy Commissioner Office with whom the **Task Force** consulted estimated that the absence of standard charges has resulted in considerable uncertainty both with custodians and individual users and constitutes the single most important subject of complaints.

*"...Access to personal health information has costs, such as for photocopies, archives staff, etc. These costs can become considerable depending on the size of the organization involved. Fair and equitable participation on the part of users appears reasonable as long as these costs are clearly defined and disseminated prior to the filing of requests." **Regional Health Authority 4***

### *Pan Canadian Framework*

The Pan Canadian Framework offers considerable guidance in this area under “Core Provisions” entitled “Duties and Obligations of Custodians to Protect Personal Health Information.” Particularly enlightening are the clauses dealing with the circumstances where custodians are expected to conduct privacy impact assessments (PIAs). It suggests that such assessments should be conducted every time there are new collections, uses or disclosures or when existing ones are changed. Also, PIAs should be conducted when creating or modifying PHI systems or communication technologies.

With regard to technological safeguards, the Framework proposes that they be based on nationally or jurisdictionally recognized information technology security standards and processes, commensurate with the level of sensitivity of the PHI to be protected.

The Pan Canadian Framework also provides specific advice with regard to data matching under Appendix A “Ancillary Provisions”, section 1.5.

### *Oral and written briefs*

Generally, briefs submitted to the **Task Force** were supportive of the obligations of data custodians found in other jurisdictions’ privacy legislation and summarized in New Brunswick’s Background Paper. These submissions also provided evidence of varying degrees of awareness and preparedness among holders of PHI as to the obligations created by health information privacy laws. Regional Health Authorities and the larger health professions have already deployed considerable efforts and resources to comply with duties and obligations created under **POPIA** and **PIPEDA**. They updated their information management policy manuals, prepared communication material for the public and their staff or members, and embarked on major staff training programs. All of this, however, was done within each organization, largely with their own resources and without much provincial assistance and coordination. This has resulted in duplication and some times conflicting interpretations, as well as lack of consistency in approaches. All would welcome more direction, assistance and coordination in the context of the adoption of the new provincial health information legislation.

Representatives of smaller organizations or professions, and of private operations such as community pharmacies, on the other hand, have expressed concerns about the considerable additional work load, delays in service and costs that could potentially result from certain of the contemplated obligations. They alluded particularly to the responsibility of individual data custodians to develop and maintain patient records but also to the possibility that all of this information may need to be connected. In the context of the eventual establishment of a comprehensive patient electronic health record, they emphasized the need for common electronic system requirements so as to minimize spending on multiple software and hardware packages. One major pharmacy retailer representative was particularly concerned about the ad hoc approach to e-pharmacy being taken in Atlantic Canada. It strongly opposed individual provincial “one-of” information technology solutions and suggested that New Brunswick delay implementation of any e-pharmacy initiative until such a time as the experimentations currently underway in Prince Edward Island and Newfoundland and Labrador can be tested and implemented.<sup>48</sup>

There was no consensus on the advisability of charging service fees for accessing and copying health records. Some favored fees as way of paying for the service or as a deterrence to frivolous request. Others saw fees as a barrier to accessing one’s own health information. There was general agreement, however, on the need to make whatever charges uniform across the province and across all custodians.

Finally, on the issue of a privacy impact assessment, most wanted to minimize the instances where it would need to be conducted as it has the potential of consuming significant time and resources, to say nothing of the service delays it can occasion.

*Recommendation(s)*

19. It is recommended that new PHI legislation establish common obligations and powers for all designated custodians of personal health information.

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<sup>48</sup> Shoppers Drug Mart, “Issue Brief. Electronic Health Records- Atlantic Canada”, **Pharmacy Professional Affairs**, March 2005. This publication was brought to the attention of the **Task Force** by Shoppers Drug Mart itself.

