

# 9th Annual Privacy and Security Conference and Exposition

**Digital Dilemmas, Digital Dreams: Privacy,  
Security and Society in New World  
Networks**

**February 7 - 8, 2008**

**Victoria, BC**

# PANEL C: PUTTING HEALTH RECORDS ONLINE: IS IT "GOOD FOR YOU"?

**Thursday February 7 , 2008, 3:25 - 4:30 PM**

**Richard S. Rosenberg, Professor Emeritus  
Department of Computer Science  
University of British Columbia  
Vancouver, BC**

**President, BC Freedom of Information and Privacy Association**

**[rosen@cs.ubc.ca](mailto:rosen@cs.ubc.ca)**

# OUTLINE

- INTRODUCTION
- MEDICAL INFORMATION SYSTEMS
- PRIVACY PROTECTION
- PRIVACY ISSUES AND THE MEDICAL RECORD
- CONCLUSIONS

# INTRODUCTION

- What is the Electronic Medical Record?**
- What are the benefits?**
- What are issues of concern?**
- How can privacy be protected?**
- What is the consultation process, if any?**

# MEDICAL INFORMATION SYSTEMS

- **“... the province [BC] plans to implement by 2009 an electronic system that will see all paper-based patient files, now growing dusty in doctors’ filing cabinets, put on computers and shared throughout the province.”**

▪ *The Vancouver Sun, May 2, 2006, B6.*

# Networking Health: Prescriptions for the Internet

- ❑ Enable consumers to access their health records, enter data or information on symptoms, and receive computer-generated suggestions for improving health and reducing risk;**
- ❑ Allow emergency room physicians to identify an unconscious patient and download the patient's medical record from a hospital across town;**
- ❑ Deliver care instructions to a traveling businessperson who begins to feel chest pains while in a hotel room;**

# Continued

- ❑ Enable homebound patients to consult with care providers over real-time video connections from home, using medical devices capable of transmitting information over the Internet;**
- ❑ Support teams of specialists from across the country who wish to plan particularly challenging surgical procedures by manipulating shared three-dimensional images and simulating different operative approaches;**
- ❑ Allow a health plan to provide instantaneous approval for a referral to a specialist and to schedule an appointment electronically;**

# Continued

- ☐ Enable public health officials to detect potential contamination of the public water supply by analyzing data on nonprescription sales of antidiarrheal remedies in local pharmacies;**
- ☐ Help medical students and practitioners access, from the examining room, clinical information regarding symptoms they have never before encountered; and**

# Finally

❑ **Permit biomedical researchers at a local university to create three-dimensional images of a biological structure using an electron microscope a thousand miles away.**

➤ **National Research Council. *Networking Health: Prescriptions for the Internet*. (Washington, DC: National Academy Press, 2000). Available at [http://books.nap.edu/html/networking\\_health/](http://books.nap.edu/html/networking_health/)**

# PRIVACY PROTECTION

## □ Privacy as a Fundamental Right:

- Privacy, the Canadian Supreme Court has said, is at the heart of liberty in a modern state, and the limits the *Charter* imposes on government to pry into the lives of its citizens go to the essence of a democratic state.
- the right to be let alone—the most comprehensive of rights and the right most valued by civilized men. (Justice Louis D. Brandeis, US Supreme Court, 1928)

# A Definition for the Information Age

**Privacy is the claim of individuals, groups or institutions to determine for themselves when, how, and to what extent information about them is communicated to others.**

**Alan Westin, *Privacy and Freedom* (New York: Atheneum Publishers, 1967), p. 7.**

# Canada: Personal Information Protection and Electronic Documents Act (PIPEDA)

## □ Three Stages of Implementation:

- **Stage 1. As of January 1, 2001, the Act applied to every organization which operates as a federal work, undertaking or business.**
- **Stage 2. On January 1, 2002, the Act applied to personal health information.**
- **Stage 3. From January 1, 2004, the Act applied to every organization that collects, uses or discloses personal information in the course of commercial activity within a province.**

# BC and Alberta Personal Information Privacy Acts

- On October 12, 2004, the federal Cabinet exempted any organization to which BC's PIPA applies from application of the federal PIPEDA “in respect of the collection, use and disclosure of personal information that occurs in the Province of British Columbia.”**
- BC PIPA took effect on November 10, 2004.**

# PRIVACY ISSUES AND THE MEDICAL RECORD

- ❑ **Although health Web sites now provide a wide range of clinical and diagnostic information; opportunities to purchase products and services; interactions among consumers, patients, and health care professionals; and the capability to build a personalized health record, they have not matured enough to guarantee the quality of the information, protect consumers from product fraud or inappropriate prescribing, or guarantee the privacy of individuals' information.**

