



Ombudsman &
Information and Privacy
Commissioner

Yukon Ombudsman and Information & Privacy Commissioner

Submission on the draft *Mandatory Testing and Disclosure Act*

February 11, 2009

INTRODUCTION AND SUMMARY

I am providing this submission pursuant to my responsibility to comment on the implications for access to information or for protection of privacy of proposed legislative schemes as authorized by the *Access to Information and Protection of Privacy Act* (ATIPP Act¹) and in response to an invitation from the Minister of Justice to participate in a consultation process.

The proposed *Mandatory Testing and Disclosure Act* (the Act) contemplates the creation, collection and disclosure of extremely sensitive personal health information of Yukoners.

This submission recommends that the *Mandatory Testing and Disclosure Act* not proceed, in the absence of a comprehensive legislative scheme to adequately protect personal health information.

However, if the proposed *Mandatory Testing and Disclosure Act* is to proceed to law, it is imperative that the government use every possible measure to protect the personal health information that will be created, collected and disclosed through the Act. This should be done by: a) making the ATIPP Act apply to the *Mandatory Testing and Disclosure Act* and b) where necessary, including specific wording in relevant sections of the *Mandatory Testing and Disclosure Act*, to make those sections paramount to the ATIPP Act.

The ATIPP Act provides a universal scheme of access to information and protection of privacy principles for the Yukon government. The creeping repeal of those principles through the creation of a patchwork of access and privacy rules in various legislation should be avoided.

The ATIPP Act also includes a process for independent oversight and accountability. This is absent in the proposed *Mandatory Testing and Disclosure Act*. Therefore, the ATIPP Act must apply to the proposed legislation in order to ensure this oversight and accountability.

¹ The ATIPP Act refers to the Yukon legislation throughout this submission.

COMMENTARY AND RATIONALE

The format used in this submission is to provide statements followed by supporting rationale.

1. In order to provide the most comprehensive protection for Yukoners, it is essential that the government adopt specific legislation to protect personal health information, prior to proceeding with the *Mandatory Testing and Disclosure Act*.

In considering the adoption of the proposed legislation, the government must be mindful of the limited scope of our current access and privacy legislative regime. The Yukon does not have legislation designed to specifically protect personal health information and the ATIPP Act does not apply to all aspects of personal health information governance, which has implications for the privacy and security of that information. The ATIPP Act has limited application in this respect, that being to protect only the personal health information in the custody or under the control of medical professionals who are employed by the Yukon government. It does not apply to personal health information in the custody or under the control of medical professionals who are NOT employed by the Yukon government.

The ATIPP Act has a narrower scope than similar legislation in most other Canadian jurisdictions. As well, all other territories and provinces have, or are currently developing, legislation specifically designed to protect personal health information, in the hands of either government or other health professionals such as pharmacies, labs, doctor's offices, etc. In short, the absence in the Yukon of specific legislation to protect personal health information, when it is the hands of those not subject to the ATIPP Act, results in inadequate privacy protection for Yukoners.

The proposed legislation will require individuals to submit to testing which will result in factual information about their own health being recorded and disclosed to others. This in effect creates information which did not previously exist. This information is created without the consent of the individual and in fact may be information that he or she does not want to know.

In my view, the threshold for protecting personal health information is very high and is magnified when an individual is required by legislation to submit to the procedure which creates that piece of information. The proposed *Mandatory Testing and Disclosure Act* will permit the creation and collection of personal health information and its disclosure to individuals such as doctors, laboratory technicians or others, all of whom are not subject to the ATIPP Act, without providing adequate protection for such information.

2. The *Mandatory Testing and Disclosure Act* must be subject to the ATIPP Act. However, where provisions in the ATIPP Act are not adequate to protect the very sensitive personal health information that is created or obtained under the *Mandatory Testing and Disclosure Act*, additional protections should be built into the proposed legislation. Only those very limited provisions which are required to enhance the protection of personal health information should be permitted to operate outside the scope of the ATIPP Act. This approach is pursuant to section 4(1) of the ATIPP Act.