20. It is recommended that where new PHI legislation permits a custodian to employ or retain the services of an agent, the custodian should be required to enter into a formal written agreement with the agent to ensure that the agent's handling of PHI meets all of the obligations imposed, by law, on the custodian.
21. It is recommended that new PHI legislation :
- a) provide for the viewing of one's own health record at no cost;
  - b) authorize the charging of fees by custodians to offset certain or all of the copying cost associated with access and authorize the Minister of Health to set, by regulation, a common province-wide fee schedule for that purpose;
  - c) grant discretion to custodians to waive copying fees where such fees are a barrier to access for low income individuals or when they believe the public interest would be better served by the waiver of fees;
  - d) permit custodians to refuse a request for viewing a record or for copies of a record if they reasonably believe that the request is frivolous or vexatious, recognizing that such refusal may be grounds for appeal to the Information and Privacy Commissioner.
22. It is recommended that new PHI legislation specify the circumstances in which privacy impact assessments should be conducted.

In drafting the obligations and powers of custodians' provisions, drafters are encouraged to review **PIPEDA**: Schedule 1, Principle 6 – “Accuracy”, Principle 7 – “Safeguards” and Principle- 8 “Openness”. Additional guidance can be found in Sections 15, 16 and 17 of **PHIPA**.

## **Section 13: Independent Oversight**

### *Policy Issues and Inter-jurisdictional Context*

It is commonplace for Canadian jurisdictions with PHI legislation to have an independent oversight and review mechanism, usually known as a Privacy Commissioner who is an officer of the Legislative Assembly. The powers of the Privacy Commissioner vary somewhat by jurisdiction but tend to include, as a minimum, the power to receive and act on complaints, the

power to mediate, the power to investigate (including on their “own motion” or initiative) and the power to make public recommendations for action or change on the part of a PHI data custodian. More robust powers can be found in Ontario and Alberta where the Privacy Commissioners can also make binding orders.

*“Current problems arise either because of lack of adequately resourced independent oversight, or none at all. Without adequate resources any independent oversight is ineffective. Without effective oversight controls are ignored. Requirements for independent audits should be set in legislation.”* **Canada’s Health Informatics Association**

When an individual in a province with PHI legislation is dissatisfied with the response or refusal to respond on the part of an organization possessing their PHI, they may refer their complaint to a Privacy Commissioner who will act in an independent oversight and review capacity. Typically, a Privacy Commissioner will also have a public education role as well as an advisory role in relation to policies and practices bearing on the obligations of PHI custodians. In Ontario, the Privacy Commissioner may “offer comments on the custodian’s actual or proposed information practices.” Inherent in such an arrangement, if it is thoughtfully established, is a Privacy Commissioner who is a resource for those who fall under his purview rather than an enforcer lying in wait for transgressors.

Most provinces have a Privacy Commissioner whose purview includes all privacy issues, not only those pertaining to PHI. Additionally, it is common practice to combine the Privacy Commissioner’s role with that of the Information Commissioner.

### *Pan Canadian Framework*

The Pan Canadian Framework prescribes the following functions and powers for a PHI Privacy Commissioner: i) active monitoring, ii) the conduct of investigations including audits, iii) dispute resolution, iv) public education, v) the promotion of best practices, vi) advice to custodians, vii) the authority to issue an order or make a recommendation and viii) the authority to recommend sanctions against those who have contravened the legislation.

### *Oral and Written Briefs*

Several briefs received by the **Task Force** recommended that an independent, full time Privacy Commissioner be established in New Brunswick in relation to PHI. It was perceived that the Ombudsman has too many roles currently and that he could not properly discharge a robust set of additional duties in relation to PHI. This advice took particular note of the time and resource implications that arise with an educational and advisory role for the Privacy Commissioner in addition to the traditional role of conducting investigations, audits and handling complaints. The current Ombudsman is of the same opinion.

