

The Implications of Bill C-54 on Medical Information:

An Analysis of the Submission to the House of Commons Standing Committee on Industry by the Ontario Ministry of Health Concerning Bill C-54 (*Personal Information Protection and Electronic Documents Act*)

The views expressed in this study are those of the author and do not necessarily reflect the views of Industry Canada. In particular, nothing in the study should be taken as an interpretation of the "substantial similarity" to Bill C-54 of the draft Ontario Bill on health privacy.

Montreal, June 14, 1999

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Re: Response by Industry Canada to the submission to the House of Commons Standing Committee on Industry by the Ontario Ministry of Health concerning Bill C-54 (*Personal Information Protection and Electronic Documents Act*)

Madam,

We are in receipt of the submission of last March by the Ontario Ministry of Health to the House of Commons Standing Committee on Industry concerning Bill C-54: *Personal Information Protection and Electronic Documents Act (C-54)* or (*Bill C-54*).¹ In submitting the document to us for review, you asked us to respond by identifying any errors of construction that it might contain and assessing the merits of statements made therein concerning the effect of Bill C-54 on on-going health care delivery and management of the health system in Ontario.

You also asked whether, in light of experience gained in the Province of Quebec which, as you are aware, has had private sector personal information protection legislation in

¹ Ontario Ministry of Health. *Submission to the House of Commons Standing Committee on Industry Regarding Bill C-54 - Personal Information Protection and Electronic Documents Act*. March, 1999.

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place since January 1994², we could reassure the Government of Ontario concerning the effect that implementation of Bill C-54 would have on Ontario's health system.

Our study is divided into three parts. In Part I, we list the problems raised in the submission by the Ontario Ministry of Health and attempt to establish, on the basis of our reading of Bill C-54, the extent to which these problems really exist or, conversely, whether its provisions, including the exceptions, offer a solution. In this part, we examine Ontario health care legislation to establish whether it is compatible with the exceptions provided in Bill C-54.

In Part II of our study, we review the legal system within the Province of Quebec applicable to medical information, in the context of relations between public organizations and private sector enterprise, and go on to examine whether Quebec's experience can offer explanations or reassurances to the Ontario Ministry of Health concerning the effect of implementation of Bill C-54 on the health system.

Finally, in Part III of our study, we examine potential problems relating to application if Bill C-54 is passed. In this section, we attempt to establish whether recent amendments proposed by the Minister of Industry would provide effective solutions to the problems raised.

For the purposes of our analysis, we have considered Part 1 of Bill C-54, including amendments filed in the House of Commons on April 13, 1999. We have also examined Ontario's Bill, referred to by the Ontario Ministry of Health in its submission and entitled "*Personal Health Information Protection Act, 1997*", as well as major legislation relating to management of Ontario's health care system³. Finally, for the purposes of this part of our study, i.e., the section entitled "Conclusions", we have considered the proposed amendments submitted by the Minister of Industry on April 15, 1999.

Given the scope of our mandate and the short notice provided, it must be understood that this study cannot claim to be comprehensive. An in-depth study of the effect of Bill C-54 on public and private health service delivery in Ontario would be a monumental task, requiring detailed examination of the many applicable statutes and regulations, as well as of existing practices in the health care field. Our mandate is considerably narrower in scope.

² *Act Respecting the Protection of Personal Information in the Private Sector*, R.S.Q., c. P-39.1.

³ *Health Insurance Act*, R.S.O., 1990, chapter H.6; *Mental Health Act*, R.S.O., 1990, chapter M.7; *Independent Health Facilities Act*, R.S.O., 1990, chapter I.3; *Private Hospitals Act*, R.S.O., 1990, chapter P.24; *Health Care Accessibility Act*, R.S.O., 1990, chapter H.3; *Ministry of Health Act*, R.S.O., 1990, chapter M.26; *Health Care Consent Act*, 1996 Statutes of Ontario, 1996, chapter 2 Schedule A; *Laboratory and Specimen Collection Centre Licensing Act*, R.S.O., 1990, chapter L.1; *Regulated Health Professions Act*, 1991 Statutes of Ontario, 1991, chapter 18.

I. **PROBLEMS RAISED IN THE SUBMISSION BY THE ONTARIO MINISTRY OF HEALTH AND POSSIBLE RESPONSES.**

1. **The Ontario Health Ministry says that the ability of nursing homes, health clinics, laboratories and pharmacies to function as part of an integrated health system would be severely restricted by Bill C-54.**

a) **Commercial character of the activities of private nursing homes, clinics, laboratories and pharmacies.**

In all likelihood, private sector nursing homes, health clinics, laboratories and pharmacies carry on commercial activities, within the meaning of ss. 2(1) and 4(1)(a) of Bill C-54, since these organizations dispense services in exchange for payment by users, their insurers, their employer or the Ontario government. As a result, Bill C-54 would be applicable to the personal information that these private organizations collect, use or disclose concerning their clients, i.e., the recipients of private health care or services. Therefore, the individual's consent would probably be required in order to permit these organizations to collect, use or disclose personal information, subject to the exceptions set out in s. 7 of the Bill.

Conversely, we cannot support an interpretation of the Bill whereby the obligations set out in Bill C-54 would not apply to the disclosure of medical information between, on the one hand, a private nursing home, a private laboratory, a private pharmacy or a private clinic and, on the other, a public sector health organization, on the grounds that disclosure would not occur in the course of commercial activities. We believe that such a restrictive interpretation could compromise Parliament's purpose in proposing Bill C-54, which was to ensure the protection of personal information as soon as it is collected as a result of a commercial activity, regardless of whether or not the subsequent use or disclosure of the information is of a commercial character. Furthermore, such an interpretation is belied by the wording of s. 7(3) of the Bill which, in fact, offers several cases of disclosure of personal information to government organizations.

b) **Obtaining consent for health service delivery.**

In general, obtaining consent for the collection, use or disclosure of personal information will be easy and pose no serious difficulty, in the case of health services delivered by a private organization. Obviously, a nursing home or health clinic will have its clients sign an admission form, to identify the person requiring care and the contact persons in case of emergency, as well as to define the limits of its civil liability. There should be no difficulty in designing this form to include the name of persons from whom the personal information will be collected, an explanation of how the information

will be used, and the names of the persons and organizations with whom the information will be exchanged. It is generally for the benefit of the individual that such personal information is exchanged with a third party, specifically with public health facilities, in order to ensure that the person receives appropriate health services.

An individual who received and paid for health services from a private clinic (or from a health professional practising outside the health insurance plan) may, however, prefer that medical information held by the clinic not be disclosed to the Ontario government. Such a refusal could be fully justified and legitimate. As an example, a woman who has had an abortion in a private clinic and paid for the service herself should not be forced to disclose this information to the Ministry of Health, or to a public health facility, simply because an integrated health information system would provide a detailed medical profile of Ontario's population. As it is presently worded, Bill C-54 would ensure, and rightly so in our opinion, that this information could not be disclosed to government authorities or included in a centralized medical information system.

In the case of private laboratories, there are a number of possible scenarios. For example, a health professional working in a public health facility requests from a private laboratory a sample (blood, urine, etc.) analysis because the hospital does not offer an equivalent service. In this case, the costs relating to these tests and analyses will be paid by the provincial health insurance scheme. If the health professional informs the patient that the tests will be done in a private laboratory, consent to the clinic communicating the results to the physician or health professional who requisitioned them, on behalf of the patient, will be implied. The results of these tests and analyses will become part of the records of the hospital or public facility concerned and be subject to the legal system applicable to the health records of public facilities. This information, when held by a hospital or public institution, should not be part of a commercial transaction. Bill C-54 should therefore not apply to this information which may be stored in physical or computer records under the authority of the Ontario Ministry of Health.

Furthermore, where, for reasons of convenience, a physician or health professional operating a practice recommends that his client obtain sample analyses or other tests from a private laboratory, these services are usually paid for by the patient himself or by his insurance company. The exchange of medical information between the physician or health professional and the private laboratory is likely covered by Bill C-54 since, at the very least, it is a commercial activity for the laboratory. In our opinion, however, a patient who has been informed of the situation and has agreed to use a private laboratory will consent, implicitly or tacitly, to the exchange of the medical information in question between his physician and the private laboratory. Furthermore, it should not be difficult to obtain his implicit or tacit consent to the use of this information, in order to provide him with professional services.

As for the inclusion of the results in a central data bank under the authority of the Ontario Ministry of Health, we believe that consent must be obtained. However, in such a case, the patient would have legitimate grounds for objecting to inclusion of the medical information in a central database since, if he pays for these services, he should be permitted to determine how the information should be disclosed and used.

