

# **For Better, Not Worse: Data Protection and Health Research**

Professor Valerie Steeves  
Department of Criminology  
University of Ottawa

“Privacy rules may threaten research: Following PIPEDA has led to biased data for Canadian Stroke Network”

- Medical Post  
April 20, 2004

- Busby, A. et. al. (2005). Survey of informed consent for registration of congenital anomalies in Europe. *British Medical Journal* 331:140-141.
- Tu, J. et al. (2004). Impracticability of Informed Consent in the Registry of the Canadian Stroke Network. *The New England Journal of Medicine*. 350 (14): 1414 - 1422.
- Ingelfinger J. & J. Drazen. (2004). Editorial: Registry research and medical privacy. *The New England Journal of Medicine* 350(14): 1452-1453.

# Misconception No. 1

Data protection laws restrict access to health information for research purposes.

# Ontario Personal Health Information Protection Act, 2004

Section 44(1) Disclosure for research

A health information custodian *may disclose personal health information* about an individual *to a researcher if the researcher submits* to the custodian ... *a research plan* ... and a copy of the decision of a research ethics board that approves the research plan.

## **Misconception No. 2**

Research is an unencumbered public good free of any private interest.

- American Medical Association - \$20 million (US) for doctors' biographies
- Big Pharmas - \$12 billion (US) for direct marketing to physicians
- IMS - \$1.3 billion (US) for health information

## **Misconception No. 3**

Privacy is an individual right and so must give way to research as a public good.

- Most privacy scholars emphasize that the individual is better off if privacy exists. I am arguing that society is better off when privacy exists. I argue that society is better off because privacy serves common, public and collective purposes. If you could subtract the importance of privacy to one individual in one particular context, privacy would still be important because it serves other important functions beyond those to the particular individual

- Priscilla Regan

## Misconception No. 4

Observational research data collected without the patient's knowledge and consent will lead to unbiased data.

- Just under 10 percent feel that doctors will not use their personal health information (Mulligan, 2001).
- Over one-quarter of teens will not seek out health care if they are concerned about confidentiality (Cheng, et. al., 1993).

- One in ten people have changed their behaviour to protect their medical privacy by:
  - going to another doctor
  - paying direct
  - not seeking medical care
  - giving inaccurate or incomplete information
  - asking the doctor not to record
  
- People who know their medical privacy has been breached in the past are four times more likely to participate in these behaviours.

(California Healthcare Foundation, 1999).

# Misconception No. 5

Privacy is a road block to better health.

# Privacy as a determinant of:

- Mental health (Goffman, 1996)
- Psychological health (Altman, 1975)
- Emotional health, suicide (Westin, 1967)
- Emotional, psychological and physical well-being (Woogara, 2001)

## **Misconception No. 6**

Deidentified health information does not pose a risk of harm to the patient.

- [In a surveillance society] record linkages are so easy to accomplish that the power holders cannot resist using them to try to solve real and alleged social problems.

- David Flaherty

- [Although organizations often use surveillance to] solve problems of genuine social importance ... if all that has to be done to win legal and social approval for surveillance is to point to a social problem and show that surveillance would help cope with it, then there is ... only a qualifying procedure for a licence to invade privacy.

- Alan Westin

# Realities about Privacy and Research

- Data protection laws are a useful tool for researchers because they help to construct trust in research practices.
- Rules and regulations regarding the flow of medical information are needed to mitigate the commercial imperatives which flow from the fact that research is a public-private enterprise.
- Privacy is a social value which must be built into good research design.

# Realities about Privacy and Research

- Good privacy practices promote research because they protect the accuracy of data.
- Privacy is an essential element of psychological health and healthy social relationships.
- Research databases do not exist in isolation, and researchers must respect the fact that the non-consensual flow of information poses risks of harm.

[vsteeves@uottawa.ca](mailto:vsteeves@uottawa.ca)