

“Listening to our Patient's Concerns”

Comments on Bill C 54

(Personal Information Protection and Electronic Document Act)

Submission to the House of Commons Standing Committee on Industry

March 18, 1999

Executive Summary

Over the last year, CMA has become increasingly concerned that debate on the issues concerning health information have been framed in terms of access to information with an attendant erosion of privacy and confidentiality. This one-sided approach comes at a time of expansion in our capacity to collect, store, merge, transfer and access information, coupled with trends both in the health care sector and generally related to the use of information. To address these concerns and to ensure that privacy and confidentiality in the medical context are valued, protected and preserved, CMA developed and adopted a Health Information Privacy Code. This Code should form the basis of all legislation governing the collection, use and disclosure of health information.

Health information is special by its nature. Rules relating to health information must be developed in recognition of its special nature. Ensuring protection of privacy and confidentiality of the patient record must take precedence over other considerations. Bill C-54 fails to do this. Bill C-54 is written from the perspective of encouraging commerce. It appears to have access to information as its dominant value. CMA considers the world of health care to be very different from that of commerce and consequently requiring distinct rules.

Health information use must, in all but exceptional and justifiable circumstances, occur only under the strict control of the patient. The patient must be able to exercise control through voluntary, informed consent. Bill C-54 permits the collection, use and disclosure of information without knowledge or consent on grounds such as expediency, practicality, public good, research, offence investigation, historic importance and artistic purpose. The evident lack of protection accorded health information based on such ground, is unacceptable. The absence of protection undermines the integrity of the patient-physician relationship and has the potential to erode the trust patients have in their physicians - a trust that is essential to patients' willingness to provide the complete information needed to provide them with care. Moreover, distinctions must be made between a patient's right to know what can or must happen to health information and the right to consent to such use.

Not all purposes for the collection and use of health information are equal. Collection and use beyond the therapeutic context should be subjected to rigorous scrutiny before they are permitted to occur. Bill C-54 fails to make such a distinction and treats all purposes that could be identified for information collection or use as equal. Moreover,

the Bill has no mechanism to distinguish legitimate purposes, which should be permitted from illegitimate purposes, which should not.

In light of the clear deficits in Bill C-54 and the inadequate protection of patient privacy and health information confidentiality, CMA makes the following recommendations:

That Bill C-54 be amended to incorporate specific provisions relating to health information and that the provisions of the CMA Code provide the basis of such provisions; and

That the proposed rules for health legislation be subject to the legislative test found in CMA's Code and formulated in light of this process; and

That there be a clear definition of the information being accorded a right of privacy and that this definition, at least in the case of health information, include identifiable information, delinked information, anonymous information and any composite form produced when information is linked to any information about a person from any other source; and

That, at least in connection with health information, the provisions of the Bill apply equally to the public and the private sectors.