Having said this, we must bear in mind that, for the private laboratory, this is personal information obtained in the context of a commercial transaction, unless the test requisition was made by the physician on the basis of a patient number that the laboratory cannot use to identify the patient. Therefore the database kept by the laboratory for tests provided to physicians for identified or identifiable patients remains subject to Bill C-54. Whether the personal information contained in the database relates to insured or non-insured services under Ontario's public health system will be immaterial in this regard: Bill C-54 will be applicable.

The same rules should apply in the case of private pharmacies. When a physician working in a public facility forwards a prescription identifying the patient by name to a private pharmacy recommended by the patient himself, there is implicit or tacit consent to the disclosure of information, and to its use in filling the prescription. If the prescription is covered by Ontario's public health system, the Ministry will have the necessary authority, under provincial legislation currently in force, to request information from the pharmacist, in exchange for payment for the prescriptions⁴. Once it is received by the Ministry, the information will no longer be collected, used or disclosed in the course of a commercial activity. It may accordingly be entered in the integrated database of the Ontario Ministry of Health. On the other hand, personal information held by the pharmacist on prescriptions that were filled will be subject to the provisions of Bill C-54 relating to the disclosure and use of personal information.

Finally, it should not be difficult to obtain authorization from the individual for disclosure of medical information to his insurance company or to the Ministry of Health, for the purpose of reimbursement, since it is in his interest either to obtain direct reimbursement for the services or to ensure that the private facility that delivered the care is reimbursed. The insurer will have to comply with C-54 with regard to personal information obtained. Any change in the use of this information, or its disclosure to a third party, must be authorized by the individual, subject to the exceptions set out in s. 7 of Bill C-54.

2. According to the Ontario Ministry of Health, under Ontario's proposed health information legislation (PHIPA), information sharing

⁴ Section 29(1) of the *Health Insurance Act*, R.S.O., 1990, chapter H.6 and *General*, R.R.O., 1990, Reg. 552.

for purposes of health care, management of the health system, including fraud detection, and research would be permitted without consent. The Ministry says that these important health needs are ignored in Bill C-54.

a) Personal information sharing authorized by PHIPA.

The submission by the Ontario Ministry of Health is correct in stating that, if PHIPA were passed according to the proposed wording, the sharing of personal health-related information among the various organizations and individuals referred to in the Bill as "health information custodians" would be permitted without consent. Under s. 2(1) of the Bill, "health information custodian" includes the following persons and organizations:

- a health professional within the meaning of the *Regulated Health Professions Act, 1991*;
- a practitioner not authorized to prescribe medicine and drugs within the meaning of the *Drugless Practitioners Act*;
- a service provider within the meaning of the *Long-Term Care Act, 1994*;
- a service provider within the meaning of the *Child and Family Services Act*;
- a hospital manager within the meaning of the *Public Hospitals Act*;
- a private hospital manager within the meaning of the *Private Hospitals Act*;
- a psychiatric services manager within the meaning of the *Mental Health Act*; or an institution within the meaning of the *Mental Hospitals Act*;
- the operator of a long-term care facility;
- the operator of a special care facility within the meaning of the *Homes for Special Care Act*;
- the operator of an independent health facility within the meaning of the *Independent Health Facilities Act*;
- the operator of a pharmacy within the meaning of the *Drug and Pharmacies Regulation Act*;

- the operator of a laboratory or specimen collection centre within the meaning of the *Laboratory and Specimen Collection Centre Licensing Act*;
- the operator of an ambulance service within the meaning of the *Ambulance Act*;
- the operator of a community service for physical or mental health care;
- the operator of a financial program or service under the *Developmental Services Act*;
- the operator of an established rehabilitation program under the *Vocational Rehabilitation Services Act*;
- the operator of a home for retarded persons within the meaning of the *Homes for Retarded Persons Act*;
- the service of a corporation, partnership or association that provides employee health services;
- a board of health within the meaning of the *Health Protection and Promotion Act*;
- the Ontario Ministry of Health;
- a government authority responsible for health;
- a district health council within the meaning of the *Ministry of Health Act*;
- a professional association (college) within the meaning of the *Regulated Health Professions Act, 1991*;
- the family benefits program offered by the Ministry of Community and Social Services;
- the general welfare assistance program of a municipality;
- the Public Guardian and Trustee;
- the manager of information reported in the motor vehicle registry within the meaning of ss. 203 and 204 of the *Highway Traffic Act*;

- the Workplace Safety and Insurance Board;
- an insurer within the meaning of the *Insurance Act*;
- a registered association within the meaning of the *Prepaid Hospital and Medical Services Act*;
- a division or administrative unit of a corporation, partnership, association or other entity that administers an employee insurance plan;
- an assessment centre established under the regulations of the *Insurance Act*;
- a person who keeps a record of health information relating to a specific disease or medical condition or to donation of organs or bodily substances;
- a person who keeps a health information and health record storage centre for the purpose of analysing and networking;
- a person who administers a network or shares health-related databases for two or more health information custodians;
- any other person or class of persons who by regulation are designated health information custodians.

Under s. 14 of PHIPA, a health information custodian may, without consent, disclose information relating to the health of an individual, for the following specific purposes:

- dispense health care (s. 14(1)4);
- manage the health care system (ss. 14(1)5, 14(1)6, 14(1)7) and 14(1)8);
- combat fraud (s. 14(1)6);
- promote research (ss. 14(1)22 and 15).

b) Collection and use of information authorized by PHIPA.

Furthermore, s. 11 of PHIPA stipulates that a health information custodian may collect health information insofar as that information is necessary to achieve a lawful purpose and related to the exercise of the duties or activities of the aforesaid custodian.

Also, PHIPA stipulates that the information must be collected from the individual unless (1) that person has consented to another collection method (for example, from a third party), (2) unless the information is collected from a person authorized by law to disclose the information, (3) unless it is not reasonably possible to collect the information from the individual or (4) unless the accuracy of the information or the reason for which it was collected may be compromised.

Finally, PHIPA requires health information custodians to take reasonable measures to inform the individual of the use that will be made of the information, either before it is collected, when it is collected or as soon as possible after it is collected. This requirement to inform the individual does not apply, however, in cases where the custodian is treating the individual or supporting his treatment, or where the public guardian or a children's aid society is involved.

On the question of how the health information may be used, s. 13 of PHIPA authorizes its use, without consent, in the following cases:

- for a purpose that is compatible with the use for which the information was collected;
- for a purpose for which disclosure is permitted by PHIPA;
- for administrative purposes, including the planning, implementation or assessment of health services, as well as the prevention and detection of fraud, to the exclusion of direct marketing;
- for research purposes, as long as the research does not infringe the public interest and was authorized by an ethics committee;
- for the purpose of participating in legal proceedings to which the custodian is a party or witness, or called as a party or witness.

c) Effect of Bill C-54 on the exchange of personal information for the purpose of dispensing health care.

On the question of the collection, use and exchange of personal health information among public sector health information custodians, Bill C-54 will simply not apply, since these organizations do not conduct commercial activities. However, Bill C-54 will likely apply to personal information of a medical nature collected, used or disclosed by a private organization subject to PHIPA and defined in this Bill as a health information custodian.

With respect to the collection of information by private sector custodians for the purpose of dispensing health services, we are forced to admit that Bill C-54 is stricter than PHIPA because, under s. 7(1) of the federal Bill, it is forbidden to collect personal information without the knowledge and consent of the individual, except in the following cases:

- the collection is clearly in the interests of the individual and consent cannot be obtained in a timely way;
- the collection with the individual's knowledge or consent may compromise the availability or accuracy of the information and the collection is reasonable for purposes related to investigation of a violation of an agreement or of the laws of Canada or a province;
- the collection is solely for journalistic, artistic or literary purposes;
- the information is publicly available and is specified by the regulations.

Conversely, Ontario's Bill authorizes the collection of personal information without the consent or knowledge if the accuracy of the information collected may be compromised (whether or not there is an investigation), or where the information is collected from a person authorized by PHIPA or by other legislation to disclose health information.

In practice, the system proposed by the Ontario government should make it easy to allow private sector health information custodians to collect a considerable amount of health information from third parties without the individual's knowledge, insofar as this information is necessary for the performance of their duties or activities and the aforesaid custodians are of the opinion that it is not reasonably possible for them to apply to the individual concerned. Information could even be collected where it was prejudicial to him.

In this situation, we must conclude that if Bill C-54 came into force, it would subject private sector health information custodians to more stringent rules concerning the collection of information.