All Yukon government departments are public bodies and therefore subject to the ATIPP Act. The Act provides a universal scheme of access to information and protection of privacy principles for the Yukon government. Therefore any process or legislative scheme, certainly one as intrusive as that contemplated in the *Mandatory Testing and Disclosure Act*, should be subject to the ATIPP Act's governance.

The ATIPP Act also provides for independent oversight of decisions made or actions taken by government in relation to access to information and the protection of privacy. The right of review is a crucial component of access and privacy protections. In my view, the ATIPP Act must apply to the *Mandatory Testing and Disclosure Act* in order to provide the necessary oversight and accountability.

The proposed Act will create a number of situations that should be specifically addressed in that legislation to enhance the protection of the personal health information it will be creating and disclosing, to provide protection not found in the ATIPP Act. The overall scheme of access and protection in the ATIPP Act, however, must be paramount. A patchwork of access and privacy rules should be avoided.

Where additional protections are necessary, it will be appropriate for certain sections of the *Mandatory Testing and Disclosure Act* to be paramount to the ATIPP Act. In order for this to be done, the proposed legislation must include specific wording to that effect, as required by section 4(1) of the ATIPP Act.

For example, Alberta's *Mandatory Testing and Disclosure Act* is subject to the Alberta *Freedom of Information and Protection of Privacy Act*. It does however, recognize the importance of confidentiality by including one specific paramountcy clause with the following wording:

16(1) Despite the Health Information Act and the Freedom of Information and Protection of Privacy Act and subject to subsection (2), no person shall use or disclose any information about an applicant or a source individual that comes to the person's knowledge in the course of carrying out any responsibility pursuant to this Act or the regulations.

SPECIFIC PROVISIONS OF THE PROPOSED ACT

The following comments are based on the assumption that the *Mandatory Testing and Disclosure Act* will be subject to the ATIPP Act, with the exception of specific sections which will have paramountcy to provide greater protection. If this is not the case, I would like an additional opportunity to provide comments about the access and privacy scheme proposed before a final draft of the *Mandatory Testing and Disclosure Act* is completed.

Definitions

- 3. The *Mandatory Testing and Disclosure Act* must contain adequate and specific definitions to allow for appropriate protection of privacy and limitations of access for all personal information collected, used or disclosed under the Act. In particular, the term “bodily substance” must be defined so it is subject to the ATIPP Act.**

In the proposed legislation there is no definition of “bodily substance”. If “bodily substance” is to be defined as “personal information” and thus subject to the protections afforded other personal information by the ATIPP Act, the *Mandatory Testing and Disclosure Act* must say so. Without a clear definition, there may be a question of whether or not bodily substance is personal information. The result is inadequate protection for extremely sensitive personal information.

Most other jurisdictions define a bodily substance as “diagnostic treatment and care” information which is, in turn, considered personal (health) information either within specific legislation protecting personal health information, such as exists in Alberta’s *Health Information Act*, or in public sector privacy legislation, such as British Columbia’s *Freedom of Information and Protection of Privacy Act*.

Custody and Control

- 4. The *Mandatory Testing and Disclosure Act* must expressly state that all personal information created or obtained through the Act, regardless of where it is stored or to whom it is disclosed, remains in the custody or under the control of the Medical Health Officer.**

The draft legislation suggests the Medical Health Officer has responsibility for certain documents and items, some of which contain personal information. These include the testing order, notices, the designations to a health professional or to an analyst, any bodily substance sample tested and retained, and the written record of the results of the analysis. However, the proposed wording does not expressly state that such information remains in the custody or under the control of the Medical Health Officer.

Failure to specifically state who has custody or control of specific information will lead to uncertainty and confusion about the applicability of the ATIPP Act. When the Medical Health Officer discloses information to other entities such as laboratories or hospitals, the disclosed health information will no longer be protected under the ATIPP Act.