The brief of the New Brunswick Ombudsman recommended:

- a single integrated Information and Privacy Code
- a single independent Information and Privacy Commissioner who would be an officer of the Legislative Assembly
- a broad array of enforcement powers for the Commissioner including remedial order-making authority
- use of implied knowledgeable consent within the circle of care
- resources for the Commissioner commensurate with the mandate
- a central coordinating mechanism for information access and privacy protection within the executive branch

We find the analysis and advice of the current Ombudsman to be persuasive. Having a Privacy Commissioner for PHI alone is too narrow a task. Given that the combined role of Information and Privacy Commissioner is the model followed in eight provinces (large and small), we see no reason to separate the roles in New Brunswick. In fact, having one independent officer to conduct reviews and investigate complaints reduces the chance that contradictory orders will be issued in terms of openness practices on the one hand and confidentiality practices on the other hand. Similarly, we do not believe that adding significant new PHI privacy duties to the workload of the present multi-tasked and over-worked Ombudsman is a viable option either. The best structural solution appears to be an independent Information and Privacy Commissioner as well as an independent Ombudsman who would also retain his responsibilities as the Child Advocate as well as hearing appeals under the **Civil Service Act**.

A related consideration is whether PHI issues should be addressed through a single dedicated act or be part of a larger code or statute that deals with all privacy and information issues. We offer no opinion on this except to note that there are precedents for both in Canada. The provincial government will need to review the advice it receives from this **Task Force** as well as the **Right to Information Task Force** and then make a determination as to which legal framework is best.

*Recommendation(s)*

23. It is recommended that PHI legislation be enacted that provides for the creation of an independent Information and Privacy Commissioner who would be an officer of the Legislative Assembly and that the Commissioner be given PHI functions and powers similar to those set out in the Pan Canadian Framework and further, that those powers should include order-making authority. The Office of the Information and Privacy Commissioner should be fully funded. The Commissioner should also table an annual report in the legislative assembly.

24. It is recommended that when a data custodian breaches an obligation or whenever a privacy safeguard fails, the data custodian, in addition to notifying the individual(s) affected by the breach or failure, also be required to notify the Information and Privacy Commissioner and advise the Commissioner on the steps that have been taken to remedy the breach and the steps that will be taken to ensure that the breach or failure does not happen again.

25. It is recommended that the proposed PHI policies and procedures of a health data institute created by the Minister of Health be subject to approval and periodic review by the Information and Privacy Commissioner.

## **Section 14: Enforcement of Act**

*Policy Issues and Inter-jurisdictional Context*

Among the jurisdictions with PHI legislation, there is variation in terms of the enforcement provisions. In some jurisdictions, the Privacy Commissioner is restricted to making public recommendations for the

correction of a privacy breach. In other jurisdictions, the Privacy Commissioner can make a binding order to remedy a privacy breach. In still other jurisdictions, the order of a Privacy Commissioners can be reviewed by a court of competent jurisdiction and upheld, varied or set aside. Additionally, sanctions for specific offences or categories of offence vary by jurisdiction. Depending on the laws of the province, individuals may be able to seek damages from a court (“right of private action”) for their loss or suffering once there has been a finding or an order respecting privacy rights.

*“... without Civil and/or Criminal penalties, any monitoring and identifying of unauthorized eAccess to an eHR will be powerless and meaningless and, ultimately, harmful to the integrity of our Health Care system...”* **College of Psychologists of New Brunswick**

There is potentially a long list of acts that could be considered an offence or breach. To be a punishable offence, the act must be willful. Such willful acts include; i.) unauthorized collection, use and/or disclosure of PHI, ii.) obtaining PHI under false pretenses, iii.) destruction of records in order to evade legitimate access requests, iv.) obstruction of the Privacy Commissioner and v.) refusal to comply with an order made by the Commissioner.

PHI custodians are routinely accorded immunity from suit whenever errors are made in good faith. Additionally, it is commonplace for Privacy Commissioners and their agents to be given immunity from suit for good faith actions taken during course of their duties. In a similar vein, Ontario has also provided protection from “retaliation” for an individual who discloses to the Commissioner information about a privacy breach, an intended breach or a refusal on the part of the individual to contravene the PHI legislation (“whistle-blowing” provision).