The same would hold true for the use of personal information since, under Bill C-54, a private sector organization could not use health information for administrative purposes, including service assessment or implementation, unless the individual was informed of and consented to such uses.

Having said this, however, we must point out that the collection of person information by private organizations should pose no problems, since it is in the individual's interest

to consent to medical information being obtained about him in order to provide him with the best possible service. The same holds true for the use made of the personal information; the private organizations concerned could easily provide, on their admission forms, information concerning the various uses that may be made of the personal information obtained. If such uses are legitimate, the individual will undoubtedly consent to them. Furthermore, Bill C-54 allows such consent to be obtained through an opting-out procedure.

The disclosure of personal information by a private sector health information custodian to a public or private sector health information custodian - for the purpose of creating an integrated health information database - may, on the other hand, raise objections and problems.

Ontario legislators apparently understood this only too well, as s. 14(1)4 of PHIPA expressly acknowledged the right of individuals to oppose such disclosure:

"14(1). A health information custodian may disclose personal health information,

(...)

4. For the purpose of providing or facilitating the provision of health care to the subject of the information unless the subject has instructed the custodian in writing not to make the disclosure.
(...)"

(emphasis added)

According to Ontario's Bill, the recipient of private or public health care would thus be entitled to opt out of the health data centralization scheme that the provincial government intends to introduce.

In order for this opting-out right to be meaningful, the recipient of the health services in question would still:

- 1 need to be properly informed of his right to opt out;
- 2 require a real opportunity to exercise this right to opt out.

In any case, registration forms from public and private health facilities will have to specifically acknowledge this right to opt out, by providing a check-off box where the individual may indicate his refusal to allow medical information collected by one organization to be forwarded to other organizations or entered in a centralized data bank.

Section 4.3.7 of the *Model Code for the Protection of Personal Information CAN/CSA-Q830-96* expressly acknowledges that consent to the collection, use or disclosure of personal information may be exercised through the right to opt out.

As a result, there is apparently no significant inconsistency between the scheme set out in Bill C-54 and the one proposed by PHIPA, as far as disclosure of personal information is concerned. At most, Bill C-54 will impose, with respect to the planned integration of health information proposed by the Ontario Ministry of Health, a more complete and detailed opting-out procedure, which the courts would likely have required, sooner or later, in the wake of the decision of the Supreme Court of Canada in *Frenette v. Metropolitan Life Insurance Co.*⁵

Furthermore, if the final version of PHIPA did not contain provisions allowing an individual to oppose the transmission or use of information concerning him⁶, Bill C-54 would require the individual's consent before the information held by a private sector health information custodian could be transmitted to the Ministry of Health or to third parties. This consent could, however, be obtained in the form of the right to opt out, which would meet the aforementioned criteria.

Similarly, it should be understood that the requirements of Bill C-54 relating to use of the information could be satisfied by the use of registration forms or service requisitions in which anticipated uses were described and an opting-out right was provided.

d) Effect of Bill C-54 on the sharing of personal information for the purpose of managing the health system.

Sections 14(1)5, 14(1)6, 14(1)7, 14(1)8, 14(1)10, 14(1)21, 14(1)22, 14(1)25 and 14(1)27 of PHIPA set out a number of situations in which private or public sector health information custodians may disclose personal information to the Ontario Ministry of Health for the purpose of managing the health system. The provisions read as follows:

"14(1). A health information custodian may disclose personal health information,

(...)

5. For the purpose of obtaining payment for health care provided to the subject of the information;

⁵ *Frenette v. Metropolitan Life Insurance Company*, [1992] 1 S.C.R. 647, at pp. 674-675.

⁶ In fact, it would appear that an amended version of PHIPA precludes the opt-out right under s. 14(1)4. However, this version was neither officially published nor brought before the Ontario Legislature.

6. For the purpose of determining or verifying the eligibility of the subject of the information to receive health care or to receive other benefits provided or funded by the Government of Ontario or Canada or a municipality;

7. Subject to the regulations, for the purposes of health screening programs designated in the regulations;

8. To a public health official for the purpose of public health administration;

(...)

21. To the Minister, a ministry official designated by the Minister, another person appointed by the Minister or a prescribed health authority for a purpose described in clause 20(2)(a), (b) or (c);

22. For the purpose of a research project if the disclosure is made in accordance with section 15;

(...)

25. For a purpose described in sub-section 19(1) if the custodian is the ministry;

(...)

27. To the Government of Ontario or Canada for the purpose of auditing shared cost programs between those governments;

(...)"

It should be noted at the outset that the exception in s. 7(3)(i) of Bill C-54, whereby an organization may, without consent, disclose personal information where the disclosure is "required by law", is too restrictive to allow the wholesale implementation of the scheme proposed in the aforesaid provisions of the PHIPA. In fact, as it now reads, s. 14 of the PHIPA authorizes, but does not require, the organizations referred to as "health information custodians" to share this information. This does not mean that Bill C-54 would prohibit this type of disclosure of personal information on behalf of the Ontario Ministry of Health, without consent. As we will see *infra*, in most cases, such disclosures are covered by specific exceptions mentioned in s. 7(3) of Bill C-54, or required by an Ontario sector statute:

- s. 14(1)5 of PHIPA stipulates that a health information custodian may, without consent, disclose personal health information for the purpose of obtaining payment for health care provided to the subject of the information. This situation is covered by s. 7(3)(b) of Bill C-54, which authorizes the disclosure of personal information, without consent, for the purpose of collecting a debt. Furthermore, ss. 29(1)(a) and (b) of Ontario's *Health Insurance Act* stipulate that "every insured person shall be deemed to have authorized his or her physician or practitioner, a hospital or health facility which provided a service to the insured person and any other prescribed person or organization to give the General Manager particulars of any services provided to the insured person, (a) for the purpose of obtaining payment under the Plan for the services; (b) for the purpose of enabling the General Manager to monitor and control the delivery of insured services". In other words, since consent to disclosure of health information to the Ministry exists by the operation of law, it will probably be unnecessary to obtain it⁷;

- s. 14(1)6 of PHIPA stipulates that a health information custodian may disclose personal health information, without consent, for the purpose of determining or verifying the eligibility of the subject of the information to receive health care funded by the Government of Ontario or Canada or a municipality. It should be noted first that where health services are provided by a public facility, no commercial transaction is involved: therefore Bill C-54 does not apply to any eligibility audits that might be conducted by the Government of Ontario or Canada or a municipality with a public sector health information custodian. Conversely, if the services are provided by a private organization but funded by the government, it appears evident to us that it would not be difficult to obtain the individual's consent, as it would be in the interest of the recipient of the services to have the costs repaid to the private facility. Furthermore, the legislation currently in effect allows the Ontario government to exchange personal information in order to conduct such an audit⁸. In our opinion, the wording of these provisions is sufficiently compelling to make the exception under s. 7(3)(i) in Bill C-54 ("required by law") applicable. Finally, consent to disclosure is even assumed by the operation of s. 29(1) of the *Health Insurance Act*;

- s. 14(1)8 of PHIPA stipulates that a health information custodian may disclose personal information, without consent, to a public health official for the purpose of public health administration. As we noted *supra*, if the disclosure is between a public health official and the Ontario Ministry of Health, Bill C-54 will not be

⁷ We are assuming, for the purposes of this analysis, that when a sector statute stipulates that an individual is deemed to have consented to the disclosure, use or collection of personal information, this consent is valid in the light of Bill C-54. This question could, however, arouse debate since none of the restrictions in s. 7 of Bill C-54 specifically cover this situation.

