



June 22nd, 2007

Jean-Guy Finn and Kevin Malone
Personal Health Information Task Force
New Brunswick Department of Health
Health Planning, Policy and Legislation Branch
PO Box 5100
Fredericton, New Brunswick
E3B 5G8

Dear Messrs. Finn and Malone:

Canada Health Infoway Inc. welcomes the opportunity to provide input to the New Brunswick Personal Health Information Task Force on its *Personal Health Information, Access and Privacy Consultation Guide*.

We are pleased that New Brunswick is developing new personal health information legislation that will balance protection of the privacy rights of individuals with the public's right to an effective health system.

Our comments are guided by the following:

- First, our role to accelerate the development and adoption of electronic health records (EHR) information systems that have compatible standards and communication technologies across Canada;
- Second, our commitment to respect privacy and to promote various privacy, confidentiality and security approaches designed for the health sector, recognizing that any Canada-wide electronic health record system must abide by each jurisdiction's privacy legislation as it applies to health information ;
- Third, our desire that any health information legislation be clear, practicable and consistent in its application in order that its rules and responsibilities are unambiguous and that the flow of information in the EHR environment needed to protect patients' health, improve healthcare administration or conduct research is not impeded.

To this end, you will note that our comments reflect support of the position set out in the the *Pan Canadian Health Information Privacy and Confidentiality Framework (the Framework)* that the provisions of new legislation be as consistent across jurisdictions as is possible.

The *Pan Canadian Health Information Privacy and Confidentiality Framework* is a comprehensive set of harmonized principles and rules for the collection, use and disclosure and protection of personal health information. It is the result of extensive



analysis and consultation aimed at meeting Canadians' privacy and confidentiality expectations. It sets out a harmonized set of core provisions to protect personal health information in both the publicly and privately funded sectors. As its title suggests, it is intended to underpin new or existing health privacy legislation in each jurisdiction. As part of its commitment to privacy, Infoway has invested substantial effort in contributing to the Framework and we are pleased to refer that document to your Task Force as representing our position on the issues raised in the Consultation Guide dealing with Scope of Legislation, Consent Requirements for Collection, Use and Disclosure, Information Security and Independent Oversight.

The text of the Framework can be found at the URL below:

Pan-Canadian Health Information Privacy and Confidentiality Framework

http://www.hc-sc.gc.ca/hcs-sss/pubs/ehealth-esante/2005-pancanad-priv/index_e.html

This submission, therefore, primarily raises additional issues and comments that we hope will be helpful in dealing with the privacy of personal health information for the province of New Brunswick.

Canada Health Infoway Inc.

Infoway is an independent, not-for-profit corporation incorporated under the Canada Corporations Act. Its members are Canada's 14 federal, provincial and territorial deputy ministers of health.

Infoway's role is to accelerate the development and adoption of electronic health records information systems that have compatible standards and communication technologies across Canada.

Infoway does not deliver health services, it does not manage health data and it does not build EHR systems. It works as a strategic investor with provincial and territorial partners to fund projects that are integral to developing pan-Canadian electronic health records.

Infoway has 227 active or completed projects valued at more than \$1.175 billion through nine investment programs. Each program provides solutions in line with each jurisdiction's legislation and business plans. For example, in New Brunswick, Infoway has invested in projects such as the Post Cardiac Surgery: Home Telehealth Project, the joint iEHR Lab Project and the iEHR Meditech Integration Project, as well as numerous diagnostic imaging systems projects.

Infoway understands that respecting privacy and ensuring appropriate data safeguards will be one of the key success factors of the EHR initiative in Canada. The corporation is committed to ensuring the systems in which it invests appropriately consider privacy and security.

As part of its commitment, Infoway has worked with technology and health information privacy experts to develop a *Privacy and Security Conceptual Architecture*. This Architecture sets out the privacy and security features, such as user identity management and access controls, that developers should consider when designing, building and deploying systems that will form part of the EHR.

Infoway has also recently released a *White Paper on Information Governance in an Interoperable EHR*. This document identifies information governance topics that need to be considered and addressed in the EHR context for the system to work effectively and efficiently and be accepted and used by health care provider and end users.

Both the *Privacy and Security Conceptual Architecture* and the *White Paper on Information Governance in an Interoperable EHR* can be found at the URLs below:

<http://knowledge.infoway-inforoute.ca/en/knowledge-centre/ehrs-blueprintv2.aspx>

http://www.infoway-inforoute.ca/Admin/Upload/Dev/Document/Information%20Governance%20Paper%20Final_20070328_EN.pdf

Other Issues and Comments

Public and Private

Health care is a blend of both public (non-commercial) and private services. The information must be able to flow uninterrupted between the sectors and support the seamless delivery of service to the patient. As such 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. It should also be broad enough to capture statistical or information management types of organizations that are established to study health information, carry out research or manage the EHR system.

Finally, in an EHR environment, there may be occasions when more than one custodian may have ownership interests in a given set of records or information leading to a blurring of accountability - it may be appropriate to consider provisions that speak to this issue thereby ensuring that custodianship and its responsibilities are clear.