### *Pan Canadian Framework*

The Pan Canadian Framework has little to say about enforcement apart from noting that “*jurisdictions will apply appropriate sanctions for willful contraventions of ... privacy requirements.*” **PIPEDA** has only a bit more detail on this subject. The best treatment of the subject of enforcement can be found in the Ontario legislation entitled **The Personal Health Information Protection Act (PHIPA)**. Since the Ontario legislation has been declared substantially similar to **PIPEDA** for purposes of PHI, using

PHIPA as the standard for enforcement provisions when drafting legislation for New Brunswick seems appropriate.

### *Oral and Written Briefs*

Several briefs received by the **Task Force** noted the importance of meaningful sanctions and one brief cited, in particular, the utility of Ontario's legislation in relation to sanctions and enforcement.

### *Recommendation(s)*

26. It is recommended that PHI legislation contain enforcement provisions and that these provisions:
- a) set out meaningful sanctions for willful contraventions of the legislation;
  - b) create "good faith" immunity from suit for PHI custodians and for the Information and Privacy Commissioner;
  - c) provide protection for whistle-blowers; and
  - d) provide for a private "right of action" if the Information and Privacy Commissioner confirms a breach or failure by a data custodian.

## **Section 15: General Provisions of Act**

### *Policy Issues and Inter-jurisdictional Context*

General provisions under PHI legislation in other provinces tend to include items such as; i) consequential amendments ii) mandatory review of legislation and iii) regulation-making authority.

In regard to the latter, Ontario is noteworthy for the open and transparent approach it follows when developing *substantive* regulations under its PHI legislation. Basically, this process encourages stakeholder input in response to draft published regulations that have significant impacts before the regulations are finalized and approved by Lieutenant Governor-in-Council. This process is in contrast to the normally closed process followed in many provinces when regulations are made. The open and transparent process followed in Ontario is not only closer to the democratic ideal, it is also consistent with the highly collaborative approach followed in the

development of the legislation. Finally, the practical and political wisdom embedded in this approach recognizes that a regulation can have a significant and sometimes costly impact on those who it is intended to regulate. For a government, it is always better to know the potential impact of a proposed regulation beforehand than to be confronted by an unexpected firestorm of criticism when a regulation conceived behind closed doors is publicly proclaimed.

### *Pan Canadian Framework*

The Pan Canadian Framework is silent on consequential amendments, mandatory review and regulation-making.

### *Oral and Written Briefs*

Several RHA briefs noted the importance of having one prevailing act and one set of rules with respect to PHI. This was understood to necessitate the amendment of other New Brunswick statutes having provisions dealing with the collection, use and disclosure of PHI, statutes such as the **Mental Health Act** and the **Medical Services Payments Act**. The principal caveat expressed regarding the paramountcy of the PHI statute was that it ought not to disturb professional privileges established under the **Evidence Act** and under various private acts that endow private professional bodies with the authority to regulate their professions. *“The rationale for protecting quality assurance information from disclosure is based on the objective of encouraging health practitioners to report adverse events and participate in their review and investigation ... The public policy objective of encouraging health care practitioners to participate in quality assurance processes is reflected in legislation that protects quality assurance records from being disclosed in legal proceedings. Such legislation has now been enacted in all Canadian jurisdictions.”*<sup>49</sup>

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<sup>49</sup> Canadian Medical Protective Association, **op.cit.**  
[http://www.gnb.ca/0051/personal\\_health\\_information/submissions-e.asp](http://www.gnb.ca/0051/personal_health_information/submissions-e.asp), pp. 4-5

### *Recommendation(s)*

27. It is recommended that PHI legislation:

- a) be subject to a comprehensive review of its purposes, principles and operation no later than five years after the statute comes into force, in part or in whole;
- b) provide for regulation-making authority by the Lieutenant-Governor in Council for matters such as; i.) forms and fees, ii.) the designation of custodians, iii.) what is PHI for purposes of the act, iv.) technical standards for safeguards and v.) processes for anonymizing PHI;
- c) provide for a regulation-making process which requires public notification for any proposed regulation of a substantial nature; provide a reasonable period of time for public comment and establish a requirement for a report on public comments received on the proposed regulation to accompany the proclamation of the regulation;
- d) ensure the continued protection of professional privileges regarding disclosure of PHI in quality assurance and peer review proceedings.