⁸ See, in particular, ss. 4.2 and 29(1) of the *Health Insurance Act*, R.S.O., 1990, chapter H.6 and s. 3.1 of the *General*, R.R.O., 1990, Reg. 552.

applicable because it is not a commercial activity. In the case of disclosure between a private organization and the Ontario Ministry of Health for administrative purposes, it is only relevant where the party assuming the service costs is the government. In such a case, current legislation vests in the Ministry of Health the necessary authority to demand the relevant personal information from private organizations⁹. Section 29(1) of the *Health Insurance Act* even stipulates that the user is assumed to have consented to the disclosure of health information to the General Manager in order to allow him to audit and monitor payments made under the health insurance plan, as well as the nature of the treatment provided;

- s. 14(1)21 of PHIPA authorizes a health information custodian to disclose personal information, without consent, to the Ontario Minister of Health, a Ministry official or other authority designated by the Minister, for the purpose of resources planning, fraud detection, determining the accuracy of information held by the Minister or a health authority, or ensuring compliance with legislation administered by the Ontario Minister of Health or health authorities. As for fraud detection, s. 7(3)(d) authorizes such disclosure when it is made on the initiative of the organization that holds the information. This condition is not included in Ontario's Bill. As for the other situations, the legislation currently in effect in Ontario stipulates that the designated authority may require this information¹⁰;

- s. 14(1)22 of PHIPA authorizes a health information custodian to disclose personal information, without consent, for the purpose of a research project. Disclosure for this purpose is permitted under s. 7(3)(f) of Bill C-54, although the wording of this section is more restrictive than that found in Ontario's Bill. The research must be scholarly and it must be impracticable to obtain consent. Ontario's Bill, on the other hand, does not restrict disclosure for research purposes to scholarly works; it does, however, stipulate that the research project must be in the public interest and approved by an ethics committee. The requirement that consent must be impracticable to obtain is not found in Ontario's Bill either. As a result, we must conclude that passage of Bill C-54 would affect the plan contemplated by the Ontario government, as private health organizations would find the sharing of personal information for research purposes more difficult than under PHIPA;

⁹ See, *inter alia*, s. 23 of the *Private Hospital Act*, R.S.O., 1990, chapter P.24; s. 37.2 of the *Independent Health Facilities Act*, R.S.O., chapter I.3; ss. 29(1) and 37.1 of the *Health Insurance Act*, R.S.O., 1990, chapter H.6.

¹⁰ Apart from the provisions mentioned in note 6, see also: ss. 29(1) and 40.1 of the *Health Insurance Act*, R.S.O., 1990, chapter H.6; s. 23 of the *Private Hospital Act*, R.S.O., 1990, chapter P.24; s. 3(6) of the *Laboratory and Specimen Collection Centre Licensing Act*, R.S.O., 1990, chapter L.1.

- s. 14(1)25 of PHIPA authorizes a health information custodian to disclose personal information to the Ontario Minister of Health for purposes of administering the health plan, preventing or detecting fraud or ensuring compliance with the law. Section 7(3)(i) of C-54 resolves this situation to a large extent since, as we noted *supra*, such disclosure is generally required under the legislation administered by the Ontario Minister of Health. Section 29(1) of the *Health Insurance Act* specifies that the user is deemed to have authorized disclosure of health information to the General Manager for the purpose of enabling the latter to monitor and control payments made and services delivered under the health insurance plan. In addition, it is questionable whether the Ontario Minister of Health would seek to exercise such authority over private organizations, unless he was asked to pay the costs of services delivered. If the Minister simply wants to obtain a picture of the nature of services delivered in private facilities when he does not pay the costs of those services, we are inclined to think that he does not need information that includes names. In any case, if this were the situation, s. 7(3)(f) of Bill C-54 would allow him to obtain the necessary information, including names, in order to conduct a statistical analysis of both health needs and quality of the provided services;

- s. 14(1)27 of PHIPA authorizes a health information custodian to disclose, without consent, personal information to the Government of Ontario or Canada for the purpose of auditing shared cost programs between those governments. Naturally, such audits could only be performed with private sector health organizations where the costs were assumed by the Government of Ontario or Canada. There is a presumption of the user's consent to disclosure under s. 29(1) of the *Health Insurance Act*, while s. 37(1) of that Act requires health professionals and private facilities to provide this information to the Ministry.

e) Effect of Bill C-54 on exchanges of personal information to combat fraud.

On the issue of disclosure of personal information of a medical nature for the purpose of combating fraud, we are of the opinion that ss. 7(1)(b) and 7(3)(d) of C-54 permit disclosure, without consent, for the purpose of detecting fraud. Furthermore, where the Ontario Ministry of Health is called upon to pay the cost of the health services offered, either by a public facility or by a private organization, legislation currently in force in Ontario authorizes it to require any information necessary to conduct such an audit or to detect fraud, or to compel the various private organizations, on demand, to provide the Ministry's inspectors with the information necessary to conduct an audit or investigation¹¹.

¹¹ See, in particular: ss. 4(2), 29(1), 37(1), 37(2) and 7.1 of the *Health Insurance Act* R.S.O., 1990, Chapter H.6.

f) Effect of Bill C-54 on exchanges of personal information to promote research.

Finally, with respect to the exchange and use of personal information for statistical or research purposes, ss. 7(2)(c) and 7(3)(f) of Bill C-54 permit the collection and exchange of information without requiring that names be removed, in the case of statistical or scholarly research. Any organization intending to disclose personal information for such purposes must, however, establish that the purposes cannot be achieved without transmitting the information and that it is impracticable to obtain consent. Furthermore, the Privacy Commissioner of Canada must be notified.

PHIPA, on the other hand, would permit private sector custodians to disclose health information to third parties for research purposes in a number of situations where Bill C-54 does not. Under PHIPA, as long as the research is in the public interest, the intended purpose cannot be achieved without obtaining the personal information and an ethics committee has approved the research, the information may be disclosed. PHIPA also stipulates that an agreement must be signed between the custodian and the recipient of the information and that certain rules of confidentiality in handling the data must be followed¹².

It is clear that the types of research authorized by Bill C-54 are more limited than those allowed by PHIPA. Any scholarly research is likely dedicated to the advancement of knowledge. It would be questionable, at first glance, whether s. 7(3)(f) could authorize the disclosure of personal information without consent for the purpose of conducting research on the effectiveness or management of services, or user habits. In the case of statistical data, organizations will likely have greater leeway, although they will not be permitted to use the information obtained for specific actions with respect to users. Finally the test under Bill C-54 requiring that consent be impracticable appears to us to be more stringent than the simple criterion under PHIPA that the purpose cannot be achieved without the personal information. It is therefore unnecessary, within the meaning of PHIPA, to show that consent could not be obtained.

Under the circumstances, it must be admitted that Bill C-54 offers researchers less leeway than the federal Bill.

3. According to the Ontario Health Ministry, the success of an integrated health care system based on technological support is dependent upon authorized professionals being able to access the

¹² PHIPA, s. 15(2).

necessary information when required. The Ministry says that Bill C-54 would only permit the exchange of health information among health system suppliers if the patient had consented to such a disclosure, except in an emergency situation.

At the risk of repeating ourselves, the exchange of personal information among various public sector health information custodians in Ontario will not be addressed by Bill C-54, as these organizations do not carry on commercial activities.

However, Bill C-54 may affect the ability of private organizations, referred to as "health information custodians", to exchange personal information among themselves or with public sector organizations. If the purpose of integrating in a single database of information held by private sector and public sector organizations, referred to as "health information custodians" in Ontario's legislation, is to ensure better service delivery to individuals, it is reasonable to think that, on an individual basis, these persons will by and large consent to the collection, use and disclosure of personal information among the organizations. This consent may be in the form of the right to opt out and could be obtained when the persons register with a private facility or when they require the services dispensed by that private facility.

Some could argue that the efficiency of such an integrated system could be compromised, if a substantial number of persons refused to consent to the exchange of personal information between private and public sector health information custodians. In other words, the purpose of the *Personal Health Information Protection Act* could be jeopardized if persons using private health services routinely refused to allow their own medical information to be included in the database that the Ontario Ministry of Health intends to establish. In our view, this statement is unjustified, for the following reasons in particular.

First, in its Bill, the Ontario government expressly acknowledges in s. 14(1)4, that the individual may instruct a health information custodian not to disclose to a third party his health information. In other words, PHIPA expressly recognizes that the integrated health information system must consider the wishes of those covered by the plan to participate or not. Likewise, by providing the opt-out option, PHIPA implicitly acknowledges that the integrated system can still function, even when a number of citizens refuse to allow their health information to be included in it.

As for other situations where s. 14 of PHIPA would allow private and public health information custodians to exchange personal information, these do not appear to pose significant problems:

- Section 14(9) of PHIPA permits a health information custodian to disclose personal health information, without consent, to a person who assumes

responsibility for the individual, if the purpose of the disclosure is to ensure the physical or mental health of that individual. In most cases, the person responsible for the safety of an individual is either his agent or his representative. Disclosure of personal health information to that person is equivalent to disclosure on behalf of the individual himself. In any case, s. 12 of the General Regulations passed pursuant to the *Independent Health Facilities Act* acknowledges that an individual's representatives are entitled to consult his health record held by a private facility.

