

June 20, 2007

BY COURIER

Personal Health Information Task Force
Department of Health
Health Planning, Policy and Legislation Branch
Government of New Brunswick
P.O. Box 5100
Fredericton, NB E3B 5G8

Dear Sir or Madam:

Thank you for giving the Canadian Institute for Health Information (CIHI) the opportunity to contribute to the Personal Health Information Task Force's consultation on upcoming new legislation that will regulate access to, and privacy of, personal health information in New Brunswick. Our general comments on the Background Paper and the Consultation Guide dated May 2007 follow. For your information, I have enclosed a background document that describes CIHI's privacy policy as well as our role and mandate in supporting the Canadian health system ("Backgrounder").

General Comments on the Consultation Paper

Overall, CIHI's key interests with evolving health information privacy legislation are that:

- a) the legislation be transparent as to:
 - the collection, use, and disclosure of health information for the purposes of health system management;
 - the root and route of authority enabling the flow of defined data sets to occur for those purposes; and
 - the processes required for researchers to access and use health information.
- b) the principles embodied in the legislation be as consistent across jurisdictions in Canada as is possible, in the interests of furthering health information analysis in Canada.

With these interests in mind, we have considered the questions posed in the consultation paper. In so doing, we have identified the following areas of particular interest that are explained in more detail below:

1. the application/scope of the proposed legislation;
 2. CIHI's status under that proposed legislation;
 3. consent of the individuals to whom the information relates; and
 4. disclosure to other jurisdictions, third parties.
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- 1. The application/scope of the legislation envisioned in the consultation paper, in particular, whether the proposed legislation will apply to: (i) both personal health information as well as other health information; and (ii) private as well as public health care facilities**

As noted in our enclosed Backgrounder, CIHI is a national, not-for-profit organization with the broad general mandate of providing the public, policy-makers, managers and data providers within the health system with timely, accurate, objective information about health and health care in Canada. New Brunswick currently discloses personal health and other health data to CIHI, and CIHI manages that data pursuant to applicable legislation as well as under the terms of existing agreements between the two parties. These agreements are outlined in further detail in #2, below.

(i) Information to be covered by the legislation

CIHI currently manages a total of 25 data holdings covering a wide range of information dealing with multiple facets of the health care system. These data holdings are organized under three broad categories: health services information, health human resources, and health spending. CIHI receives information from a variety of sources throughout Canada, including government ministries and departments of health, hospitals, home care agencies, long-term care facilities, health professional associations, and other health care organizations. Consequently, CIHI collects not only personal health information but also health information generally as well as potentially identifiable information about health service providers. In order to ensure the continued flow of data from New Brunswick under our existing agreements with the Government of New Brunswick (the "Government") and in order that we may carry out our national mandate, CIHI would like to see legislation of more general application that would govern the collection, use and disclosure of the types of information noted above.

(ii) Private health care facilities

Moreover, while the sources of that information, the primary data collectors, principally come from New Brunswick public bodies, CIHI would like to see the application of any health information legislation extend to private health care

facilities. This would provide for more consistency in the collection, use and disclosure of health information in both the public and private spheres and, in turn, facilitate the analysis and reporting of accurate, timely and quality provincial and national data to support policy-making through national longitudinal, retrospective and concurrent analyses. This will enable CIHI to provide the New Brunswick Government with better and more complete information that can assist it with health planning, management of health resources, and the evaluation of the efficiency of the health system in the province.

Finally, the definition of health care and, indeed, the definitions of health care facility, health service provider, and health professional within any health information protection legislation are critical to CIHI being able to ensure continued data flow from New Brunswick for health services provided both within and outside a hospital setting. We would like to see each of those terms clearly defined.

2. CIHI's status under any proposed legislation and the authorities relating to the collection, use and disclosure of health information that the Government now provides to CIHI under the terms of the Bilateral Agreement, the umbrella data sharing agreement and the specific data sharing agreement, relating to the National Prescription Drug Utilization Information System ("NPDUIS"), all between CIHI and the Government

On pages 4-5 of the Task Force's Background Paper CIHI is listed as a possible data custodian, along with Statistics Canada and the Canadian Institutes of Health Research. We wish to note that in other Canadian health information protection regimes, CIHI's status is that of an information manager or prescribed entity, an approved third party to which data custodians are authorized to disclose personal or other health information, and CIHI is authorized to receive, use and disclose that information for limited and specific purposes. Unlike the case of hospitals and other health facilities, in those jurisdictions CIHI is not treated as a data custodian.

Moreover, the designation of CIHI as a data custodian and the responsibilities it entails would be problematic for CIHI. An example of this is in the area of an individual's right to access their own personal health information. In most circumstances, CIHI may not be able to provide access to personal health information it holds about an individual. Health information that we obtain from New Brunswick data providers (with the exception of two of the registries noted on page 2 of our Backgrounder) is both identifiable and de-identified. CIHI does not collect the name, address (number, street name and city) and contact information (for example, telephone number). While CIHI may, pursuant to the agreements with New Brunswick, collect data elements (such as gender and year of birth) that could, in combination with other information, lead to the identification of an individual, CIHI does not have access to information that would permit, for example, the association of a particular birth date with the name or contact information for a particular individual. This makes it difficult for CIHI to provide an account of the existence, use and disclosure of an individual requestor's personal health information in certain circumstances.