An express provision that the custody or control of personal health information remains with the Medical Health Officer, will help alleviate any uncertainty of what protections exist for that information when it is exchanged with others. In addition, retaining the custody or control of this information in the Yukon may prevent unintended access or disclosure of that information, if it is exchanged with another jurisdiction in which different laws may apply.

Collection of Personal Information

5. The *Mandatory Testing and Disclosure Act* should provide express authorization for the Medical Health Officer to collect personal information as may be required for the operation of the Act.

The ATIPP Act states that personal information must be collected directly from the individual the information is about unless it is done:

- i) with the consent of the individual;
- ii) when authorized by the Information and Privacy Commissioner; or
- iii) when specifically authorized by federal or Yukon legislation.

The Medical Health Officer is subject to the ATIPP Act and therefore is restricted from collecting personal information from other sources except in those three circumstances. The practical application of the *Mandatory Testing and Disclosure Act* may on occasion require the Medical Health Officer to collect the personal information of individuals from other sources. The *Mandatory Testing and Disclosure Act* must contain a provision specifically authorizing him or her to do so.

Disclosure of Personal Information

6. The *Mandatory Testing and Disclosure Act* should expressly state that the confidentiality provisions in section 14 are to operate despite the provisions of the ATIPP Act. Making section 14 of the proposed legislation paramount to the ATIPP Act will provide more stringent protection of the personal health information obtained through the operation of the Act than the ATIPP Act provides. The ATIPP Act should apply to all other sections of the *Mandatory Testing and Disclosure Act*.

Section 14 of the *Mandatory Testing and Disclosure Act* restricts the disclosure of any information obtained through the operation of the Act. That section describes the only circumstances in which any person can disclose information that comes to his or her knowledge in the course of performing duties under the Act. Given the sensitive nature of the information that will be dealt with under the proposed Act, such a limitation is appropriate.

In order for section 14 to restrict disclosure, that section must be designated to operate despite the provision of the ATIPP Act, as the ATIPP Act provides authorization for disclosure of personal information that, in certain specified circumstances, is broader than that proposed by section 14 of the *Mandatory Testing and Disclosure Act*.

7. The ATIPP Act should apply to the disclosure of a minor’s personal information under the *Mandatory Testing and Disclosure Act*.

Sections 5(2) and 8(1)(b) of the *Mandatory Testing and Disclosure Act* require disclosure of the personal information of a minor to his or her parent or guardian. The proposed legislation requires that the parent or guardian will be notified if the source individual is a minor (section 5(2)) and be notified that results of the analysis have been received (section 8(1)(b)). The Act goes further to state that the parent or guardian is entitled to receive a “copy of the results” upon request (section (8)(1)(b)(i)).

The ATIPP Act does not permit the disclosure of another individual’s personal information without their consent, even to a parent or guardian, unless the disclosure would not be an unreasonable invasion of the privacy of the minor. This principle should be respected in the *Mandatory Testing and Disclosure Act* and the ATIPP Act should apply to the disclosure of a minor’s personal information.

8. Section 8 of the *Mandatory Testing and Disclosure Act*, as drafted, is contrary to law. If the Act is to authorize the disclosure of personal information as proposed by section 8, a specific provision must be included to have that section operate despite the provisions of the ATIPP Act.

The ATIPP Act does not permit the disclosure of a “copy of the results” as contemplated by section 8 of the *Mandatory Testing and Disclosure Act*. Pursuant to the ATIPP Act, a “copy of the results” would be a record containing an individual’s personal information and therefore disclosure of that record would be limited to the circumstances set out in the ATIPP Act.

The ATIPP Act principles for the protection of privacy of personal information should be respected. The disclosure of personal information permitted by section 8 of the *Mandatory Testing and Disclosure Act* is contrary to law.

If the Act is to authorize such disclosure of personal information a specific provision must be included to have that section operate despite the provisions of the ATIPP Act.

IN CONCLUSION

I request the opportunity to provide further comment on the proposed *Mandatory Testing and Disclosure Act* when wording for section 20 is determined and when the submissions made during the consultation process have been incorporated into the proposed Act.

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