- Section 14(1)10 of PHIPA permits a health information custodian to disclose personal information, without consent, to the person authorized to make a decision concerning custody of that individual. This disclosure poses no problems either, since the person in which authority is vested is acting as the individual's representative, either pursuant to a court order or by the operation of law;
- Section 14(1)11 of PHIPA permits a health information custodian to disclose personal health information, without consent, for the purpose of an inspection or investigation authorized pursuant to a statute of Ontario, a statute of Canada or judicial warrant. Persons who may exercise powers of inspection, or investigation or those authorized by warrant, benefit from a special exception, under s. 7(3)(c) of Bill C-54, which allows them to receive personal information without consent. Nearly all of Ontario's health statutes stipulate that inspectors and investigators of the Ministry enjoy the powers necessary to demand information¹³;
- Section 14(1)12 of PHIPA permits a health information custodian to disclose personal information, without consent, for the purpose of reducing or eliminating risks that could endanger an individual's health or safety when such risks are significant. Section 7(3)(e) of Bill C-54, however, provides an exception to the consent rule for emergencies that is broad enough to cover this situation;
- Section 14(1)14 of PHIPA permits a health information custodian to disclose personal information, without consent, to a professional association, within the meaning of the *Regulated Health Professions Act, 1991*. In most cases, professional associations enjoy powers of investigation and inspection that allow them to require information disclosure¹⁴. Sections 7(3)(c), (d) and (i) of C-54 would authorize this form of disclosure;
- Section 14(1)15 of PHIPA permits a health information custodian to disclose personal information, without consent, for the purpose of determining, monitoring

¹³ See, *inter alia*, s. 40.1 of the *Health Insurance Act*.

¹⁴ See, *inter alia*, the powers of an investigator under ss. 75 *et seq.* of the *Health Professions Procedural Code*.

or confirming his capacity within the meaning of the *Health Care Consent Act, 1996*, the *Substitute Decisions Act, 1992* or the *Personal Health Information Protection Act, 1997*. Under the *Substitute Decisions Act*, the capacity of a person can be assessed at the request of either the court or the representative of the person whose capacity is in question. Where an assessment of capacity is ordered by the court, s. 7(3)(c) of Bill C-54 authorizes the disclosure of relevant personal information. Where an assessment of capacity is requested by the incapacitated person's representative, the latter is empowered to consent to disclosure¹⁵.

- Section 14(1)16 of PHIPA permits a health information custodian to disclose personal information, without consent, to a person who makes a declaration under the *Substitute Decisions Act, 1992* that he intends to request, on behalf of the individual, that a guardian (of property or of an individual) be designated. Since the person making the declaration, within the meaning of the *Substitute Decisions Act, 1992* is deemed to act as the representative of the person who is incapable of managing his property or looking after himself, we believe that such disclosure would not be in violation of the principles set out in Bill C-54. Specifically, s. 12 of the General Regulations passed pursuant to the *Independent Health Facilities Act* acknowledges that the guardian or representative of an incapacitated person may consent to disclosure;
- Section 14(1)17 of PHIPA allows a health information custodian to disclose personal information to the public guardian or to the representative of a children's aid society, without consent, so that the latter may perform their statutory duties. These organizations also represent the child in question and are therefore authorized to consent to disclosure for the child¹⁶;
- Section 14(1)18 of PHIPA permits a health information custodian to disclose personal information, without consent, to a person authorized under the rules of civil procedure or by court order to initiate or proceed with a legal action on behalf of the individual and to represent him in the aforesaid proceedings. It goes without saying that this person represents the individual and may therefore consent to disclosure of personal information for the latter;
- Section 14(1)19 of PHIPA allows a health information custodian to disclose personal information, without consent, to the executors of the deceased or to the person who assumes responsibility for administering his property, as long as the information is necessary for this purpose. Sections 12(2) and 12(3) of the *General Regulation* passed pursuant to the *Independent Health Facilities Act* stipulate that the representatives of the deceased and his executors are not only

¹⁵ *Independent Health Facilities Act*, Regulation 57/92, ss. 12(2) and 12(3).

¹⁶ See in particular: s. 43 of the *Health Care Consent Act, 1996* Statutes of Ontario, 1996, chapter 2 Schedule A.

entitled to examine the medical record but also empowered to authorize its disclosure to third parties. As a result, disclosure would be required within the meaning of s. 7(3)(i) of Bill C-54;

- Section 14(1)20 of PHIPA permits a health information custodian to disclose personal information, without consent, to the spouse, partner or family of the deceased on compassionate grounds, unless the individual previously informed the custodian that he objected to the aforesaid disclosure. Such disclosure can easily be made on the basis of s. 7(3)(i) of Bill C-54, since ss. 12(2) and 12(3) of the General Regulation pursuant to the *Independent Health Facilities Act* stipulate that members of the deceased's family are entitled to access his health records and to authorize disclosure to third parties;
- Section 14(1)23 of PHIPA authorizes a health information custodian to disclose personal information, without a person's consent, to its successors. When a private health organization ceases its operations or transfers its responsibilities to another organization, we believe that the disclosure of records is not a form of disclosure covered by Bill C-54. In such a case, there is a transfer of business or sale of assets and the new organization assumes legal responsibility for its predecessor. Under Québec's protection of personal information legislation, such transfers were never considered disclosure of personal information requiring consent;
- Section 14(1)24 of PHIPA authorizes a health information custodian to disclose personal information, without consent, when required under rules of court or by court order. Section 7(3)(c) of Bill C-54 already covers such a situation. Disclosure of personal information may also be deemed to be required by law in such a case;
- Section 14(1)26 of PHIPA authorizes a health information custodian to disclose personal information subject to the *Freedom of Information and Protection of Privacy Act*, or the *Municipal Freedom of Information and Protection of Privacy Act*, without consent. The information in question is exclusively information belonging to public organizations or held by public organizations. Bill C-54 does not apply to such information;
- Section 14(1)29 of PHIPA authorizes a health information custodian to disclose personal information to Ontario's Information and Privacy Commissioner for appeal purposes, without consent. Section 7(3)(c) of Bill C-54 permits such disclosure because the Commissioner has authority to compel disclosure;
- Section 14(1)30 of PHIPA authorizes a health information custodian to disclose personal information to Ontario's Information and Privacy Commissioner, without consent, so that he may exercise the authority, power and duties vested in him

by the *Personal Health Information Protection Act*. This situation is also covered in s. 7(3)(c) of the Bill.

Having said this, we must admit that the exchange of personal information between private and public sector health information custodians for the purposes of improving quality of services or assessing the health system would be restricted if Bill C-54 were passed. In order to meet the requirements of the Act, private sector custodians would have to introduce detailed forms allowing individuals either to give their consent or to opt out. The entire philosophy of Bill C-54 is built on the right of citizens to be informed and to consent to the use and disclosure of personal information, while the philosophy of PHIPA appears to favour the needs and efficiency of the health care system.

In contrast, when it is not feasible to obtain consent or an opt-out, Bill C-54 does not prohibit legislative authorities from passing a law requiring disclosure of information without consent (s. 7(3)(i)). Such a measure would, however, be the subject of parliamentary debate in order to publicly assess its appropriateness.

4. **According to the Ontario Ministry of Health, it is a slow process to get consents signed; to determine who signs for children and for adults if they are incapable or because of disability cannot sign for themselves; to respond to refusals to sign consent when service is still needed. The Ministry says that Bill C-54 does not address these consent requirements.**

Bill C-54 does not address these consent requirements because they are not within federal jurisdiction. The issues of the age at which a child may give consent, or of who is empowered to consent on his behalf while he is a minor, or of the consent of incapacitated persons, fall within provincial jurisdiction. It is therefore incumbent on the Ontario government to enact legislation applicable to these issues.

As an example, s. 20 of the *Health Care Consent Act, 1996*, provides a number of rules applicable to persons who can consent to health care for an individual who is incapacitated, by reason of his age or physical or mental condition. Furthermore, according to Ontario law, a person's guardian is authorized to act on his behalf¹⁷. Ontario legislation also authorizes persons with parental authority to act on behalf or their minor children¹⁸. In accordance with Ontario law, the parents of a minor and the legal representatives of an incapacitated persons may therefore consent to disclosure of personal information so as to fulfil the requirements of Bill C-54.

¹⁷ Section 20(1) of the *Health Care Consent Act*, R.S.O., 1990, chapter 2 Schedule A.

¹⁸ See: *Substitute Decisions Act, 1992*, Statutes of Ontario, 1992, chapter 30.

5. **The Ontario Ministry of Health says that in order to fulfil its legal mandate, the Ministry and health planners need to collect and analyse a broad range of health information to determine unmet and changing needs, for utilization management, guideline development and quality management to ensure that resources are used appropriately and effectively.**

When the Ontario Ministry of Health collects information from hospitals and public health facilities to determine unmet and changing needs, to manage the public health care system, to develop guidelines and to ensure that the resources of the public system are used appropriately, Bill C-54 is not applicable. In fact, for both public facilities and the Ministry, information is not exchanged in the course of commercial activities.

