

PRIVACY OF PERSONAL HEALTH INFORMATION

Privacy is a fundamental right of individuals. It is a core value deeply rooted in the nursing profession (Canadian Nurses Association [CNA], 2003). CNA's *Code of Ethics for Registered Nurses* (2008) states "informational privacy is the right of individuals to determine how, when, with whom and for what purposes any of their personal information will be shared." Personal health information is essential for the functioning of the health system in its interaction with individuals. However, the collection, use and disclosure of personal health information require special consideration in order to protect the privacy of Canadians and to protect the integrity of information.

There are laws in place at the federal level as well as at the provincial and territorial levels to protect personal health information. Privacy acts and regulations in Canada provide individuals with the right to access and request correction of their personal information. Several provinces have passed legislation to deal specifically with the collection, use and disclosure of personal health information (Office of the Privacy Commissioner of Canada, 2010).

This fact sheet describes the methods that are used to protect privacy, federal and provincial/territorial acts that govern personal health information, and resources that facilitate compliance with these laws.

BACKGROUND

- Privacy has become a matter of increasing concern in health care. With the growing adoption of electronic medical records, there are increasing demands for the use of electronic clinical data in health research (Emam, Jabbouri, Sams, Drouet & Power, 2006). Ethical issues arise and may potentially compromise privacy.
- To ensure privacy, ethics boards require that data be de-identified. Privacy-enhancing technologies include encryption, audit trails, electronic consents and layered and role-based access (CNA, 2003).
- Two core projects conducted by Health Canada to advance the use of information and communication technology to ensure privacy in the health infrastructure are the Centre for Surveillance Coordination and the First Nations and Inuit Health Information System (Assadi, 2003).
- CNA's *Ethical Research Guidelines for Registered Nurses* (CNA, 2002) provides guidelines on preventing privacy breach in research. CNA's *Code of Ethics for Registered Nurses* (CNA, 2008) lists maintaining privacy and confidentiality as one of the seven primary values of nursing.

FEDERAL PRIVACY LAWS

Privacy Act

- This act came into force on July 1, 1983.
- It limits the collection, use and disclosure of personal information in federal government departments and agencies.
- It sets out rules for how institutions of the federal government must deal with personal information of individuals.

Personal Information Protection and Electronic Documents Act (PIPEDA)

- This act came into full effect on January 1, 2004.
- It governs the collection, use and disclosure of personal information in connection with commercial activities, including personal health information.
- It stipulates the following (Department of Justice, 2010):
 - Organizations are required to obtain informed consent from individuals before collecting, using or disclosing their personal information; exceptions to the above include investigations related to law enforcement and responses to emergencies.
 - Organizations must protect personal information with security safeguards appropriate to the sensitivity of the information.
 - Individuals have the right to withhold consent, to access personal information about themselves held by an organization, to have it corrected if necessary and to have recourse for a suspected breach.
 - In cases of privacy breach or complaints, PIPEDA sets out an ombudsman model in which complaints are taken to the Office of the Privacy Commissioner of Canada.

PROVINCIAL/TERRITORIAL PRIVACY LAWS

The Government of Canada requires all provinces and territories to comply with PIPEDA. Organizations subject to provincial or territorial laws that have been deemed “substantially similar”¹ to PIPEDA are exempt from the federal act. Specifically, this exemption applies to all intra-provincial collections, uses or disclosures of personal information. However, PIPEDA will continue to apply to the federally regulated private sector and to personal information in interprovincial and international transactions (Industry Canada, 2009b).

Information on laws that govern the privacy of personal health information within each jurisdiction follows (Office of the Privacy Commissioner Canada, 2010).

The following provincial/territorial privacy legislation is deemed “substantially similar” to PIPEDA and is thus exempt:

- Alberta: *Personal Information Protection Act*
- British Columbia: *Personal Information Protection Act*
- Ontario: *Personal Health Information Protection Act*
- Quebec: *Loi sur la protection des renseignements personnels dans le secteur privé (Act Respecting the Protection of Personal Information in the Private Sector)*

¹ Under the policy, laws that are substantially similar have the following characteristics: they provide privacy protection that is consistent with and equivalent to that found under PIPEDA; they incorporate the 10 principles in Schedule 1 of PIPEDA; they provide for an independent and effective oversight and redress mechanism with powers to investigate; and they restrict the collection, use and disclosure of personal information to purposes that are appropriate or legitimate.



The following provincial/territorial privacy legislation governs personal health information specifically; this legislation is not deemed similar to PIPEDA and thus PIPEDA still applies:

- Manitoba: *Personal Health Information Protection Act*
- Saskatchewan: *Health Information Protection Act*

The provinces/territories without “substantially similar” privacy legislation and thus where PIPEDA applies are as follows:

- Canada’s Atlantic provinces (Newfoundland, Nova Scotia, Prince Edward Island and New Brunswick)
- The three territories (Yukon, Nunavut and Northwest Territories)

RESOURCES TO SUPPORT THE PROTECTION OF PRIVACY OF PERSONAL HEALTH INFORMATION

Pan-Canadian Health Information Privacy and Confidentiality Framework

- This framework has been adopted by all provinces and territories except for Saskatchewan and Quebec (Health Canada, 2005).
- It consists of a set of core provisions for the collection, use and disclosure of personal health information in the use of information and communication technologies in both the publicly and privately funded sectors (Anderson, Frogner, Johns & Reinhardt, 2006).

PIPEDA Awareness Raising Tools Initiative

- The Government of Canada has developed tools to assist organizations in the health-care sector in understanding the scope and requirements of PIPEDA. Examples of the tools include a sample poster and brochure that help organizations meet the PIPEDA requirement that they inform their patients and clients of the purpose for the collection of their personal health information and how it will be used and disclosed (Industry Canada, 2009a).

CNA’s Code of Ethics for Registered Nurses

- In nursing practice, CNA’s *Code of Ethics for Registered Nurses* (2008) helps to guide nurses through the decision-making process for ethical dilemmas involving privacy issues.

*This document has been prepared by CNA to provide information.
The information presented here does not necessarily reflect the views of the CNA board of directors.*

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