



Protecting Privacy and Health Information

A Brief to the Standing Committee on Industry
on the matter of Bill C-54

(Personal Information Protection and Electronic Documents Act)

Submitted by the
Canadian Health Coalition

March 18, 1999

1. The Canadian Health Coalition (CHC) is a not-for-profit, non-partisan organization founded in 1979 at the S.O.S. Medicare Conference attended by Justice Emmett Hall, Tommy Douglas and Monique Bégin. Membership consists of national, provincial, and local organizations representing the people who first came together to fight for public health care in Canada: seniors, farmers, labour, nurses, poor people, and churches.
2. We support the leadership the government is taking on this important matter and we thank the Standing Committee on Industry for this opportunity to participate in a panel of health organizations and provide views from the perspective of public health policy.
3. The Coalition strongly supports the purpose of the Personal Information and Electronic Documents Act which is to provide Canadians with a right of privacy with respect to their personal information.
4. The application of the legislation is much wider than the health sector but it does have direct and important application to commercial health care activity including: pharmacies, pharmaceutical manufacturers, pharmaceutical information corporations, nursing homes, laboratories, health clinics, health maintenance organizations, health insurers, medical equipment firms, medical transcription firms, research enterprises, health data collection and management firms, other health system organizations like the Canadian Institute for Health Information (CIHI), and all other health organizations engaged in commercial activities.
5. **Health care industries must not be exempt from the privacy rules in Bill C-54.** Fears about the misuse of health information technology in the commercial sector are well founded in light of the widespread access to personal information by commercial enterprises and the lack of privacy legislation.
6. The CHC rejects the argument that private, for-profit providers of health services and products and others engaged in commercial activity, should be exempted from the legislation. Members of this committee should beware of this argument especially if it is put forward by federal or provincial government health officials or officials from publically funded health information organizations.
7. Simply stated, having received commercial and investment rights under the North American Free Trade Agreement, the health industry is not in a position now to argue for exemptions from privacy rules for commercial activities as laid out in Bill C-54. If they are commercial enough to be granted rights in the trade agreements, these businesses are commercial enough to be covered by this legislation. **If anything, privacy requirements for health information should be greater and definitely not of a lesser standard than those in other areas of trade and commerce.**

8. There is currently little or no protection in Canadian law against improper disclosure of health and medical information. Medical information is considered valuable for many commercial enterprises as well as by employers, detectives, police, information brokers, political campaign managers and many others. The linkage of medical data bases with other data bases (banks and insurance companies) will create new opportunities for harmful and abusive behaviour. A real life example is the case of the Maryland banker who cross-referenced a list of patients with cancer against a list of people who had outstanding loans at his bank and then called in the loans. [*New England Journal of Medicine*, 23 Nov. 1995].
9. Federal and provincial governments are spending hundreds of millions of dollars to assist in the development of privately controlled and managed patient information data banks. Strategic partnerships are being formed with global corporations to manage health records and provide links on the health information “highway”. Have governments thought through the strategic implications of bringing large U.S.-based corporations into the Medicare system? Have health policy makers thought through the implications for the quality of human care when computer based practice guidelines crowd out the professional judgment, skill and healing care of providers?
10. There is no sign as yet that governments intend to install adequate patient-directed safeguards on health information that is now moving across borders, between providers, and among a growing number of corporations with a financial stake in the technology and the information. In Manitoba, for example, the government signed a deal with the Royal Bank of Canada and its newly created subsidiary called SmartHealth, to develop a health information network. SmartHealth promised to link doctors, hospitals, and pharmacies across the province to patient medical records detailing prescriptions received and drugs used, treatment histories, laboratory and X-ray results. Manitoba privacy legislation does not prohibit the selling or trading of public health information.
11. The Royal Bank sold a 51% stake in SmartHealth to EDS Canada Ltd., a subsidiary of Electronic Data Systems, a global corporation based in Texas. Why would a government health department, mandated to protect the public health care system as stipulated in the Canada Health Act, hand over the responsibility for the collection and management of highly sensitive information to a commercial bank linked to a large U.S.-based multinational, instead of the public sector? [Colleen Fuller, “Traffic on the Information Highway”, in *Caring For Profit: How Corporations Are Taking Over Canada’s Health Care System*, CCPA:Ottawa, 1998].
12. Why was the head of SmartHealth and a director of CANARIE, Inc, John Williams, appointed to the federal Minister of Health’s Advisory Council on Health Infostructure? Do public-private partnerships mean that conflict of interest is no longer recognized or to be avoided?