## **Section 16: Implementation**

Under this heading, two observations are in order. First, when compared to other jurisdictions with PHI legislation, the proposed development and approval timeline for New Brunswick is comparatively brief. A number of provinces have made several efforts to put PHI legislation in place before finally achieving consensus on a legislative bill. It took some time before there was sufficient understanding of the issues among the stakeholders and before the appropriate balances were struck between competing interests. This experience has been especially the case in Newfoundland and Ontario and was also reflected in the process surrounding the mandatory five-year reviews in Alberta and Manitoba. This means that if the timeline in New Brunswick is adhered to, stakeholder groups and the general public may be less closely involved in the policy and legislative development process than their counterparts in other provinces. Offsetting this observation is the fact that this type of legislation has been around for 10 years and the national organizations of the provincial stakeholders most affected by this legislation

have developed an expertise in the field and this has been evident in the briefs this **Task Force** has received.

The second observation is that the value of sound policy advice and excellent legislative drafting can be significantly undermined if there is poor implementation planning and if there are inadequate resources for implementation and ongoing operations. There is no bargain basement or deep discount method for implementing privacy legislation. When **PHIPA** became the law in Ontario, the already substantial budget of the Information and Privacy Commissioner was increased by 30%. We need to remind ourselves that the budget of the New Brunswick Ombudsman who is presently responsible for privacy and access to information is the least, by far, of all comparable offices in Canada. If New Brunswick can spend hundreds of millions of dollars putting an electronic health record in place, it can afford to properly protect the privacy rights of citizens whose PHI will be electronically collected, stored, used and distributed to an unprecedented number of individual and organizations.

*Recommendation(s)*

Taking these facts into consideration, it is recommended:

28. That, prior to the introduction of PHI legislation, this report be sent to all stakeholders who received the consultation guide and discussion paper issued by the **Task Force** along with an indication of the government's anticipated legislative timeline. It is also recommended that stakeholders be given an opportunity to comment on the report.
29. That, at the time of introduction of the PHI legislation, the Minister of Health should release a high level phased implementation plan including:
  - a) the expected timeline for proclamation of the new act or parts of the act;
  - b) the principal activities required for provincial agencies to be in compliance with the new act;
  - c) the principal activities required of private sector health care providers for coming into compliance with the new act and the time allowed to meet these requirements;

d) the estimated time to appoint an Information and Privacy Commissioner and to have the Office of the Commissioner in operation.

30. That consideration be given to holding legislative hearings after second reading of the bill if there is sufficient interest.

31. Given that the development and implementation of Ontario's **Personal Health Information Protection Act (PHIPA)** has been, by all accounts, highly successful, and given that much of the reason for this success lies in the close cooperation between the Ministry of Health, the custodians and the Information and Privacy Commissioner, it is recommended that the implementation approach employed in Ontario be adapted to New Brunswick.

## **A Final Note**

The recommendations contained in this report are intended as guidance for the government in choosing the policy and legislative details that work best. We expect that Ministers, officials and legislative drafters may, with additional information and reflection, decide that one or more pieces of our advice should be modified. We wish them well with their work.

## **Appendix 1: Summary of Recommendations**

### **Section 3: One Set of Rules for New Brunswick**

1. That New Brunswick enact PHI legislation that regulates the collection, use and disclosure of PHI in the public and private sectors and that the drafting of this legislation be guided principally by the Pan Canadian Framework, **PIPEDA** and Ontario's **PHIPA**.
2. That in order to reduce legal uncertainty arising from the current application of federal and provincial privacy statutes to the management of PHI in New Brunswick, the New Brunswick provincial government should seek, at the earliest practical opportunity, a federal declaration that New Brunswick's PHI legislation is substantially similar to the federal legislation (**PIPEDA**).