Given CIHI's mandate and activities, we would see our role and responsibilities in relation to the collection, use and disclosure of personal health information as those of an "information manager", a secondary data collector that is public in nature (as opposed to a public body such as Statistics Canada or the Canadian Institutes of Health Research) and not as a data custodian. This status would support the flow of limited personal health information to CIHI for authorized purposes. CIHI believes that this status has worked well in other jurisdictions, such as Alberta and Manitoba that have personal health information protection legislation in place. CIHI is a recipient of the health data that was legally collected by the public body and disclosed in compliance with law.

If not an "information manager" under any proposed legislation, an alternative would be to specifically designate CIHI in the Regulations as a body that is entitled to receive personal health information from data custodians for purposes of compiling and analyzing statistical information to assist New Brunswick in managing, evaluating or monitoring the allocation of resources, health system planning and/or delivery of services. Although there is mention in the Background Paper under the section entitled "General Provisions" regarding the regulation-making authority of the Minister of Health and the Department of Health to create bodies to fulfill some of the obligations of the legislation, we believe that there needs to be further elaboration as to the nature and responsibilities of those bodies in order to ensure that any such designation does not limit the amount of personal health information that CIHI now receives from New Brunswick under the terms of the three agreements noted above. Without certainty around what personal health information New Brunswick can disclose to CIHI within the scope of health information protection legislation, there is a risk that CIHI would not be able to effectively meet its current obligations to New Brunswick to assist with health planning, management of health resources, and evaluation of the efficiency of the health system.

3. The circumstances under which the collection, use and disclosure of personal health information would be permitted without an individual's express or implied consent, in particular when disclosure is to third parties for the purposes of statistical analyses or compiling of statistical information by the third party with respect to the planning, monitoring or evaluation of the health system

Both the Background Paper and the Consultation Guide address the issue of consent, the types of consent, and under what circumstances consent may or may not be required.

CIHI's Privacy Policy states that "the knowledge and consent of the individual are required for the collection, use or disclosure of personal health information, except where inappropriate."¹ CIHI also recognizes that each jurisdiction will determine its own approach to consent for the collection, use and disclosure of health information.

¹ CIHI's Privacy Policy, Principle 3, page 13.

At the same time, the level of consent required or, whether consent is required at all, may significantly inhibit or make impossible, important statistical analysis, in spite of potential public benefits of the dissemination of the results of that data analysis. A health information protection law should take into account legitimate uses of health system information where obtaining express or implied consent may not be appropriate, necessary or required. As a secondary collector/user of health data, we strongly recommend, as mentioned previously, that any health information privacy legislation make provision for the disclosure of personal health information to third party entities such as CIHI (whether as an "information manager" or a designated body) for specific purposes related to analysis or compiling statistical information which will be used to inform population health or health system management and planning and the development of best practices at the local and national levels. In such cases, the collecting entity (such as a hospital) must meet certain requirements, such as having in place privacy policies, practices and procedures for the protection of personal information and personal health information in its custody and control.

Examples of this approach are in Ontario's *Personal Health Information Protection Act, 2004*, S.O. 2004, c. 3, Sched. A ("PHIPA") where a health information custodian (as the term is defined in PHIPA) may disclose personal health information to a prescribed entity (such as CIHI), and in Alberta when the health information custodian has entered into an agreement with an information manager (such as CIHI) so designated under the *Health Information Act*, S.A., cH-4.8.

It is noted in both the Consultation Guide and Background Paper that if information is, in fact, collected, used and disclosed without an individual's consent, the individual has a right to be notified of this action and of their right to appeal this action to a person charged with enforcing the legislation.

As noted earlier, CIHI is a secondary collector/user of health data. We rely on primary data providers to have the statutory or other authority to disclose personal health information to CIHI. Moreover, the health data is not collected or used by CIHI for an administrative purpose, that is, it is not used or collected for the purpose of making a decision about the individual to whom the information relates, but for statistical purposes. It would be highly problematic if the primary data providers were required to notify, on a case-by-case basis, individuals to whom the personal health information relates that they have shared agreed-upon data elements (including identifiable information) with CIHI for statistical purposes. This could result in only a subset of personal health information being provided (i.e. only individuals that do not appeal this action would have their personal health information disclosed to CIHI). For individuals who do appeal this action, CIHI would not obtain their information. Consequently the information in our data holdings would be incomplete, and of limited value, and use to jurisdictions, including New Brunswick for purposes of data quality, comparability and reporting at the local, regional, provincial and national levels.

From our perspective, it would still be prudent for any health information legislation to require primary data collectors, at a minimum, to inform patients of any standard uses and disclosures of their personal health information to appropriate third parties (whether

information managers or designated bodies) that support New Brunswick in planning and managing its health system effectively. This would be consistent with other general data protection laws in Canada and would meet the purposes identification and openness principles as embodied therein.

