

By Courier

June 9, 2004

Honourable Jim Rondeau
Minister of Healthy Living
Room 310, Legislative Building
Winnipeg MB R3C 0V8

Dear Mr. Rondeau:

I am pleased to have the opportunity to add our input and suggestions relating to *The Personal Health Information Act* (PHIA) as part of the mandatory, comprehensive, and public review of the operation of the Act required under section 67 and now underway. We believe that Legislature's decision to approve the provision requiring a timely and full review of the stature was wise, and should be renewed, especially in view of changing information and communication technologies that are rapidly and radically transforming our information and knowledge environment.

Dedicated to the protection of personal health information, PHIA was pathfinding legislation in Canada when it was passed by the Legislature in 1997. Since that time, Alberta and Saskatchewan have brought into force their own versions of such legislation.

The Freedom of Information and Protection of Privacy Act (FIPPA) was drafted at the same time as PHIA and these companion statutes share a common base of internationally accepted principles of fair information practices with respect to their privacy provisions, including access to one's own personal information. PHIA applies solely to access to and privacy of personal health information, and covers health information trustees as defined in the Act, which include certain health professionals, health care facilities, health services agencies, and public bodies that collect or maintain personal health information. Some entities that collect and maintain personal health information are not covered including professional associations, regulatory bodies, and private sector employers.

This statutory review of PHIA is particularly timely in view of the seemingly ever rising emphasis on and the development of electronic health information networks regionally, provincially, and nationally intended to facilitate better healthcare services and administration. We have flagged this issue in a number of our annual reports and elsewhere since PHIA was introduced. In addition, diverse, opportune, and judiciously selected health research using or deriving from personal health information is of fundamental importance to everyone. Electronic information and communication technologies (ICTs) have made extraordinary strides since 1997 that open up both great opportunities and privacy challenges. It is important to ensure that PHIA

maintains a considered balance between the use of ICTs and personal health information privacy.

The Manitoba Office of the Ombudsman has provided independent oversight of *The Personal Health Information Act* since 1997. During these years, we have investigated complaints, made recommendations, conducted special investigations and commented on the administration of the legislation both in special reports and annual reports to the Legislature.

Based on the lengthy experience of our office, we are providing the attached comments on specific provisions of the legislation along with highlights of certain issues for consideration.

Generally speaking, I believe the purposes and principles incorporated in PHIA are consistent with principles of fair information practices. These principles have been incorporated into most privacy legislation in other Canadian jurisdictions.

While I have previously commented on Manitoba's personal health information legislation in my annual reports to the legislature, I appreciate this opportunity to reinforce and expand on some of these thoughts.

Our experience suggests that those who are involved in the administration of PHIA require ongoing training, advice, and support to ensure that there is consistency among personal health information trustees in terms of an understanding and commitment to the legislation. From time to time, we have encountered a phenomenon apparently called "PHIAnoia" wherein it seems the legislation is not adequately understood or is applied very legalistically sometimes to the detriment of common sense and reasonableness. To help overcome this unfortunate misapprehension, I would suggest that the government establish an annual public forum where privacy issues can be brought forward and discussed, where specialists can share their expertise with those responsible for administering legislation, and where trustees have the opportunity to share their experiences and knowledge. I believe this step would strengthen their commitment to the principles of privacy rights. A number of provinces hold these forums annually.

Our specific comments for consideration of changes relating to PHIA are provided in the attached PHIA Overview document (*Appendix 1*) and spreadsheets for the Act and its Regulation (*Appendix 2*). The *Elements of Consent for Personal Health Information under PHIA* prepared by our Office is also attached for reference purposes, not as a specific suggestion for change (*Appendix 3*). These documents, together with my letter, should be taken as representing our legislative concerns based on our experience with PHIA since its proclamation. Once the Government has developed and introduced amendments to the legislation, we anticipate that there will be a further opportunity to comment.

We have provided our comments on the spreadsheets with regard for the roles of the Government and the Legislature in making amendments to the Act. We have refrained from using the word "recommend" at this stage in our comments since it carries a distinct meaning for our office under Manitoba's access and privacy legislation. We have generally urged that "consideration" be given to changing the legislation. Our use of this rather low-key word should not be taken to downplay the seriousness of our suggestions.

I should also note that we have refrained from commenting on a number of important provisions in the statute that may be subject to amendments since we do not feel that this is the

appropriate stage to anticipate or presuppose amendments that may be introduced to the Legislative Assembly.

There are several comments that I wish to cover in this letter rather than in the attachments. They are:

1. **PRIVACY IMPACT ASSESSMENT (PIA)**

PIAs are analytical tools that are particularly useful in assessing and understanding the potential impact on information privacy of a proposed program, practice, service or system. They may also be applied to existing programs. A number of jurisdictions have made the use of PIAs mandatory, either by law or policy including Alberta, British Columbia, Canada, and Ontario. We strongly support the open and transparent use of PIAs to ensure compliance with PHIA to the extent possible and to maintain or obtain the trust and confidence of Manitobans on how personal health information trustees, including the Government, manage personal and personal health information.

We understand that Manitoba Health has taken what seems to be a very appropriate step of introducing a privacy impact assessment requirement by policy, though its scope of application and focus might be usefully expanded beyond the department and its partners in electronic health information system projects to include other personal health information trustees.

