

# The CMA's Health Information Privacy Code: Does it go too far?



*Editorial*

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**T**he CMA has adopted an expanded and comprehensive policy statement (page 997) that will, if implemented, severely limit the use of any health information arising from the physician–patient relationship. This policy was developed in response to the increasing facility with which patients' medical records can be stored and manipulated electronically. The development of numerous potential applications for the use of such information — the federal government's proposal for a Population Health Institute is perhaps the most prominent of these — creates the potential for third-party users of health information to intrude on the private medical histories of patients. The Health Information Privacy Code asserts the patient's right to know and to exercise control over what happens to the information he or she discloses to health care professionals and draws up an exacting framework to protect patients from the collection, use, accessing or disclosure of information without their consent.

Physicians' interactions with patients are governed by a number of ethical precepts; these include patient autonomy, the patient's right to informed consent and the physician's duty to ensure that patients' decisions are well informed and voluntary. The right to privacy is one of the guarantors of the dignity and respect that is due to all patients as persons. The expectation of privacy is also fundamental to patients' trust in their physicians. If patients are not confident that their medical information will be kept private they will be less likely to disclose their health problems and hence less likely to benefit from their interactions with health care professionals. For this reason the CMA code asserts the patient's right to privacy as paramount in any determination of policy with respect to the use of patient information. The rights of the patient as an autonomous individual, not the needs of researchers, administrators or society at large, must be considered first.

Much will depend on how the code's requirement for informed consent is interpreted. A draconian implementation could make it extremely difficult to use any information derived from the physician–patient relationship without informed consent for that specific use; this seems reasonable enough with respect to the use of patient information in case reports, for example, but it would also apply to research involving chart reviews and even anonymous and "delinked" administrative databases such as those maintained by the Canadian Institute for Health Information. Although the policy does foresee legislated uses of patient health information by third parties without patient consent, strict criteria would apply and patients would have to be informed of such use. The policy also encompasses the use of patient information for teaching and research; for example, it would no longer be possible to review a series of chest radiographs with a group of students or residents unless each patient had given consent for the radiographs to be used in this way. Presumably, clinical teaching rounds and continuing medical education programs would be subject to the same strictures.

Many of us feel a certain disquiet that unprecedented access to private information in the computer age somehow brings the Orwellian nightmare of totalitarianism closer to reality. A privacy code is a reassuring and necessary response to this fear. But will it have the effect of unduly constraining legitimate re-



search? To what extent will it impede the dissemination of information that has consequences for public health?<sup>1</sup> How are the principles of the privacy code to be reconciled with the physician's duty to warn?<sup>2</sup> In Holland, where strict laws similar to the CMA code have already been enacted, there is concern that such vital activities as the reporting of adverse drug reactions and contact tracing might amount to an infringement of the law.<sup>3</sup> Although obtaining informed consent from patients for the use of health information appears to supply an answer to these difficulties, in many cases such a task will be onerous if not impossible. Recently the *Journal of the American Medical Association* decided against the publication of a report on an outbreak of drug-resistant tuberculosis by the US Centers for Disease Control and Prevention on the grounds that certain patients were identifiable; in that case, obtaining informed consent was impeded by legal considerations and, ironically, by ethical concerns.<sup>1</sup> Some retrospective research involving, for example, hospital chart reviews may become impracticable. One may ask whose interests are being served by weighing a hypothetical loss of privacy (and the equally hypothetical harms this may entail) against the benefits to society at large of epidemiologic investigation. In envisaging what "compelling reasons" might be given to waive the requirement for privacy and informed consent, the code places the values of safety and harm avoidance above that of actively pursuing public health goals. Arguably, this reflects a shift in the culture of medicine away from paternalistic beneficence in favour of the autonomy of the individual.

None of us wants our privacy to be violated or the details of our medical history to be released willy-nilly to just anyone. But most of us also recognize that our particular experiences with illness, when combined with those of others, provide for an understanding of disease and its management and are essential for the teaching of the health care professionals of the future. Although politicians may win points by introducing legislation designed to allay our distrust of Big Brother surveillance in all its forms, what we really want is a balance — slightly tipped toward ensuring the confidentiality of our disclosures to physicians — between a respect for privacy and the sane use of valuable data. Does the CMA code go too far?

### References

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