# Privacy Issues Related to Medical Information

**Whoever, in connection with my professional service, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret.**

- **Hippocratic Oath, circa 4<sup>th</sup> Century B.C.**

# Supreme Court of Canada

- ❑ **Personal health information is personal information of a particular nature. The Supreme Court of Canada has characterized medical records as sensitive, highly private and personal to the individual.<sup>1</sup> Moreover, the Supreme Court has recognized that the therapeutic relationship is trust-like in nature and is one in which patients have a high expectation that their personal information will remain confidential. As a result, the individuals maintain a fundamental interest in controlling the dissemination of that personal information, especially, as the Supreme Court has said, where aspects of the individual's identity are at stake.<sup>2</sup>**

*1 McInerney v. MacDonald*, [1992] 2 S.C.R. 138, p 148.

*2 R. v. Mills* (2000), 180 D.L.R. 1, p. 46.

# The Privacy Commissioner of Canada

- ❑ **Personal health information stored in electronic systems is becoming fair game for bureaucrats, researchers, as well as insurance and pharmaceutical companies, among others. Many such organizations are already surreptitiously collecting and using personal health information without even the courtesy of telling us that our lives are being categorized and our records dissected.**

**Privacy Commissioner of Canada, Annual Report 1999-2000, May 2000, p. 32. Available at <http://www.privcom.gov.ca>**

# Concern

**Privacy, confidentiality and security are among the most pressing concerns of Canadian citizens as the knowledge-based economy and society emerge. These issues are of special importance in the field of health, where protecting personal information related to health status, ensuring traditional doctor-patient confidentiality in telehealth sessions, and safeguarding the networks that connect the parts of the health system have to be given special priority.**

**Health Canada, Statistics Canada, *Health Information Roadmap: Beginning the Journey* (Canadian Institute for Health Information: Ottawa, 1999) at 6.**

# Recommendation (Mine)

- All health information records should receive uniform coverage under a single law to provide adequate protection for all Canadians, independent of where they receive health treatment. A seamless system of protection is the ideal, whether the coverage falls under provincial or federal jurisdiction or private or public treatment. It is not and should not be the concern of the individual to determine under what conditions his or her medical records receive full protection under the law.**

# Medical Research and Privacy

- ❑ **Optimal and humane medical care requires trust and privacy and confidentiality. No one but the patient has the right of access to personally identifiable medical information. Except for a public health urgency, no personally identifiable medical information should be released to anyone, particularly the government, without the knowledge and consent of the patient (or authorized agent). Particularly in these "electronic times," carefully constructed legislation is sorely needed to effect this protection of patients' individual rights.**

# **“Privacy Law Freezes Health Research”**

- ❑ Numerous B.C. health studies are not proceeding, languishing on hold or facing long delays because privacy legislation prevents researchers from actively recruiting participants.**
- ❑ Scientists say the problem is a 2003 amendment to the B.C. Freedom of Information and Protection of Privacy Act prohibiting government from releasing information to scientists for the purpose of contacting individuals about participating in research.**

# Continued

- ❑ **Previously, the legislation allowed the government to disclose contact information to research scientists, without the consent of individuals, as long as confidentiality was protected**
- ❑ **... but prior to 2003, scientists were allowed to collect a random sample of names from data banks such as the Medical Services Plan (MSP) registry and election lists to recruit control subjects for studies.**

- **Pamela Feyerman, Privacy Law Freezes Health Research, The Vancouver Sun, January 9, 2008, p. A1**

# Continued

□ **“Research, which while of great importance, is secondary to individual rights. It can be carried on apace by accommodating its designs to the protection of rights of privacy, just as is done with clinical care.”**

- **Dr. H. E. Finkel, Clinical Professor of Medicine at Boston Medical Center, as quoted in Massachusetts Medical Society Policy on Patient Privacy and Confidentiality (1999).**

**Accessed from:**

**[http://www2.mms.org/pages/privacy\\_policy.asp](http://www2.mms.org/pages/privacy_policy.asp)**

# Four Major Current Issue Clusters

## □ **Secondary research use of data, and data linking**

**As databases are maturing and increasing in size and quality, their appeal as research resources also is growing. Thus the databases of healthcare finance systems and managed-care organizations, among others, are much in demand.**