13. Another disturbing example is a commercial pharmaceutical information company, IMS Canada, which purchases customer and physician information from 4000 out of 6500 retail pharmacies in Canada. This same firm has a detailed data base on the daily activities and prescription practices of 1200 Canadian physicians. The client is not a provincial ministry of health, but 70 of the large pharmaceutical manufacturers operating in Canada. These pharmaceutical companies are not registered charities or educational institutes. They are commercial businesses with a fiduciary duty to maximize profits for their shareholders. According to IMS, the international market in pharmaceutical products alone will reach \$406 billion U.S. in 2002.
14. Health information is power. Health information is a public good. Health information has the potential of making physicians accountable in the health care system and accountable to their patients. Governments, however, may be on the road to handing the power over to the commercial sector to increase its involvement in, and control over, the health care system, leading to a more privatized, less-efficient U.S.-style system. Private sector partnerships in health information may mean that scarce health care budgets are used to introduce corporate management techniques into the health care system and thereby reduce the money spent on care while increasing the money going to the giant information technology corporations.
15. Bill C-54 is an important first step in establishing privacy rights for personal information. Other legislation is also needed to protect health research from commercial activity. **Canada is the only developed nation in the world without a legislated code of ethics and privacy for health research.**[*The Lancet*, September 13, 1997, p.794.] As the Privacy Commissioner points out, the private sector can opt in or out of privacy codes and still gain access to health research data and transactions. Industry Canada is to be commended for groundbreaking leadership in the privacy field.
16. It raises the question: Where is Health Canada? If the ambitious plans for the Health Infoway and the electronic patient record are to receive public support and trust, **there will have to be legislated protection for the integrity of health research and health information.** As the National Forum on Health reported: “federal legislation must distinguish between the use of data to advance the public interest and its use in pursuit of a private or commercial interest” [Final Report, *Creating a Culture of Evidence-Based Decision Making in Health*, p.34]. This assumes that Health Canada’s client is the public and not industry. The technology should not be operationalized until there is adequate legislation to protect patients and the information from commercial activities, conflict of interest and improper disclosure.

With respect to Bill C-54, the Canadian Health Coalition recommends to the following:

- Recommendation 1: That the \$20,000 limit on punitive damages be eliminated from par.16(2). This is not a strong penalty and may become a cost of doing business instead of serving as a deterrent.
- Recommendation 2: That penalties should include: a prohibition on violators from conducting business in the electronic data field for a minimum of two years; an independent auditing process and probation period for offenders. To stop abuse, penalties must include more than financial measures. Because large data management corporations do not rely on consumer “brand loyalty” they are less likely to be affected by public shame in the event of a conviction of privacy violation.
- Recommendation 3: That the \$10,000 limit on the fine for an offence punishable on summary conviction be removed from par.28(a) and that the \$100,000 fine for an indictable offence be removed from par.28(b) in light of potential for harm and abuse and the fact that the electronic data sector is a multibillion dollar transnational industry.
- Recommendation 4: That par.28 include a provision for prison terms as a possible punishment for serious abuse of personal privacy rights.
- Recommendation 5: That the Privacy Commissioner be given the resources to fulfill all the duties related to public education, research, analysis and planning, policy development, investigation, complaint resolution, enforcement assessment, and public reporting on personal information protection.
- Recommendation 6: That the amendments to this Bill tabled with the Committee by the Parliamentary Secretary be incorporated into the legislation.