As for service delivery by private health organizations, we should distinguish between cases where the cost of those services is paid by the Ontario Ministry of Health and those where it is not. In the first case, a user seeking reimbursement from the government for those services is deemed to have consented to disclosure of information relating to services received¹⁹. Furthermore, under the legislation, the government also enjoys the necessary authority to demand this information²⁰.

On the other hand, where the Government of Ontario does not provide reimbursement for private health services, there is no benefit to the user in consenting to the disclosure of medical information to the Ministry. Incidentally, one may wonder whether the Ministry requires personal information to determine unmet and changing needs, to develop guidelines or to ensure that resources are used appropriately and effectively. We strongly believe that statistical data or data from which names have been removed are generally sufficient to enable the Ministry to fulfil its mandate. And where the objectives may not be achieved unless the information includes the name, the Ministry may rely on s. 7(3)(f) of Bill C-54 to obtain all the necessary information, without consent. It must, however, establish that obtaining the consent of each person would be impracticable and inform the Privacy Commissioner of the situation. In our opinion, moreover, it should be possible for the Ministry, under these circumstances, to establish that it is necessary to obtain individualized information in order to analyse patterns of service or to make connections between services received by the individual at various times. Furthermore, it should be easy for the Ministry to show that obtaining statistical data on the basis of which to assess service should not be dependent on the consent of the individual.

6. **The Ontario Ministry of Health says that Bill C-54 would not permit the Ontario government to demonstrate that the funds it spends on**

¹⁹ Section 29(1) of the *Health Insurance Act*, R.S.O., 1990, chapter H.6.

²⁰ Sections 37 and 40.1 of the *Health Insurance Act*, R.S.O., 1990, chapter H.6.

the health system translate into concrete deliverables which benefit its population. According to the Ministry, the Bill has no provision permitting personal information collected for health care delivery to be used without consent for purposes of planning and management of the health system. There is not even a provision permitting use without consent for "consistent" purposes.

We previously responded to the first part of this statement, by noting that Bill C-54 would not prevent the Ontario Ministry of Health from obtaining information necessary to assess the health care system or to identify unmet needs.

However, it is true that Bill C-54 does not permit an organization to use personal information for a consistent purpose, without consent. Bill C-54 requires organizations to define precisely how they intend to use the information. On the other hand, if an organization has not stipulated certain uses when the information is collected, it may define the new purposes to the individual, before using the information, and then obtain his consent. Section 7(2)(d) also provides that it is not compulsory to inform the individual of the planned use, nor to obtain his consent, if the collection is clearly in the interest of the individual and his consent cannot be obtained in a timely way, or if the information is collected for purposes relating to investigation and that the availability or accuracy of the information could be compromised.

Conversely, s. 13 of PHIPA provides that health information may be used for a number of purposes without consent, in particular for administrative purposes (planning, operation, assessment and management of services).

In this regard, we must recognize that Bill C-54 would constrain the Ontario Ministry of Health with respect to the use made of health information held by private sector custodians. As we noted previously, consent to the use of information may, according to Bill C-54, be obtained through the opt-out procedure. The fact remains, however, that users of private health services could object to the use of information that they provided to a private clinic or laboratory being used for administrative purposes, when it was not directly related to the service rendered.

7. **Private organizations like the Canadian Institute for Health Information (CIHI) and the Institute for Clinical Evaluative Sciences (ICES) track the incidence of fatal disease for the Ontario Ministry of Health. According to the Ministry, Bill C-54 would prevent them from obtaining the information required to fulfil their mandate and promote the effective management of the health system.**

We noted earlier that, despite Bill C-54, the Ontario Ministry of Health would be empowered to obtain most, if not all, of the health information that is necessary to fulfil its mandate, and whose disclosure is authorized by s. 14 of PHIPA, without consent. When this personal health information is obtained by the Ontario Ministry of Health, in fulfilling its mandate, the rules of Bill C-54 will no longer apply to its disclosure to third parties. Instead, the disclosure of this personal information by the Ontario Ministry of Health on behalf of third parties will be governed by Ontario's *Freedom of Information and Protection of Privacy Act*. Since this statute stipulates that a public organization may disclose personal information without consent when authorized by law²¹, the Ontario Ministry of Health will thus be permitted to disclose the same information to CIHI, ICES or similar organizations as long as the various Ontario statutes relating to health authorize this disclosure.

Finally, private sector health information custodians may disclose health information directly to CIHI or ICES, on the authority of s. 7(3)(f) of the Bill, which permits disclosure for statistical purposes that cannot be achieved without disclosing personal information. It is not difficult to conceive of situations where it will, in fact, be necessary to forward information including the patient's name to CIHI or ICES so that the latter may compile significant and accurate statistical data concerning health needs, etc. It will, however, be up to the federal Privacy Commissioner to assess these issues.

8. **The Ministry of Health of Ontario says that Bill C-54 would not permit the collection, use or disclosure of personal information, without consent, for the detection and prevention of fraud or for the prevention of abuse such as visiting several physicians in search of a particular medication, repeated testing for the same condition, or the use of stolen health insurance cards.**

The meaning and import of this statement by the Ontario Ministry of Health are unclear to us. First, the Ministry could only investigate user visits to several physicians or repeated testing if the visits and tests were covered by the provincial health insurance plan. In such cases, however, the Ministry receives from the physician's office, public and private health facilities, clinics, laboratories or pharmacies all the information it needs to administer the public health care plan²². Where information is shared between a public sector organization and the Ministry, Bill C-54 does not apply. Where disclosure involves a private organization, ss. 37 and 37.1 of the *Health Insurance Act* require that the health professional disclose the information to the Ministry, for payment purposes. Furthermore, s. 29(1) of the Act stipulates that the user is deemed to have

²¹ Sections 21(1)(d) and 42 of the *Freedom of Information and Protection of Privacy Act*, R.S.O., 1990, chapter F.31.

²² See: ss. 37 and 37.1 of the *Health Insurance Act*.

consented to disclosure. The disclosure is accordingly required by law, within the meaning of s. 7(3)(i) of Bill C-54.

As for the investigation of stolen health insurance cards or users who visit several physicians in search of a particular medication, both activities are violations of the law. Investigators with the Ministry, as well as police forces, have the necessary authority to demand this information in their investigations. Section 7(3)(c) authorizes this type of disclosure, without consent.

9. **According to the Ontario Health Ministry, Bill C-54 has no provisions to safeguard the use of personal information in the hands of researchers.**

This statement invites two comments. First, Parliament's objective in passing Bill C-54 is to set minimal rules governing the collection, use and disclosure of personal information by organizations, in the course of their commercial activities. The fact that a number of provisions in the Bill allow personal information to be used or disclosed for research purposes is only incidental.

Second, the provisions of Bill C-54 allowing the use and disclosure of personal information for research purposes stipulate that the federal Privacy Commissioner must be informed of the situation. Under the authority vested in him by the legislation, the Commissioner may, if he deems it appropriate, recommend that researchers conform to guidelines for the purpose of ensuring privacy²³.

Finally, it must be understood that Bill C-54 does not prevent in any way provincial legislatures from setting guidelines or codes of ethics for researchers who use personal information. If they do, these guidelines will be in addition to the principles set out in Bill C-54 and supplement the protection scheme applicable to information used for research purposes.

10. **According to the Ontario Health Ministry, Ontario's *Mental Health Act* has for 20 years permitted disclosure of psychiatric clinical records without consent for research purposes. The Ministry asks if Bill C-54 will prevent this type of disclosure.**

Here again, it should be noted that Bill C-54 will not apply to disclosure of personal information between a public sector psychiatric hospital or psychiatric treatment facility and researchers working within a public organization, such as a university or hospital.

²³ Sections 24(c) and (d) of Bill C-54.

However, Bill C-54 could apply when a private psychiatric treatment facility is requested to disclose psychiatric records to a public or private sector research organization. Section 35(3)(f) of Ontario's *Mental Health Act, 1990* permits an official of a psychiatric facility to disclose clinical records to a third party for purposes of research, compiling statistical data, or academic pursuits. As we noted earlier, this type of disclosure would not be considered "required by law", within the meaning of s. 7(3)(i) of Bill C-54.