4. CIHI's ability to disclose health information to: (i) other Canadian governments in carrying out our activities related to our national mandate, for example benchmark comparisons; and (ii) other third parties, where appropriate, as permitted under applicable legislation and our Privacy Policy

There is also the question of CIHI's ability to further disclose health information that New Brunswick has provided to CIHI. CIHI currently discloses identifiable data to other provinces, territories or the federal government (such as Statistics Canada) in certain circumstances, as authorized by law and in accordance with the terms of the agreements that it has with New Brunswick. We would like to see some certainty around the authority for CIHI to disclose identifiable health information to third parties in certain limited and specific circumstances.

(i) Disclosure of out-of-province data

One particular circumstance worth mentioning is the disclosure of out-of-province data. For any patients treated in a hospital outside of their home jurisdiction, CIHI receives the discharge abstract for that patient, and, if requested, includes the information in the discharge abstract database report of the home province or territory, with the authorization of the province where treatment occurred. The record provided to the home jurisdiction includes the patient's personal health number. It is important for the patient's home jurisdiction to receive information on the services its residents are receiving elsewhere to assist in health policy and service planning decisions. The information is particularly important to smaller jurisdictions, such as Prince Edward Island, whose residents receive many health services outside of their home jurisdiction.

The provision of out-of-province care data is a very limited and specific disclosure and an important component to managing the health system. It would be helpful if specific and limited authorization were included in any health information legislation to facilitate this important activity. Indeed, the Ontario model specifically provides CIHI with this authority for Ontario resident information. Hence, we propose that out-of-province disclosure be authorized where:

- a) the disclosure is for the purpose of health planning or health administration;
- b) the information relates to health care provided in New Brunswick to a person who is a resident of another province or territory of Canada; and
- c) the disclosure is made to the government of that province or territory.²

(ii) Disclosure to other third parties

² See subsection 18(7) of O. Reg. 329/04 of Ontario's *Personal Health Information Protection Act* S.O. 2004, c. 3, Schedule A ("PHIPA")

CIHI discloses health information in accordance with our Privacy Policy. As mentioned earlier, the issue of CIHI disclosing person-identifiable data could be addressed either in the legislation, or through the mechanism of a data sharing agreement should CIHI's status be that of an "information manager" under any health information protection legislation. At this time CIHI and New Brunswick are ready to execute an umbrella data sharing agreement that will also govern CIHI's collection, use and disclosure of New Brunswick personal health data.

Health research is also an essential requirement for improving individual and population health, supporting health policy, and strengthening health system management. CIHI's data holdings on various aspects of the health system form an important resource for certain types of studies and research internal to CIHI.

For your information, external requests for data from CIHI must be made using one of CIHI's two-part Client Information Request Forms (separate forms for aggregate and record-level data), available on the CIHI web site.³ Part 1 requires information on the proposed analysis, the individuals involved, and the data being requested. Part 2 is a *Non-Disclosure/Confidentiality Agreement*. The Agreement details the limits on the use of the data and binds the data requestor to properly protect the information, to respect the sensitivity and confidentiality of the data, and to not attempt to re-identify anyone in the data set. In accordance with CIHI's current Privacy Policy, all data are de-identified prior to release except as authorized by the data provider.

Conclusion

CIHI recognizes the importance of protecting personal health information and the need to establish a clear legal regime for that purpose. At the same time CIHI also recognizes the need to have such a legal regime strike the right balance between enabling health care providers to give the best possible care while also ensuring that other participants in health and health care are able to adequately and effectively support the Government in planning and managing the health system.

The value of the analysis of the health system is widely recognized. Provincial and federal privacy commissioners who have recently reviewed the health system have all supported such activities. In fact, policy makers at the provincial and national levels look to information from organizations such as CIHI to inform the discussion of health reform initiatives and health system management. Findings and reports, either from organizations such as CIHI, or supported by data from them, contribute in a fundamental way to the quality and effectiveness of the care provided in the health

³ Copies of the Client Information Request form for aggregate and record-level information are available on our website located at http://secure.cihi.ca/cihiweb/en/downloads/reqdata_e_aggregate.pdf, and http://secure.cihi.ca/cihiweb/en/downloads/reqdata_e_record.pdf respectively.

system, as well as to the efficiency of the system as a whole and to the population's health.

We believe that CIHI's policies, practices and procedures in relation to all of the information provided to us, whether it is personal, personal health or other information, provide the right balance between ensuring the protection of Canadians' personal health information with the public need for accountability in the health system.

Alberta, Manitoba and Ontario have recognized the importance of our role by designating CIHI as an "information manager" or prescribed entity under their respective health information protection legislation. It is our position that with the addition of a provision within any new health information protection legislation reflecting the activities of CIHI, a similar arrangement would work well in New Brunswick.

Thank you again for the opportunity to contribute to the consultation process regarding New Brunswick's proposed health information protection legislation. CIHI would be more than happy to participate in further consultation processes on future possible iterations of draft legislation. Please do not hesitate to contact Elspeth Gullen, Senior Counsel, Privacy and Legal Services, CIHI at (613) 694-6953 or by e-mail at egullen@cihi.ca if you have any questions or wish to further discuss CIHI's position.

Yours truly,



Louise Ogilvie
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Enclosure