Recorded and Unrecorded Information

Consideration should be given to extending the application of the act to include both "recorded" and "unrecorded" information. In the context of the EHR, for example, it would be important to ensure that transmitted images (such as those used in Telehealth applications) be considered to fall within the ambit of personal health information (whether they are recorded or not) and thus be subject to the protections offered by the legislation.

Withdrawal of Consent

The withdrawal of consent in the health care setting is complex. In addition to the implications for the provision of care and treatment, there are EHR related operational and system implications. For example, determinations must be made as to whether the withdrawal applies to the entire record or to specific data elements in the record, how to handle changes to the consent and how to follow those individual choices throughout the system. These choices may have implications for system development.

In view of this, it may be valuable to approach jurisdictions such as Ontario, Manitoba, Saskatchewan or Alberta, regarding their experiences.

It should also be noted that Infoway's *Privacy and Security Architecture* includes a feature in the consent management service that addresses withdrawal of consent and accommodates whatever approach is taken by the jurisdiction.

Alignment of Provisions dealing with Collection, Use and Disclosure

Consideration should also be given to aligning references in the collection, use and disclosure provisions of any new law such that information collected for an authorized purpose can also be used and disclosed for that purpose.

Research

Infoway also supports provisions for research being included in any new law. It is noted that a project is currently underway under the auspices of the Canadian Institutes of Health Research (CIHR) called "CIHR Best Practices For Protecting Privacy in Health Research" to develop a harmonized framework for addressing privacy and confidentiality issues in health research. The criteria established under this project for research activities may be valuable to consider in the development of any new personal health information legislation. As well, a project conducted through the Institute for Clinical Evaluative

Sciences called "Privacy Best Practices for Secondary Use Data" may also be a useful reference to consider.

Privacy Impact Assessments

Privacy Impact Assessments are useful risk assessment tools that can contribute to assuring Canadians that privacy principles are taken into account in the design, implementation and evolution of programs and services that involve personal information. By providing a means for identifying privacy risks and mitigating strategies they can help prevent costly program, service or process redesign.

Consideration might be given to including Privacy Impact Assessment provisions in the new legislation and that these be harmonized with similar provisions in jurisdictions such as those found in the equivalent legislations of British Columbia and Alberta.

Data Matching

Data matching/linkage is an increasingly important tool used by researchers to study the determinants of health and health outcomes. It is plausible that the EHR will enable research that involves data matching or linkage. As such, it may be valuable for consideration to be given to ensuring data matching/linkage activities are addressed in the legislation possibly within those provisions that address research, analysis and/or statistical activities and statistical analysis and that they do so in a manner that is consistent with other jurisdictions.

Transfers across jurisdictions

Over time, as the EHR becomes more and more a part of the health system, it can be anticipated that cross border data flow of personal health information will increase as patients travel to receive care at identified specialty centres, as telehealth services are increasingly used to facilitate access to specialists, and as jurisdictions seek efficiencies in centralizing procurement or information management activities. There is a generally recognized need to take reasonable steps to protect confidentiality of the individual's health information and to set out the authorities and conditions under which cross border data flows can occur. However, it may be valuable to include specific provisions in the new legislation governing transborder data flow that are consistent with those in other jurisdictions.

Paradigm Shift

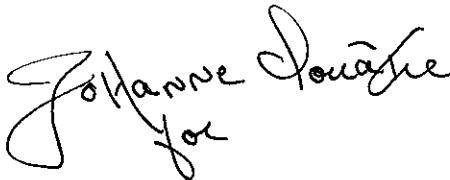
Current health privacy laws and regulations focus on the disclosure of health information by health information custodians and trustees. In an EHR environment, that focus may shift away from a “controlled disclosure” model to one of controlled “access.” In the interoperable EHR end-users access information based on their identified role and authority in the system. Custodians and administrators of the EHR Infostructure will need to ensure that individuals are properly authorized before they can access information at a given level of detail. This will require the development of appropriate accompanying policies, procedures and technologies and may do well being referenced in legislation.

Accountability

Finally, to be effective, accountability for personal health information needs to be clearly assigned throughout the EHR Infostructure. This assignment does not have to be dealt with specifically in legislation; however, legislation may have to consider the mechanisms needed to support accountability responsibilities (such as the use of contracts and agreements among healthcare providers, institutions and IT service providers) and the importance of transparency and public scrutiny in how the data is being managed and who is accountable. Therefore, this may be an area of consideration for the Task Force.

In conclusion, this submission makes the case that the harmonizing provisions set out in *The Pan-Canadian Health Information Privacy and Confidentiality Framework* is a valuable resource for the Task Force to review in the development of New Brunswick's health information legislation. Our submission also highlights other areas that the Task Force may wish to consider. We would be pleased to provide clarification on any of these matters as the Task Force sees fit.

Thank you for the opportunity to make this submission.

A handwritten signature in black ink that reads "Joanne Roch" with a stylized flourish underneath.

Joan Roch
Chief Privacy Strategist