



17th Legislative Assembly of the Northwest Territories

Standing Committee on Social Programs

Report on the Review of
Bill 4: *Health Information Act*

Chair: Mr. Alfred Moses

MEMBERS OF THE STANDING COMMITTEE ON SOCIAL PROGRAMS

Alfred Moses
MLA Inuvik Boot Lake
Chair

Daryl Dolynny
MLA Range Lake
Deputy Chair

Wendy Bisaro
MLA Frame Lake

Jane Groenewegen
MLA Hay River South

Norman Yakeleya
MLA Sahtu

COMMITTEE STAFF

Gail Bennett
Committee Clerk

Patricia Langlois
Committee Researcher

**STANDING COMMITTEE ON
SOCIAL PROGRAMS**

**REPORT ON THE REVIEW OF
BILL 4: *HEALTH INFORMATION ACT***

TABLE OF CONTENTS

Introduction..... 1

Key Issues..... 1

 Purpose Statement 1

 Implementation 1

 Regulations..... 3

 Mandatory Review 3

Conclusion.....

**STANDING COMMITTEE ON
SOCIAL PROGRAMS**

**REPORT ON THE REVIEW OF
BILL 4: *HEALTH INFORMATION ACT***

INTRODUCTION

Bill 4, the *Health Information Act*, is the product of extensive work undertaken over the better part of a decade to develop health-specific privacy legislation for the Northwest Territories. The Standing Committee on Social Programs commends the Minister of Health and Social Services for developing the Bill. With its passing, the Northwest Territories will join a growing number of Canadian jurisdictions that have enacted legislation of this kind.

Bill 4 was referred to the Committee on November 7, 2013. The public hearing was held on February 20, 2014. Numerous stakeholders and citizens provided written submissions and made oral presentations. The clause-by-clause review was held on March 10, 2014.

It is the considered view of the Committee that the *Act* strikes an appropriate balance between the rights of patients and the need for efficiency within the system. At the same time, a great deal is riding on proper implementation.

The Committee proposed and adopted two amendments during the clause-by-clause review of the Bill, with the concurrence of the Minister. Both amendments are discussed in this report.

KEY ISSUES

Purpose Statement

Through an amendment, the purpose statement was broadened to address the rights of patients to access, correct and protect their personal health information. The Committee reasoned that patient rights should be treated on a par with the need for system efficiency. A comparison of purpose statements in other health-specific privacy legislation lent support to this view.

Implementation

Stakeholders stated repeatedly that the *Act* is difficult to understand. Unease about its complexity was widely expressed. Following the public review, the Committee identified this as an impediment to the provision of meaningful input and requested plain language material. The Department obliged, providing a "Frequently Asked Questions" document and an annotated version of the *Act*. The Committee in turn circulated the material to the stakeholders concerned. The Department posted the

FAQ document on the website, taking a strong first step toward informing the public about this legislation.

Given the complexity of the *Act* and its inevitable future impact, extensive public education will be required to make the legislation understandable. Extensive training will also be required to ensure that key players in the health sector implement the legislation in a consistent and accurate manner. To this end, the Committee urges the Department to widely circulate plain language material, including annotated versions of the *Act* and the regulations. Real-life scenarios and vivid illustrations should be used to explain key terms such as “health information custodian”, “implied” and “express” consent, and the “circle of care”.

In line with health-specific privacy legislation in other Canadian jurisdictions, “implied consent” is the backbone of this legislation. It does not require written authorization and occurs during the routine course of a patient visit. The *Act* places the onus on health information custodians to inform patients about implied consent and what it entails. The *Act* further states that consent must not be obtained through coercion or deception.

The *Act* gives patients the right to withhold and withdraw consent and to set limits on how their personal health information is shared. It is the patient’s responsibility to exercise these rights. During implementation, patients should be given repeated opportunities to absorb this information.

Special efforts must be taken to ensure that unilingual aboriginal language speakers understand their rights and what this legislation means.

The Department has allocated \$462,000 in 2014-2015 for implementation. To ensure delivery of a comprehensive public awareness campaign and thorough training for custodians and health care providers, the Committee urges the Department to allocate approximately double this amount.

Several citizens raised concerns about the extent to which personal health information is shared with the “circle of care”. Patients should be able to obtain a log of everyone who has viewed their personal health information. This message should be clearly communicated to the public.

Concerns were expressed about what happens to personal health information when it leaves our borders. Through information-sharing agreements with Alberta, our most frequent partner in the provision of health care, and other jurisdictions, the Department should ensure that personal health information is protected to the greatest extent possible when shared with health providers outside the NWT.

“Express consent” is a formal method of giving consent which typically requires written authorization. This method is used for some research purposes and when health care providers collaborate with other professionals such as teachers and social workers. Information about express consent should be communicated to the public and to helping professionals.