However, s. 7(3)(f) of Bill C-54 stipulates that an organization may, for statistical, or scholarly study or research purposes, disclose personal information, without consent, when these purposes cannot be achieved without disclosing the information and it is impracticable to obtain consent. We believe that this exception should solve the problem raised by the Ontario Ministry of Health, where private psychiatric treatment facilities are concerned.

11. **According to the Ontario Health Ministry, PHIPA includes safeguards to protect personal health information that are much more restrictive and stringent than those provided in Bill C-54, particularly with regard to the use of information, disclosure to third parties, computer linkage, duties of health information custodians, etc.**

PHIPA is a sector law relating specifically to health and containing detailed provisions that consider the context and the contingencies peculiar to this field. Conversely, Bill C-54 establishes a general framework for the protection of personal information. The specific rules in PHIPA concerning health information management are generally not incompatible with the rules set out in Bill C-54. As a result, these specific rules will supplement those provided in the federal statute.

12. **The Ministry of Health of Ontario says that Bill C-54 would create roadblocks for the transfer of personal health information among provinces even if the latter designated "substantially similar" personal health information statutes in place.**

Where two or more Canadian provinces exchange health information, they are obviously not engaging in commercial activities. Therefore Bill C-54 does not apply to interprovincial exchanges of personal health information between governments or Health ministries of the various Canadian provinces.

On the question of interprovincial exchanges of health information involving private clinics, private research centres, pharmaceutical companies or private health professional practices, Bill C-54 will likely be applicable. If the exchange of information

is for the benefit of patients, obtaining their consent should not pose a problem. If the purpose of the disclosure is to foster research or compile statistical data, we have seen that s. 7(3)(f) will allow disclosure, without consent. If the purpose of the disclosure is to combat fraud or to permit reimbursement for services delivered, here again, specific exceptions are provided under s. 7 of Bill C-54.

Under the circumstances, the fears of the Ontario Ministry of Health are hard to understand, especially as it has provided in PHIPA the possibility for individuals to refuse disclosure of personal information to third parties.

13. The Ontario Health Ministry asks if Bill C-54 would apply to pharmacists, dentists and nurses practising in the private sector.

Since pharmacists, dentists and nurses practising in the private sector sell goods and services in return for remuneration, one might well think that Bill C-54 applies to them. We refer you on this question to the comments and analysis in Section I of our study. We do not believe, however, that the application of Bill C-54 to private sector practitioners presents serious difficulties since, in the vast majority of cases, consent to the disclosure of personal information, for the purpose of offering the best possible service, will be easy to obtain.

14. The Ontario Health Ministry asks what would happen if personal information were exchanged between a hospital (public sector) and a private laboratory for the purpose of obtaining sample analyses or tests. Would the test be subject to Bill C-54 while at the private laboratory even when paid for with public funds?

Where a public health facility uses the services of a private laboratory to obtain sample analyses or tests, disclosure of the results poses no problem, as there is an implied consent, by the person receiving the service, that the hospital or physician may receive this information. The test results will be part of the record of the public facility and will not be subject to Bill C-54's protection scheme.

If the private laboratory keeps the test results, which will likely be the case, the personal information will probably be subject to Bill C-54. The laboratory will not be able to use or disclose the test results without consent, unless one of the exceptions in Bill C-54 applies.

If the tests are covered by the Ontario health insurance plan, Ontario law stipulates that the patient is deemed to consent to the disclosure of information for the purpose of

verifying that he is eligible and that his request for payment is justified²⁴. The private laboratory is then required to provide the information to the Ministry²⁵. This is therefore a situation where disclosure of personal information is required by law, under s. 7(3)(i) of Bill C-54.

15. The Ministry of Health of Ontario asks what rules would govern private laboratories, clinics or pharmacies operating within a public hospital.

The fact that a private clinic or pharmacy operates within a public health facility makes no difference to the principles set out earlier. If these private organizations conduct commercial activities, Bill C-54 will be applicable

16. The Ontario Ministry of Health says that electronic patient health records, the National Health Surveillance Network and telehealth would be "stalled" by the implementation of Bill C-54.

The fact that personal health information is in electronic rather than paper form makes no difference to the application of the principles and rules set out in Bill C-54. In the case of health records held by of public facilities, Bill C-54 is not applicable. In the case of health records held by private organizations, we have seen that consent, in the form of the right to opt out, will allow the organization to comply with the requirements of Bill C-54. Since the right to opt out is already provided in PHIPA, we must conclude that Bill C-54 would not impose any new, or more stringent, requirements than those that the Ontario government is preparing to adopt.

17. According to the Ministry of Health of Ontario, Bill C-54 would hinder the collaborative effort under way between the federal and provincial governments to harmonize health information.

Exchanges of health information between the federal and provincial governments are not a commercial activity. Therefore Bill C-54 does not apply to exchanges of personal health information.

II. THE LEGAL SYSTEM WITHIN THE PROVINCE OF QUEBEC APPLICABLE TO MEDICAL INFORMATION, IN THE CONTEXT OF RELATIONS BETWEEN PUBLIC ORGANIZATIONS AND PRIVATE SECTOR ENTERPRISE.

²⁴ Section 29(1) of the *Health Insurance Act*, R.S.O., 1990, chapter H.6.

²⁵ Section 37 of the *Health Insurance Act*, R.S.O., 1990, chapter H.6.

1. **Major differences between the legal system applicable in Quebec and the plan proposed in Bill C-54.**

It should be noted from the outset that the rules for the protection of personal information found in Quebec's *Act Respecting the Protection of Personal Information in the Private Sector* are, in large part, similar to those proposed in Bill C-54. In both statutes, we find rules relating to the collection, use and disclosure of personal information. Consent of the individual concerned is also the cornerstone of both statutes, although in a number of respects Quebec's statute is less strict or stringent than Bill C-54:

- 1 The *Act Respecting the Protection of Personal Information in the Private Sector* applies to all enterprises in Quebec, whether or not they carry on a commercial activity. In fact, the concept of enterprise, as defined in s. 1525 of the Civil Code of Quebec, relates to any organized economic activity, whether or not it is commercial in nature. As a result, Quebec law applies to any private sector organization that delivers health services, as well as any health professional who operates a practice.
- 2 As for the collection or gathering of personal information, Quebec's law, contrary to the federal statute, does not require consent. Section 5 of Quebec's statute provides that it is up to the enterprise to determine the subject of the file that it intends to establish. The individual must, however, be informed of the subject of the file, at the time when the personal information is collected from him (s. 8). Once he is informed of the subject of the file, the individual will be in a position to assess whether the collection of personal information is justified and whether the purposes for which the information will be used are acceptable. The individual may then refuse to provide the information on the grounds that it is not necessary or that the enterprise does not have a serious, legitimate purpose in mind. When personal information is collected from a third party, rather than an individual, Quebec's statute does not require the enterprise to inform the individual of the subject of the file, or to obtain his consent with respect to the use that will be made of the information;
- 3 Regarding the use of personal information, s. 13 of Quebec's statute stipulates that it may only be used for purposes relevant to the subject of the file. Consent is only required when the enterprise intends to change the use that it makes of the information to one that is not relevant to the subject of the file;
- 4 Like Bill C-54, Quebec's statute stipulates that, as a general rule, personal information held by an enterprise may not be disclosed without consent. This consent, according to s. 14 of Quebec's statute, must be manifest, specific and

enlightened. Therefore it cannot simply be a matter of opting out. The *Act Respecting Personal Information in the Private Sector* provides a number of situations, however, where an enterprise may disclose personal information without consent. Section 18(5) of Quebec's statute stipulates that "*an enterprise may, without the consent of the person concerned, communicate personal information to a public body which, through a representative collects such information in the exercise of its functions or the or the implementation of a program under its management*". This restriction means that disclosure of personal information between a private enterprise and a public organization is nearly always permitted, as long as the public organization collects the information in exercise of its mandate. Furthermore, s. 18(4) of Quebec's statute authorizes disclosure, without consent, "*to a person to whom it is necessary to communicate the information under the law of a collective agreement, who requires it in the performance of his duties*". Finally s. 20 of Quebec's statute permits an enterprise to disclose personal information, without consent, "*to mandataries or agents for the performance of their duties or the execution of their mandate*".

Thus, exceptions to the general rule that an enterprise may not disclose personal information without consent found in Quebec's statute are broader and easier to apply than those found in the federal Bill. The simple provision in the provincial statute that a public organization is empowered to collect or obtain personal information serves as authorization for the private organization to disclose information to it, without consent. Furthermore, it is sufficient for a public organization to establish that it requires personal information held by a private enterprise in order to carry out its duties or mandate, for the enterprise to be authorized to disclose the information.

