



April 14, 2008

Hon. George Abbott
Minister of Health
Parliament Buildings
Victoria BC V8V 1X4

Dear Minister:

Bill 24—E-Health (Personal Health Information Access and Protection of Privacy) Act—OIPC Files F08-34100 and F08-34731

This letter comments on Bill 24, the main driver of which, quite clearly, is the development of electronic health records in British Columbia, notably the provincial government's electronic health record initiative. Electronic health records are under development elsewhere in Canada and, like other Canadian privacy commissioners, I acknowledge that electronic health records may improve health care delivery and achieve cost efficiencies in delivering publicly funded health services.

Privacy must, however, be designed and built into electronic health record systems from the outset. Privacy is a legal obligation, but it is also a fundamentally important value given the sensitivity of personal health information and the need to retain patients' trust in their health care providers.

Bill 24 enables creation of health information banks that, subject to the ministerial orders creating them, authorize disclosure and use of personal health information for purposes other than those narrowly required for diagnosis and treatment of individual patients. The other purposes include health research; health services planning, maintenance or improvement; health services billing; assessment of public health needs; and assessing and addressing public health threats.

These important public policy objectives are appropriately balanced by provisions in Bill 24 and in British Columbia's other privacy laws. It is important to bear in mind that Bill 24 supplements but does not supplant the privacy rules that apply to the public health care sector under the *Freedom of Information and Protection of Privacy Act* ("FIPPA") and to the private sector under the *Personal Information Protection Act* ("PIPA"). Because those laws override Bill 24, the privacy rules they contain will continue to apply to personal health information in health information banks, including:

- rules limiting collection, use and disclosure of personal health information,
- a right of access by individuals to their own personal health information, with limited grounds on which access may be refused,
- the obligation to take reasonable steps to ensure personal health information is accurate and complete,
- the right of an individual to request correction of personal health information,
- a duty to make reasonable security arrangements against such risks as unauthorized access, collection, use, disclosure or disposal of personal health information.

My office will, of course, continue to discharge its duties and functions as the independent oversight agency charged with ensuring compliance with Bill 24 and British Columbia's other privacy laws. We will also continue to comment on the privacy implications of individual electronic health record initiatives, with a view to ensuring (among other things) that privacy is designed into systems from the outset.

Bill 24 raises the following specific issues, which I ask you to address.

1. *Making disclosure directives available*

Section 8 provides that the minister "may", in an order designating a health information bank, authorize individuals to make disclosure directives respecting their own personal health information. Disclosure directives will give individuals an appropriate degree of control over disclosure and use of their personal health information. This welcome feature of Bill 24 is consistent with internationally accepted privacy principles and with the scheme of both FIPPA and PIPA.

Section 8, however, leaves disclosure directives in the discretion of the minister. I acknowledge that the technology of health information systems associated with some health information banks—for example, those residing with health authorities operating legacy systems—may not be able to accommodate disclosure directives at this time. As regards the information systems under development by your ministry, I urge you to ensure that the systems accommodate disclosure directives and that associated ministerial designation orders authorize disclosure directives. Respecting information systems already operating within health authorities, or in development by health authorities, I urge you to ensure that these legacy systems are, within a reasonable period, able to and do accommodate disclosure directives.

2. *Timelines & transparency for data stewardship committee*

Under s. 14 of Bill 24, the data stewardship committee may, on application, disclose information for health research purposes, but no time for response by the committee is specified. Authority to disclose personal information for

research already exists under FIPPA and PIPA. I acknowledge that neither of these specifies a time within which a public body or organization must respond to a research request. I also recognize that research applications can be complicated, may need clarification and may otherwise require time for consideration. Nonetheless, the data stewardship committee should be required to respond to applications within a specific response time, such as 90 business days (with authority to extend where necessary on specified grounds).

Section 16 will require the data stewardship committee to report annually to the minister about its activities, about information-sharing agreements entered into by an administrator of a health information bank, and about other matters the minister may require. Provision should be made for publication of these reports by the minister promptly after their receipt each year. This is necessary in the interests of transparency and accountability for the exercise of the powers granted under Bill 24 respecting disclosure and use of personal health information for research and other purposes.

3. *Access to personal health information*

Section 17 requires administrators of health information banks to make personal health information available to individuals, with the authority to withhold information as permitted under FIPPA. I understand this provision is intended to underpin systems that will give individuals electronic access to their own personal health information without a formal access request. An example of routine access would be secure web-based access by patients from their own homes. It is important that individuals be aware that—particularly where their own information has been denied under s. 17—they can make a formal request for access under FIPPA or PIPA, as the case may be. They should know this at the time they gain access. One way to do this would be to alert individuals to their right of access through a log-on screen notice telling them this. This would help ensure that, where some of their information has been withheld, they will at once know what steps they might take under FIPPA. I urge you to ensure that this issue is addressed in systems of routine electronic disclosure of personal health information.

4. *No fees for access to one's own personal health information*

As noted earlier, s. 17 is intended, I understand, to underpin routine electronic access to personal health information, not the more resource-intensive kind of access entailed where specific requests are made under FIPPA. Under FIPPA, a public body cannot charge a fee to an individual who requests access to her or his own personal information. (Under PIPA, a private sector organization may only charge a “minimal” fee for access.) Yet, s. 26(2)(g)(iv) of Bill 24 will authorize regulations to be made “respecting fees that may be charged by administrators for making available” under s. 17 personal health information and records mentioned in s. 17.

If the intention is to authorize fees for access to information or records other than personal health information, s. 26(2)(g)(iv) is not so limited and it should be. Moreover, the fact that the charging of fees will be discretionary is not enough protection against financial barriers to access.

Given the nature of the access being enabled by s. 17, and the importance of the right of access to one's own personal information, s. 26(2)(g)(iv) should be deleted.

5. Clarifying the access rules that may be prescribed by regulation

Section 26(2)(g)(i) will authorize regulations to be made "respecting the types of information that may, or must not, be made available" under s. 17. Section 26(2)(g)(iii) will authorize regulations to be made "respecting information that must be removed from a record before the record is made available" under s. 17. These provisions refer to "information", not "personal health information", but clarification is needed that "information" under these provisions is a class of information that excludes "personal health information". This is necessary because s. 17(2) expressly provides that personal health information may be denied under s. 17 only on the grounds available under FIPPA and, to avoid any doubt about the interplay between s. 17(2) and subsidiary requirements in regulations, ss. 26(2)(g)(i) and (iii) should be amended. In each case, the words "other than personal health information" should be inserted after "information".

In closing, Bill 24 is welcome because it provides a sound framework for the creation of health information banks and collection, use and disclosure of personal health information for the purposes specified in the Bill. Bill 24 and British Columbia's existing privacy laws provide a sound framework for the protection of the privacy of personal health information.

Consistent with our longstanding practice when commenting on a Bill tabled in the Legislative Assembly, I am sending a copy of this letter to the Opposition critic for your Ministry. This letter will also be posted on our website.

Yours sincerely,

ORIGINAL SIGNED BY

David Loukidelis
Information and Privacy Commissioner
for British Columbia

cc: Adrian Dix MLA
Opposition Critic, Ministry of Health

Gordon Macatee
Deputy Minister of Health