

**“Putting Patients First”**

**Comments on Bill C-6**

*(Personal Information Protection and Electronic Documents Act)*

**Submission to the Senate Standing Committee on Social Affairs, Science and Technology**

Nov. 25 1999

**Executive Summary**

CMA commends the federal government for taking this important first step that begins the debate on privacy and the protection of personal information. The issues are complex and the interests at stake significant. CMA welcomes the opportunity to provide comments on Bill C-6 and hopes that its input will strengthen the Bill by ensuring that patient privacy and the confidentiality of medical records are adequately protected.

CMA’s chief concern with Bill C-6 is the inadequacy of its provisions to protect the right of privacy of patients and the confidentiality of their health information. The right of privacy encompasses both the right to keep information about ourselves to ourselves if we so choose and to exercise control over what subsequently happens to information we confide in trust for the purpose of receiving health care. In recent years, this right, and the ability of physicians to guarantee meaningful confidentiality, have becoming increasingly threatened.

Computerization of health information facilitates easy transfer, duplication, linkage and centralization of health information. Captured in electronic form, patient information is potentially more useful for the purpose of providing care. However, thus captured, it also becomes much more valuable and technically accessible to various third parties -- private and public, governmental and commercial -- wishing to use this information for other purposes unrelated to providing direct care. An additional concern is that the demand for health information, referred to by some commentators as ‘data lust’, is growing, partly as a consequence of ‘information hungry’ policy trends such as population health. There is also a disturbing tendency toward ‘function creep’, whereby information collected for one purpose is used for another, often without consent or even knowledge of the individual concerned and without public knowledge or scrutiny.

Furthermore, initiatives concerning health information technology tend to be dominated by those who seek access to this information for secondary purposes. From this perspective, privacy may appear less as a fundamental right than as a hindrance or even roadblock. As we move further into the information age there is some danger that we will become so spell-bound by the promise of information centralization and database linkages that we lose sight

of the patients who confided this information or reduce them to impersonal ‘data subjects’. To avoid this danger and the allure of the technology we need to ground the application of information technology and practices in well-tested, enduring principles. We need to put privacy first rather than treat it as a nuisance or impediment. Rules and regulatory regimes concerning health information should be based on the principle of patient privacy because ultimately health information technology is not about ‘bits and bytes’ or ‘data’ or even ‘data subjects’ but about patients, and patients deserve to be treated with respect and dignity and to have their wishes and choices valued and respected.

If we are to put patients first the right of privacy must be given primacy in rules concerning health information. This does not mean that this right is absolute. What it does mean is that the burden of proof must rest with those whose purposes, however compelling they may be, encroach upon the right of privacy. It means that we value patient privacy at least enough to demand explicit justification of any proposal that would diminish privacy.

Bill C-6 begins with the right premise: that “rules to govern information collection, use and disclosure” should recognize the “right of privacy”. However, it fails to recognize the special nature of health information and to tailor its provisions accordingly. In consequence there is confusion and uncertainty about Bill C-6’s application to health care. Even more seriously, however, Bill C-6 fails to recognize that health information requires stronger or greater privacy protection than other types of information.

The inadequacy of Bill C-6 for health care is not surprising because clearly it was not drafted with health information in mind. Rather, it is written from the perspective of encouraging commerce. It appears to have access to information as its dominant value. The world of health care is very different from that of commerce and consequently requires distinct rules that are more protective of privacy. Confiding information to your physician under the trust of the patient-physician relationship is not on par with giving your address to a salesclerk when you purchase a toaster or rent a movie. Health information is special by nature. Canadians know this. In a recent Angus Reid poll commissioned by CMA Canadians told us loudly and clearly that they regard their health information as especially sensitive.

However, the obvious sensitivity of health information is not the only thing that makes it special and in virtue of which it warrants distinct rules to strengthen privacy protection. It is important to recognize that this information is typically collected under the trust patients vest in their physicians. Patients confide their information for the purpose of receiving care and in the expectation that it will be held in the strictest confidence. This purpose, and the preservation of this trust, should be given primacy in rules concerning health information. It is also important to recognize that the trust under which patients confide in their physicians is fundamental to the patient-physician relationship. If patients can not trust their physicians to protect their information and keep it secret they will not confide it as freely as they do. In consequence, the ability of physicians to provide the care needed would be severely diminished.

Rules relating to health information must be developed in recognition of its special nature and the circumstances of trust and vulnerability in which it is initially collected or confided. Patients confide in their physicians for the purpose of receiving care. The potential that the information thus confided may subsequently be used for other purposes must not impede the therapeutic purpose or diminish the trust and integrity of the patient-physician relationship.

In recent years the secondary use of information for purposes other than those for which it was collected has been increasing without adequate oversight or public knowledge. This 'function creep' undermines the trust of patient-physician relationship. Collection and use beyond the therapeutic context and for purposes unrelated to the provision of direct care should be subjected to rigorous scrutiny before they are permitted to occur. To the extent that they are permitted to occur without patient consent they should be explicitly authorized in legislation to ensure transparency and adequate oversight.

Putting patients first means ensuring that health information, in all but exceptional and justifiable circumstances, is used *only* under the strict control of the patient. The patient must be able to exercise control through voluntary, informed consent. Moreover, a distinction 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. Bill C-6 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 laxness and breadth of these exemptions as applied to health information is unacceptable. These uses, without the patient's consent (or even knowledge), reduce the patient to a means to someone else's end, however worthwhile that end may be. Moreover, the absence of consent (or even knowledge) 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.

CMA has developed and adopted a Health Information Privacy Code (Appendix A) in recognition of the special nature of health information and to give primacy to patients and to the right of privacy. This Code begins from the same starting point as Bill C-6, the Canadian Standards Association (CSA) Code which the Bill includes as Schedule 1. However, unlike Bill C-6, the CMA Code tailors the CSA Code to the specific circumstances of health information. The CMA Health Information Privacy Code, therefore, is able to address issues specific to health information that Bill C-6 either fails to address or, even worse, exacerbates.

In light of the clear deficits in Bill C-6 and the inadequate protection of patient privacy and health information confidentiality, CMA urges this committee to accept the recommendations put forward in this brief to strengthen the Bill's provisions for protecting privacy and to accept the amendment (Appendix B) CMA has prepared to give effect to these recommendations. CMA believes that Canadians desire and deserve no less than this as concerns the right of privacy with respect to health information.