2. **CONSENT**

Authorization to Collect

PHIA section 13(1)

Section 13(1) of PHIA sets out that a trustee may not collect personal health information unless authorized to do so. In our experience, there are circumstances where individuals need programs or services so much that they essentially feel compelled or coerced into giving consent, regardless of the merit of the purpose of collection. In our view, an “authorization to collect” model with good notification requirements may arguably provide stronger protection than a “consent to collect” model.

Consent to Use and Disclose

PHIA sections 21(b), 22(1)(b), 24(3)(c) and s.66(1)(e)

Although trustees must be authorized to collect personal health information, the use and disclosure of such information requires consent. The concept of consent occurs in the following provisions of PHIA: use (section 21), disclosure (section 22) and research (section 24). While the requirement for consent is set out, the form of that consent has not been articulated. Under section 66(1)(e), this could be addressed in a regulation.

As noted in the “Elements of Consent for Personal Health Information under PHIA” developed by our Office (*Appendix 3*), it may be appropriate for consent to take different forms in different situations. We are not certain that prescribing the form that consent should take would solve issues where individuals feel compelled by circumstances to provide their consent. There also may be circumstances where notice provides a sufficient degree of transparency to provide protection comparable to consent.

3. **SPIRITUAL CARE**

In 2000, our office was asked to comment, under PHIA, on privacy issues surrounding the provision of spiritual care to individuals in health care facilities. This generated considerable

discussion within our office and from interested parties who contacted us after we issued our comment in the following year. It is our view that whether or not spiritual care is health care is not a PHIA (legislative) matter, and we have not approached it from this perspective. We have specifically said that our comment did not address the issue of spiritual care as part of holistic patient care.

It is the view of our office that, where the collection of personal information is involved, this is a best practice issue most easily addressed at the outset by simply asking patients or patients-to-be whether they want spiritual care. We do not see a problem in any facility providing these individuals with the information that a facility offers spiritual care services. If the answer to the question is “yes”, then appropriate measures within the provisions of PHIA could be undertaken to provide this service in whatever form is requested and available. Use and disclosure of information received and a patient’s personal health information would be fully subject to the use and disclosure provisions of PHIA, including the limitations entailed by the “need to know” principle and the obligation on health information trustees to provide the minimum information necessary.

As this matter is being addressed under Bill 43, our Office could provide further comments on request.

4. PHIA & FIPPA AND THE FEDERAL PERSONAL INFORMATION PROTECTION AND ELECTRONIC DOCUMENTS ACT – (PIPEDA)

There is a serious gap in the privacy rights of employees who work in the provincially regulated private sector that is not covered by PHIA or by PIPEDA. FIPPA, of course, does not apply at all to the private sector. These employees do not have the same personal and personal health information protections as those who are within the scope of access and privacy legislation. This is inequitable.

5. Access and Privacy Commissioner versus Ombudsman

Most jurisdictions in Canada have an established independent office of the Ombudsman that promotes fairness through the investigation of complaints relating to administrative acts, decisions or omissions by public bodies. Most jurisdictions also have an independent office of an Access and Privacy Commissioner that promotes respect for access and privacy rights and ensures compliance with their jurisdiction’s access and privacy legislation. At the federal level there is both an Access Commissioner and a Privacy Commissioner.

In Manitoba, the independent oversight role under access and privacy legislation has been added to the Ombudsman role. Some have suggested that the more formal order power oversight model, such as exists in British Columbia, Alberta, Ontario, and Quebec, can be more effective and timely than the recommendation model in terms of compliance with access and privacy rights. Others feel that the less formal recommendation power model as practised by the federal level, Saskatchewan, Manitoba, New Brunswick, Nova Scotia, and the Yukon Territories is just as effective and timely. I believe that each model has its merits, and that issues of effectiveness and timeliness are influenced more by the degree of commitment than by order or recommendation power.

My concern is that the independent oversight body should be clearly identified as an Access and Privacy Commissioner’s office. I believe it is in the interest of the government and the Legislative Assembly to indicate to the public the importance of access and privacy rights by clearly establishing an Access and Privacy Commissioner role.

After many years of undertaking this role as Ombudsman, I find it is unfortunate that this important role in promoting access and privacy rights is unknown in far too many circles. Manitobans and Canadians need to know that our province has, in fact, not only enacted legislation that respects access and privacy rights, but also has established an independent oversight office dedicated to investigating complaints, auditing and monitoring to ensure compliance with the statutes.

Whether or not there is a separate Commissioner and office or the Ombudsman is appointed to that role in addition to the role under *The Ombudsman Act* is not the issue. In my opinion, I believe the role of Access and Privacy Commissioner for the province needs to be visible and this can be accomplished by referring to the head of the independent oversight office as an Access and Privacy Commissioner.

In view of the complementary nature of PHIA and FIPPA, I am providing a copy of these comments to your colleague, the Honourable Eric Robinson, Minister of Culture, Heritage and Tourism.

In concluding this part of our comments, I would be pleased to meet with you or staff of your department to discuss any matter arising from these comments or relating to possible amendments to FIPPA.

Yours truly,

Barry E. Tuckett
Manitoba Ombudsman

cc. Honourable Eric Robinson, Minister of Culture, Heritage and Tourism
Heather McLaren, Manitoba Health

Attachments