### **Section 4: Purposes of an Act and Definition of Personal Health Information**

3. The purposes of new PHI legislation should:
  - a) establish rules for the collection, use and disclosure of PHI that balance the privacy rights of individuals with the access requirements of health service professionals, health system managers and other legitimate users of PHI;
  - b) confirm the right of an individual to request access to their PHI, to ask for correction(s) to their PHI and to have any changes recorded;
  - c) provide for independent review of the application of the act and for resolution of complaints;
  - d) provide for effective remedies in the event of contraventions.
4. It is recommended that, for the purpose of its PHI legislation, New Brunswick adopt a definition of PHI similar to that proposed in the Pan Canadian Framework and **PHIPA**. We recommend, however, that New Brunswick's definition exclude unrecorded information.

## **Section 5: Scope and Application of the Act**

5. The following is recommended with regard to the scope of application of new PHI legislation:
  - a) that a custodian of PHI be defined as an individual or organization that collects, uses, or discloses PHI for the purposes of care and treatment, for planning and management of the health system, for health research and health education;
  - b) that the obligations imposed on custodians of PHI be based on the role they play in the health care system and on the use they make of PHI rather than on where they work and how they are remunerated;
  - c) that the definition of custodian apply uniformly in both the private and public sectors;
  - d) that the legislation make provision for the Minister of Health to identify and list, by regulation, entities and classes of health care professionals that will be considered as custodians;
  - e) that the legislation specifically identify persons or organizations who contribute to, maintain and administer electronic health record (EHR) systems as custodians;
  - f) that PHI held by employers continue to be regulated by PIPEDA or POPIA, as the case may be;
  - g) that rules dealing with PHI in existing health-related legislation be removed or made consistent with the provisions of PHI legislation wherever possible, and that in the event of conflict between PHI legislation and any other legislation, the former should prevail.

## **Section 6: Right of Access to Personal Health Information**

6. It is recommended that the legislative provisions of a new act dealing with individual access to PHI should confirm, subject to exceptions where access would cause harm to the individual or someone else or where access would reveal information about a third party:

- a) the right to view one's PHI in a timely way including the right to know who has accessed the record;
- b) the right to receive copies;
- c) the right to challenge the accuracy of the record, and to have the health record corrected or, in the event that a correction is refused, to appeal the refusal to an independent Privacy Commissioner; and
- d) the obligation of the custodian to record the correction and to notify other custodians (who have recently accessed the record) of the correction or, if there is an irreconcilable disagreement between the custodian and the patient, to affix a statement of the disagreement to the patient's record and to notify other custodians (who have recently accessed the record) of the patient's disagreement.

### **Section 7: Models of Consent**

7. It is recommended that new provincial PHI legislation adopt *implied knowledgeable consent* as the consent standard within the circle of care and *express consent* as the standard outside the circle of care including the exceptions set out in the Pan Canadian Framework. It is also recommended that capacity to consent or object to the collection, use and disclosure of PHI ought to be presumed for any person of 16 years of age or older unless circumstances indicate otherwise to the custodian. And it is recommended that time limits on express consent ought to vary by circumstance and be established in regulations that are made when the requirement is apparent.
8. When an individual lacks the capacity to make decisions about his/her PHI and where there is no substitute decision-maker, it is recommended that new personal health information legislation establish procedures for determining a substitute decision-maker
9. It is recommended that the disclosure of PHI to the media, to fund-raisers and to hospital visitors (including clergy) require the express consent of the patient or of the substitute decision-maker.
10. It is also recommended that the proclamation of PHI legislation be preceded by a public education campaign led by the Minister of

Health with the objective of raising awareness and understanding of PHI privacy and consent issues.