# Cont'd.

## □ **Research on private-sector health data**

**Immense volumes of personally identifiable data and lightly masked key-coded data, as well as effectively key-coded or anonymized data, are handled by managed-care organizations, pharmaceutical and related companies, and other private-sector institutions. Some State legal controls apply, as do the Privacy Act and Federal laws where there is Federal involvement.**

# Cont'd.

## □ **Cyber-security**

**It is not an exaggeration to say that all over the world, the protection of the confidentiality and security of health data, especially data that are stored, processed, and transferred electronically, is under review. Until the several intersecting (and perhaps conflicting) goals are clarified and these problems are resolved, the envisioned future of lifetime electronic medical databases, elaborate health-data networks, and the like, will not be realized.**

# Cont'd.

## □ Genetic privacy

**As the news media are constantly reminding us, the world has entered an entirely new era in genetics: The human genome has been mapped, incredibly sensitive and precise genetic tests have been developed, genetic screening has become commonplace, and a most incredible array of genetic interventions is being explored. As an area of medicine and public health practice, so much of the new genetics work is so innovative that for many purposes it must be considered "research."**

# Genetic Information

- ❑ **Genetic analyses and interventions have exceedingly sensitive attributes:**
  - **They broadly relate to health, to qualities of life, and to sense of fairness in the lottery of birth and treatment of the disadvantaged.**
  - **They relate to race, ethnicity, and parentage.**
  - **They relate to gender (and maybe to sexuality).**

# Cont'd.

- **They relate to mental competencies and tendencies, and to behavioral predispositions.**
- **They have relevance for descendants, and therefore possibly to reproductive choices.**

- **William W. Lowrance, “Privacy and Health Research”, Office of the Assistant Secretary for Planning and Evaluation, U.S. Department of Health and Human Services, May 1997, Section 7. Major Current Issue Clusters. Available at <http://aspe.hhs.gov/datacncl/PHR.htm#Contents>**

# Another Example

## ❑ Implanted Patient-Data Chips

➤ **The two D.C. residents are among just a handful of Americans who have had the tiny electronic VeriChip inserted since the government approved it two years ago. But the chip is being aggressively marketed by its manufacturer, which is targeting Washington to be the first metropolitan area with multiple hospitals equipped to read the device, a persuasive factor for Fischer and Hickey. Within weeks, the first hospital is expected to announce plans to start routinely scanning all emergency-room patients.**

- **Rob Stein, Use of Implanted Patient-Data Chips Stirs Debate on Medicine vs. Privacy. *Washington Post*, March 15, 2006, A01.**

# Definition of Consent in the CMA Privacy Code

- ❑ **Consent means a patient's informed and voluntary agreement to confide or permit access to or the collection, use or disclosure of his or her health information for specific purposes.**
- ❑ **Distinguish between express and implied.**
  - **CMA Health Information Privacy Code (1998) Approved by the CMA [Canadian Medical Association] Board of Directors, August 15, 1998. Accessed from the Web page with URL: <http://www.cma.ca/inside/policybase/1998/09-16.htm>**

# Informed Consent: My Comments

- ❑ My basic argument is that the individual must give informed consent for the collection, use and disclosure of his or her medical records or for other personal information as well.**
- ❑ Cost and difficulty in obtaining such permission are not sufficient reasons to ignore this principle.**
- ❑ Only in very special cases, such as incapacity and life-threatening emergencies, can it be abrogated.**

# Continued

- ❑ While recognizing the importance of personal medical information to medical research, it cannot be assumed that such information is automatically available without permission.**
- ❑ Other costs of research are factored into research budgets; so must be privacy concerns.**

# CONCLUSIONS

- ❑ **Consider the following recommendations:**
  - **Recommendation 1: The right to, and the protection of, health information privacy must be established as a basic human right.**
  - **Recommendation 2: Separate legislation for health privacy protection may be necessary. Given that medical information is of such a special character, it requires protection, which may be lacking in general privacy legislation.**

# Continued

- **Recommendation 3: The Canadian Medical Association's Health Information Privacy Code should form the basis for forthcoming federal legislation. Provinces are also encouraged to take advantage of this Code as well, in formulating their own legislation, if they so desire.**
- **Recommendation 4: Adequate penalties must be levied for violations of the regulations and the role of the Privacy Commissioner of Canada must be expanded for the purposes of monitoring the operation of the legislation.**

# Finally.

- **Recommendation 5: In addition, the Privacy Commissioner's responsibility to investigate and adjudicate complaints must be expanded to publicize the outcomes of these investigations.**
- **Recommendation 6: Furthermore, the responsibility of the Office of the Privacy Commissioner to educate Canadians about their privacy rights in general and their health information rights in particular, requires that the budget be adequate.**