



Canadian Internet Policy and Public Interest Clinic
Clinique d'intérêt public et de politique d'internet du Canada

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Richard Simpson
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BY EMAIL AND FACSIMILE

Dear Mr. Simpson:

Health Information Custodians in the Province of Ontario – Exemption Order

This is in response to Industry Canada's proposed exemption order for health information custodians in Ontario, pursuant to paragraph 26(2)(b) of the *Personal Information Protection and Electronic Documents Act* (PIPEDA). As stated in the notice,

Based on the recommendation by the Minister of Industry that the *Ontario Personal Health Information Protection Act, 2004*, (PHIPA) is substantially similar to the *Personal Information Protection Act* (PIPEDA), the Order propose to exempt from the federal Act, health information custodians subject to PHIPA, in respect of the collection, use or disclosure of personal health information that takes place within the province. The PIPEDA will continue to apply to the collection, use or disclosure of all personal information outside the province, in the course of commercial activity.

CIPPIC has not had the time or resources to conduct a comprehensive review of the Ontario PHIPA with a view to its substantial similarity with PIPEDA. We have instead focused on one particular issue: that of disclosure of personal health information for research purposes.

We note, however, that the PHIPA permits (or in some cases requires) disclosure of personal health information by health information custodians without consent in a number of circumstances, some of which are similar to exceptions set out in subs.7(3) of PIPEDA, but some of which are not. For example, s.47 of PHIPA

requires custodians to disclose patient information to designated "*health data institutes...for analysis with respect to the management of, evaluation or monitoring of, the allocation of resources to or planning for all or part of the health system, including the delivery of services,...*", even if the patient objects to such disclosure. There is no comparable exception, permissive or mandatory, in PIPEDA.

In this context, before exempting Ontario health information custodians from the application of PIPEDA, it is important – at a minimum - to ensure that PIPEDA's silence on the issue is not an intentional rejection of such exceptions to the consent requirement.

Use and Disclosure of Personal Health Information without consent for research purposes

Under PIPEDA, organizations may disclose personal information without consent "for statistical, or scholarly study or research, purposes", as long as:

- such purposes cannot be achieved without disclosing the information (i.e., anonymous information will not suffice);
- it is impracticable to obtain consent; and
- the organization informs the Commissioner of the disclosure in advance.

(subs.7(3)(f))

The same conditions apply to the use of personal information for research purposes, with the additional requirement that:

- the information be used in manner that ensures its confidentiality.

(subs.7(2)(c))

The Ontario PHIPA takes a somewhat different approach: instead of establishing an objective test and requiring those using or disclosing personal health information for research purposes to meet that test, it effectively delegates the matter to research ethics boards, and gives such boards the discretion to approve or deny research proposals, requiring only that they "consider" the requirements under PIPEDA.

Specifically, those wishing to use personal health information in research must first prepare a research plan and obtain approval for such plan from a research ethics board ("REB"). Health information custodians are permitted to disclose personal health information to researchers for the purpose of REB-approved research proposals. Under subs.44(3) of PHIPA,

*When deciding whether to approve a research plan that a researcher submits to it, a research ethics board **shall consider** the matters that it considers relevant, including,*

(a) whether the objectives of the research can reasonably be accomplished without using the personal health information that is to be disclosed;

(b) whether, at the time the research is conducted, adequate safeguards will be in place to protect the privacy of the individuals whose personal health information is being disclosed and to preserve the

confidentiality of the information;

(c) the public interest in conducting the research and the public interest in protecting the privacy of the individuals whose personal health information is being disclosed; and

(d) whether obtaining the consent of the individuals whose personal health information is being disclosed would be impractical.
(emphasis added)

While PHIPA has incorporated the three key considerations set out in PIPEDA (anonymous information will not suffice; confidentiality assured; impractical to obtain consent), it does not *require* that they be met. Rather, it requires only that they be *considered* by the REB. This, in our view, is a significant departure from PIPEDA and renders PHIPA substantially dissimilar to PIPEDA in an important respect.

Should patients object, *ex post facto*, to the use of their personal health information in the research context, on the basis that anonymous information would have sufficed, or that their consent could have been sought in advance of the research, the PHIPA approach (unlike PIPEDA) denies them any grounds for complaint as long as the REB can show that it considered these factors.

Thus, in order to be substantially similar to PIPEDA, the Ontario PHIPA needs to be amended so as to treat the four factors listed in subs.44(3) as requirements, not mere considerations.

All of which is respectfully submitted,

original signed

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