Mindful of the Government's goal of promoting service integration and inter-departmental collaboration, the Committee is concerned that this legislation may entrench "service silos". Reasonable measures should be taken to ensure that mental health workers, nurses and other health care providers are not unduly prevented from collaborating with teachers and social workers. Interaction between health professionals, child welfare agencies, and schools is often more influenced by institutional culture than privacy legislation. For this reason, training for health workers should include a module on how express consent works in "wrap-around" and integrated case management settings.

Concerns were raised about researchers accessing patient information without their knowledge. Under the *Act*, this can only be prevented if a patient makes an express statement to this effect. Once again, this message should be clearly communicated to patients and the public.

Regulations

The *Health Information Act* and its regulations, taken together, will constitute one of the largest information-sharing endeavours in the history of the Northwest Territories. Numerous details will be worked out in the regulations and while this affords greater flexibility to adjust legislation as required, the public has no opportunity to review them. Numerous stakeholders requested that such a courtesy be extended. The Committee strongly echoes this request.

Security procedures will be laid out in regulations to protect against hacking, viruses, and other security breaches. The serious breach of personal health information in Alberta recently illustrates the need to proceed with extreme caution. The regulations should establish meticulous and thorough procedures based on best practices nationally and internationally.

With respect to fees, the Committee urges the Department to continue the well-established practice of waiving fees under the *Access to Information and Protection of Privacy Act* (ATIPPA). To discourage repeated, frivolous or unreasonably large requests, the regulations should stipulate that a fee can only be charged if the cost of processing the request exceeds a pre-set amount.

The Committee was alerted to dangers associated with stripping, encoding or transforming information to create non-identifying data. Such dangers are amplified in a population the size of the Northwest Territories, and they are not trivial. The Committee urges the Department to ensure that custodians are trained in de-identification techniques, including measures to reduce the risks of re-identification.

Mandatory Review

An amendment was made to the Bill requiring the Minister of Health and Social Services to conduct a review of the *Act* within ten years of its enactment. This will allow legislators to test the Department's performance against its own rules.

The Standing Committee on Social Programs strongly urges the following courses of action:

- 1) That the Department of Health and Social Services develop and implement a comprehensive public awareness campaign;
- 2) That the Department of Health and Social Services provide extensive training for health information custodians and health care providers;
- 3) That the Department of Health and Social Services ensure the quality of patient care is not unduly compromised when a patient withholds, withdraws or places limits on consent;
- 4) That the Department of Health and Social Services employ a grace period during the first year of implementation, requiring custodians to provide patients with repeated opportunities to absorb the legislation;
- 5) That the Information and Privacy Commissioner be provided with additional fiscal and human resources to support implementation of the *Act*;
- 6) That the Department of Health and Social Services ensure consistent application of the legislation across all regional authorities;
- 7) That the Department of Health and Social Services take reasonable measures to ensure that unilingual aboriginal language speakers understand their rights and what the legislation means;
- 8) That the Department of Health and Social Services provide an opportunity for the Standing Committee on Social Programs to review and comment on the regulations before they come into force;
- 9) That the Department of Health and Social Services provide an opportunity for the public to review and comment on the regulations before they come into force;
- 10) That the Department of Health and Social Services review the "Pan-Canadian De-Identification Guidelines for Personal Health Information" as prepared by the Office of the Privacy Commission of Canada and ensure the regulations include measures to mitigate against the risks of re-identification;
- 11) That the Department of Health and Social Services clearly inform residents about their right to withhold consent to use of their information for research purposes;

- 12) That the Department of Health and Social Services provide training to members of the territorial research ethics committee which conforms to the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*;
- 13) That the Department of Health and Social Services establish information-sharing agreements with Alberta and other jurisdictions to ensure personal health information is protected to the greatest extent possible when it leaves the NWT;
- 14) That the Department of Health and Social Services and other custodians make it their practice to comply with access and correction requests promptly and without undue delay;
- 15) That the Department of Health and Social Services inform patients about their right to obtain a log indicating which individuals have accessed their personal health information;
- 16) That the Department of Health and Social Services take reasonable measures to ensure the Electronic Medical Records System is running smoothly prior to implementation;
- 17) That the Department of Health and Social Services ensure that mental health workers, nurses and other health care providers are not unduly prevented from collaborating with teachers, social workers and other professionals; and
- 18) That the Department of Health and Social Services include a module in their training to custodians and health-sector workers on the “wrap-around” (or team-based) approach, including how to obtain express consent from clients.

CONCLUSION

The Committee is grateful to everyone who provided input on Bill 4 and attended the public hearings.

The Standing Committee on Social Programs advises that it supports Bill 4 as amended and presented to Committee of the Whole.