### **Section 8: Withholding and Withdrawal of Consent**

11. It is recommended that PHI legislation provide for the withholding and withdrawal of individual consent in relation to the use and disclosure of PHI.
12. It is also recommended that, notwithstanding an individual's directive to withhold or withdraw consent, the legislation contain overrides to such a directive provided the overrides are modeled on the exceptions to express consent in the Pan Canadian Framework. An override to the directive should also be provided for purposes of establishing and operating a Prescription Drug Monitoring Program. However, it is recommended that there be no exception or override to an individual's directive to withhold or withdraw consent in relation to the creation of an iEHR.

### **Section 9: Collection of Personal Health Information**

13. It is recommended that new PHI legislation recognize that the primary purpose of the collection of PHI is for the diagnosis, treatment and care of the patient.
14. It is further recommended that new PHI legislation:
  - a) Establish rules to govern the collection of PHI for purposes other than diagnosis, treatment and care;
  - b) Establish rules for the indirect collection of PHI;
  - c) Provide for the collection of PHI by electronic means.

### **Section 10: Use of Personal Health Information**

15. It is recommended that new PHI legislation set conditions for use of PHI that are consistent with the purpose for which such information was collected. Use of PHI for "other purposes" should be provided for in law.
16. It is further recommended that new PHI legislation:

- a) provide that, wherever possible, PHI collected for the purpose of the provision of care be rendered anonymous when used for purposes such as system management, program evaluation or research;
- b) authorize the use of PHI for the purpose of constituting and maintaining a comprehensive patient electronic health record system; and
- c) authorize the use of PHI for the purpose of drug monitoring programs as may be required to address the misuse of certain prescription drugs.

### **Section 11: Disclosure of Personal Health Information**

- 17. It is recommended that new PHI legislation make provisions for disclosure of PHI without express consent.
- 18. It is further recommended that new PHI legislation:
  - a) provide for the creation, by the Minister of Health, of a health data institute (an independent third party) eligible to receive disclosures of PHI from health information custodians for the purpose of establishing and operating an EHR;
  - b) contain a provision allowing the Minister of Health to compel a custodian to disclose PHI to the data institute;
  - c) permit the disclosure by custodians of PHI without express consent to provincial health registries that may be established by the Minister of Health;
  - d) set the conditions under which demographic information from the Medicare system may be disclosed without an individual's express consent for use outside the health care system;
  - e) permit the disclosure, without an individual's express consent, of demographic information from the New Brunswick Medicare system for the purpose of constituting jury lists;
  - f) permit the disclosure, with an individual's express consent, of demographic information from the New Brunswick Medicare system for the purpose of maintaining a permanent Register of Electors in New Brunswick.

## **Section 12: Obligations and Powers of Data Custodians**

19. It is recommended that new PHI legislation establish common obligations and powers for all designated custodians of personal health information.
20. It is recommended that where new PHI legislation permits a custodian to employ or retain the services of an agent, the custodian should be required to enter into a formal written agreement with the agent to ensure that the agent's handling of PHI meets all of the obligations imposed, by law, on the custodian.
21. It is recommended that new PHI legislation :
  - a) provide for the viewing of one's own health record at no cost;
  - b) authorize the charging of fees by custodians to offset certain or all of the copying cost associated with access and authorize the Minister of Health to set, by regulation, a common province-wide fee schedule for that purpose;
  - c) grant discretion to custodians to waive copying fees where such fees are a barrier to access for low income individuals or when they believe the public interest would be better served by the waiver of fees;
  - d) permit custodians to refuse a request for viewing a record or for copies of a record if they reasonably believe that the request is frivolous or vexatious, recognizing that such refusal may be grounds for appeal to the Information and Privacy Commissioner.
22. It is recommended that new PHI legislation specify the circumstances in which privacy impact assessments should be conducted.

## **Section 13: Independent Oversight**

23. It is recommended that PHI legislation be enacted that provides for the creation of an independent Information and Privacy Commissioner who would be an officer of the Legislative

Assembly and that the Commissioner be given PHI functions and powers similar to those set out in the Pan Canadian Framework and further, that those powers should include order-making authority. The Office of the Information and Privacy Commissioner should be fully funded. The Commissioner should also table an annual report in the legislative assembly.