Conversely, the federal statute allows the disclosure of personal information without consent, where such disclosure is required by law. The law must therefore specify that a public organization is entitled to obtain personal information from a private organization or, conversely, that the private organization is required to provide it to the public organization, in order for s. 7(3)(i) of the federal statute to be applicable.

Furthermore, Quebec's statute does not require consent with respect to the use of personal information. Under this statute, a private sector organization only has to establish a file with a serious and legitimate subject, for it to be able to use the information for relevant purposes. For its part, Quebec's statute applicable to the public sector allows public organizations to use personal information as long as it relates to the exercise of their mandate.

According to the Quebec system, when public health authorities can justify obtaining personal information in the exercise of their mandate, private organizations are then allowed to disclose this information without the consent of individuals. The public

organizations may then use any information obtained in order to exercise their mandate or implement a program, without it being necessary for them to inform the individuals of a change in use, or to obtain their consent.

When it comes to relations between public and private sector health organizations, Quebec's statute facilitates the exchange of personal information. The proposed plan by the Ontario Ministry of Health to consolidate its health databases would likely be easier to implement under Quebec's statute than under Bill C-54. We have seen, however, that in the vast majority of situations, concerns expressed by the Ontario Ministry are groundless, since the sector statutes in effect in Ontario stipulate that information must be disclosed or that the exceptions provided in s. 7 of Bill C-54 may be applicable.

2. Problems experienced in Quebec with respect to the exchange of health information between private and public organizations.

The *Act Respecting the Protection of Personal Information in the Private Sector* came into force on January 1, 1994. It stipulated that the National Assembly review the Act every five years and strike a parliamentary committee to determine whether any amendments were required. In the course of this process, the Commission d'accès à l'information is to file a report on the implementation of the Act over the previous five years²⁶.

The first five-year review of Quebec's statute was conducted last year. We have itemized all the submissions to the parliamentary committee on the *Act Respecting the Protection of Personal Information in the Private Sector*. No organization or individual came forward with problems relating to the application of this statute to organizations delivering private health services. Under Quebec's statute, there is no doubt that private clinics, private pharmacies, private laboratories, professionals in private practice and any other organizations in the private sector that deliver health care and services are subject to this law.

Likewise, in the submission to the parliamentary committee by the Ministry of Health and Social Services of Quebec, we find no indication of difficulties or problems caused by the application of this statute to private health care.

Finally, we checked with Quebec's Commission d'accès à l'information to establish whether, since the coming into force of this Act, which applies to the private sector, any individuals or organizations had informed the Commission of any difficulty with respect to its application to private health care. The Commission confirmed, after a review of

²⁶ *Act Respecting the Protection of Personal Information in the Private Sector*, ss. 88 and 89.

its records, that it had received no request for the Act to be amended, no submission or letter relating to specific difficulties encountered in applying this Act to health care. Furthermore, the Commission had received no complaints concerning the application of the personal information protection scheme within the context of relations between public and private health care organizations.

iii. CONCLUSIONS

Having completed our study of the problems raised by the Ontario Ministry of Health with respect to the application of Bill C-54 to private organizations that deliver health care services, and their relations with public facilities and officials of the Ministry, we are of the opinion that most of the concerns raised are unfounded. For many of the problem situations raised in the submission, we have found practical or legal solutions:

- because Bill C-54 provides an exception applicable under the circumstances; or
- because the Ontario statutes currently in force require the collection, use or communication of personal information; or
- because consent to use or disclose personal information by the individual would likely be easy to obtain, particularly through the opting-out procedure.

Specifically, we have demonstrated that the plan to integrate health information, as proposed in the *Personal Health Information Protection Act*, 1997, could be implemented without significant difficulties. Furthermore, this bill already grants health service users the right to refuse consent to the disclosure of information to other health information custodians, which is compatible with the principles set out in Bill C-54.

Having said this, the fact remains that Bill C-54 would impose certain constraints on private sector health information custodians, specifically in the following situations:

- a recipient of health services from a private clinic, or from a health professional practising outside the health insurance plan and paid for his services, could refuse to consent to the disclosure of medical information to the Ontario Ministry of Health;
- a person who had uninsured tests done in a private laboratory could refuse to consent to the disclosure of results identifying him by name to the Ontario Ministry of Health;
- Bill C-54 would impose stricter rules on health information custodians in the private sector concerning the collection of personal information. In general, it

would require the information to be collected with the knowledge and consent of the individual. This consent could, however, be obtained through the opting-out procedure;

- Bill C-54 would impose stricter rules on private sector health information custodians concerning the use of personal information. In general, it would require the individual's consent to the planned use of the information. This consent could, however, be obtained through the opting-out procedure;
- Conditions imposed under Bill C-54 to authorize the disclosure of personal information for research purposes are more stringent than those found in PHIPA. The federal Bill stipulates that the project must involve "scholarly or statistical research" and that it must be impracticable to obtain consent. In other words, PHIPA would allow private sector custodians to disclose to third parties health information for research purposes in a number of situations where Bill C-54 would not. On the other hand, the scheme prescribed in Bill C-54 should allow exchanges of personal information for the purpose of assessing the health plan in terms of statistical data, or to promote the advancement of medical or scientific knowledge;
- the exchange of personal information among private sector health information custodians, or between them and public organizations, for the purpose of improving service quality and assessing the health system, would be limited by the passage of Bill C-54, in the case of uninsured services. On the other hand, consent could be obtained through the opting-out procedure. The Ontario Legislature could also prevent this problem by passing a law specifically requiring disclosure without consent.

Furthermore, we have read the proposed amendments tabled on April 15, 1999 by the Minister of Industry, who recommended, in particular, an amendment authorizing disclosure of personal information without consent, when disclosure "is requested for the purpose of administering any law of Canada or a province". This further exception, stipulated in s. 7(3)(c.1)(iii) would apply if disclosure was being made "to a government institution or part of a government institution that has made a request for the information, identified its lawful authority to obtain the information".

We understand that this exception is broader in scope than the one provided under s. 7(3)(i), which requires specific notice to be made in the sector law requiring that personal information be disclosed. Under s. 7(3)(c)(iii), it would probably be sufficient if implementation of the sector law justified the disclosure and the government institution in question was authorized to demand the information. For example, in cases where a provincial statute stipulated that an institution could obtain information, the proposed exception would authorize disclosure without consent.

As applied in the context of PHIPA, s. 7(3)(c.1)(iii) would allow the Ministry of Health to obtain personal information without the consent of private sector health information custodians to ensure effective management of the plan or its assessment. Thus the disclosures provided under ss. 14(1)5, 14(1)6, 14(1)7, 14(1)8, 14(1)9, 14(1)11, 14(1)13, 14(1)15, 14(1)21, 14(1)23, 14(1)25, 14(1)26, 14(1)27, 14(1)28, 14(1)29 and 14(1)30 could be made, without consent, as long as the information was forwarded to a government institution or to a subdivision of such an institution.

Furthermore, if s. 14(1)4 of PHIPA were amended to exclude the opt-out right of the individual, the exception of s. 7(3)(c.1)(iii) would allow disclosure without consent of health information in favour of the Ontario Ministry of Health, by private sector custodians, for the purposes of delivering or facilitating delivery of health services. The Ontario government's goals of efficiency enshrined in PHIPA could thus be fully achieved.

Finally, experience in Quebec relating to the protection of personal information in the private sector gives us no reason to conclude that the implementation of such a scheme has imposed significant restrictions on private health care organizations or impeded their activities. If this were the case, we are inclined to think that the Quebec Ministry of Health and Social Services or the organizations comprising the private health facilities would have complained to the Government of Quebec or to the Commission d'accès à l'information when the Act was reviewed. In our enquiry with the Commission d'accès à l'information and the Government of Quebec, we did not find a single document indicating any concern in this regard. By the same token, it appears to us that the effect of the *Act Respecting Personal Information in the Private Sector* on the exchange of personal information between private sector health organizations, public sector health facilities and the Department of Health and Social Services has been insignificant.

Having said this, we must acknowledge that the exceptions found in Quebec's statute to the rule of confidentiality with respect to the exchange of personal information between a private enterprise and a public organization are less stringent than those found in Bill C-54. The same holds true for the use of personal information since, as a general rule, Quebec's statute requires no consent to change the use made of the information, as long as such use is relevant to the purpose of the file held by the organization holding or receiving the information.

I hope that you find this information satisfactory. Please contact the undersigned if you have any questions or comments.

Yours truly,

LAVERY, de BILLY

Raymond Doray