24. It is recommended that when a data custodian breaches an obligation or whenever a privacy safeguard fails, the data custodian, in addition to notifying the individual(s) affected by the breach or failure, also be required to notify the Information and Privacy Commissioner and advise the Commissioner on the steps that have been taken to remedy the breach and the steps that will be taken to ensure that the breach or failure does not happen again.
25. It is recommended that the proposed PHI policies and procedures of a health data institute created by the Minister of Health be subject to approval and periodic review by the Information and Privacy Commissioner.

#### **Section 14: Enforcement of Act**

26. It is recommended that PHI legislation contain enforcement provisions and that these provisions:
  - a) set out meaningful sanctions for willful contraventions of the legislation;
  - b) create “good faith” immunity from suit for PHI custodians and for the Privacy Commissioner;
  - c) provide protection for whistle-blowers; and
  - d) provide for a private “right of action” if the Information and Privacy Commissioner confirms a breach or failure by a data custodian.

#### **Section 15: General Provisions of the Act**

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### **Section 16: Implementation**

- 28. That, prior to the introduction of PHI legislation, this report be sent to all stakeholders who received the consultation guide and discussion paper issued by the **Task Force** along with an indication of the government's anticipated legislative timeline. It is also recommended that stakeholders be given an opportunity to comment on the report.
- 29. That, at the time of introduction of the PHI legislation, the Minister of Health should release a high level phased implementation plan including:
  - a) the expected timeline for proclamation of the new act or parts of the act;
  - b) the principal activities required for provincial agencies to be in compliance with the new act;
  - c) the principal activities required of private sector health care providers for coming into compliance with the new act and the time allowed to meet these requirements;
  - d) the estimated time to appoint an Information and Privacy Commissioner and to have the Office of the Commissioner in operation.

30. That consideration be given to holding legislative hearings after second reading of the bill if there is sufficient interest.
  
31. Given that the development and implementation of Ontario's **Personal Health Information Protection Act (PHIPA)** has been, by all accounts, highly successful, and given that much of the reason for this success lies in the close cooperation between the Ministry of Health, the custodians and the Information and Privacy Commissioner, it is recommended that the implementation approach employed in Ontario be adapted to New Brunswick.

## **Appendix: 2**

### **Submissions to the Task Force on Personal Health Information**

1. Acadie-Bathurst Health Authority
2. Advisory Council on the Status of Women
3. Atlantic Health Sciences Corporation
4. Beauséjour Health Authority
5. Business New Brunswick
6. Canada Health Infoway
7. Canada's Health Informatics Association
8. Canadian Bar Association-New Brunswick Branch
9. Canadian Institute for Health Information
10. Canadian Life and Health Insurance Association
11. Canadian Medical Protective Association
12. College of Physiotherapists of New Brunswick
13. College of Psychologists of New Brunswick
14. David A. Townsend, UNB Faculty of Law, and Kevin R. Motley, Student-at-Law
15. Department of Justice and Consumer Affairs and Office of the Attorney General
16. Department of Family and Community Services
17. Department of Public Safety
18. Elections New Brunswick
19. Fredericton Sexual Assault Crisis Center
20. Louise Parker, Professor, Dalhousie University
21. Medavie Blue Cross
22. Miramichi Regional Health Authority
23. New Brunswick Association of Optometrists
24. New Brunswick Dental Technicians Association
25. New Brunswick Health Information Management Association
26. New Brunswick Lung Association
27. New Brunswick Nurses Union
28. New Brunswick Society of Medical Laboratory Technologists
29. New Brunswick Medical Society
30. New Brunswick Pharmacists' Association
31. Nurses Association of New Brunswick
32. Office of Human Resources
33. Office of the Commissioner for Official Languages of New Brunswick
34. Office of the Ombudsman
35. Populomix Cancer Research Institute
36. Regional Health Authority 4
37. Restigouche Regional Health Authority
38. River Valley Health
39. South-East Regional Health Authority