



PRIVACY AND INFORMATION SHARING FOR PUBLIC HEALTH PURPOSES

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Why is the Need to Protect the Privacy of Personal Health Information So Critical?

The need for privacy of personal health information has never been greater given the:

- Extreme sensitivity of personal health information
- Number of persons involved in health care delivery
- Electronic exchange of personal health information
- Emphasis on information technology including electronic records of personal health information
- Need to use or disclose health information for secondary purposes seen to be in the public interest (i.e. research, planning, surveillance)



Why is the Protection of Privacy in the Public Health Context Important?

- Could lead to the discrimination or stigmatization of individuals or groups of individuals
- Loss of trust or confidence in the public health system
 - “A public health agenda that ignores privacy will ultimately fail because the public will lose trust and confidence in the very system that is striving to safeguard its health. If people fear that actions taken in the name of public health are unjustifiably coercive or that their sensitive medical information is being collected and shared for unrelated purposes, then they will not fully and honestly participate in and support critical public health activities”
- Could deter individuals from seeking information, testing or treatment for certain diseases
- Could result in individuals withholding or falsifying information provided to public health authorities



How is the Privacy of Personal Health Information Protected in Canada?

Privacy of personal health information in Canada is protected through the:

- *Canadian Charter of Rights and Freedoms*
- Common law
- Ethical duties of confidentiality
- Federal, provincial and territorial statutes:
 - Public sector privacy and access legislation
 - Private sector privacy and access legislation
 - Health sector privacy and access legislation
 - Public health legislation



Canadian Charter of Rights and Freedoms

- Right to privacy not specifically protected, rather it is protected by implication through sections 7, 8 and 15
- Section 7 guarantees the right to “life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice”
- Section 8 guarantees the right to be “free from unreasonable search and seizure”
- Section 15 states “every individual is equal before and under the law and has the right to equal protection and equal benefit without discrimination”

Common Law

- May be a cause of action at common law for breach of privacy however the law is currently unclear
- Breach of privacy may also be grounds for other types of tort actions such as:
 - Negligence
 - Breach of fiduciary duty
 - Nuisance
 - Trespass
 - Defamation (libel or slander)
 - Assault or battery

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Ethical Duties of Confidentiality

Ethical duties of confidentiality contained in:

- Hippocratic oath
- Codes of ethics adopted by various health professional associations
- Standards of practice adopted by various regulatory colleges of health professions

Statutes Governing Privacy of Personal Health Information In Public Health Context

Canada

- *Quarantine Act*
- *Department of Health Act*
- *Privacy Act*
- *Personal Information Protection and Electronic Documents Act*
- *Statistics Act*
- *Emergencies Act*

Alberta

- *Public Health Act*
- *Vital Statistics Act*
- *Personal Information Protection Act*
- *Freedom of Information and Protection of Privacy Act*
- *Health Information Act*

British Columbia

- *Health Act*
- *Venereal Disease Act*
- *Vital Statistics Act*
- *Freedom of Information and Protection of Privacy Act*
- *Personal Information Protection Act*

Manitoba

- *Public Health Act*
- *Vital Statistics Act*
- *Freedom of Information and Protection of Privacy Act*
- *Personal Health Information Act*

New Brunswick

- *Public Health Act*
- *Venereal Disease Act*
- *Vital Statistics Act*
- *Right to Information Act*
- *Protection of Personal Information Act*

Newfoundland & Labrador

- *Communicable Diseases Act*
- *Venereal Disease Prevention Act*
- *Vital Statistics Act*
- *Access to Information and Protection of Privacy Act*

Yukon

- *Public Health and Safety Act*
- *Access to Information and Protection of Privacy Act*

Statutes Governing Privacy of Personal Health Information In Public Health Context

Northwest Territories/Nunavut

- *Public Health Act*
- *Disease Registries Act*
- *Vital Statistics Act*
- *Access to Information and Protection of Privacy Act*

Nova Scotia

- *Health Act*
- *Vital Statistics Act*
- *Freedom of Information and Protection of Privacy Act*
- *Part XX of Municipal Government Act*

Ontario

- *Health Protection and Promotion Act*
- *Vital Statistics Act*
- *Freedom of Information and Protection of Privacy Act*
- *Municipal Freedom of Information and Protection of Privacy Act*
- *Personal Health Information Protection Act, 2004*

Prince Edward Island

- *Public Health Act*
- *Vital Statistics Act*
- *Freedom of Information and Protection of Privacy Act*

Quebec

- *Public Health Act*
- *Act Respecting Access to Documents held by Public Bodies and the Protection of Personal Information Act*
- *Act Respecting the Protection of Personal Information in the Private Sector*

Saskatchewan

- *Public Health Act*
- *Vital Statistics Act*
- *Freedom of Information and Protection of Privacy Act*
- *Local Authority Freedom of Information and Protection of Privacy Act*
- *Health Information Protection Act*



Navigating Legislative Framework Governing the Protection of Personal Health Information

NEED TO DETERMINE:

- What statute or statutes apply to the collection, use or disclosure being contemplated?
- Does the statute or do the statutes permit the collection, use or disclosure contemplated and under what conditions (with or without consent)?
- If one or more statutes are applicable:
 - Is there a conflict between the statutes as to whether or not the collection, use or disclosure is permitted and the conditions under which it is permitted?
 - If there is a conflict, what statute prevails?



Questions That Must be Considered in Protecting Privacy in Public Health Context

- Is there a need to collect, use or disclose personal health information or will non-identifiable/aggregate information achieve the legitimate public health objective?
- Is more personal health information being collected, used or disclosed than is reasonably necessary to achieve the legitimate public health objective?
- Is access to personal health information being limited to those who “need to know” the information?



Common Themes Arising From These Statutes In the Public Health Context

Collection of Personal Health Information

- Must be collected directly from the individual to whom the information relates unless:
 - the individual consents to it being collected indirectly
 - the collection by public health authorities is permitted or required by law
 - The information is collected from a person permitted or required by law to disclose it to public health authorities
- Duty imposed on classes persons or entities to report certain diseases to public health authorities
 - Differences lie in the class of persons that must report, the scope of information reported and the diseases reported



Common Themes Arising From These Statutes In the Public Health Context

Use of Personal Health Information

- May be used with consent of the individual or may be used without the consent of the individual:
 - For the purpose for which the personal health information was collected or created or for a consistent purpose
 - For the purpose for which the law permits or requires a person to disclose it to public health authorities
 - Where the use by public health authorities is permitted or required by law



Common Themes Arising From These Statutes In the Public Health Context

Disclosure of Personal Health Information

- Personal health information may be disclosed:
 - With the consent of the individual to whom the personal health information relates
 - Without consent, to avert or minimize a danger to the health and safety of the individual or another person
 - Without consent, in order to comply with a court order
 - Without consent, where the disclosure of personal health information is permitted or required by law



Questions That Must be Considered in Protecting Privacy in Public Health Context

- Does the interest in protecting public health outweigh the infringement of the privacy of the individual?
 - “an assessment must be made as to whether in a particular situation the public’s interest in being left alone by government must give way to the government’s interest in intruding on the individual’s privacy in order to advance its goals” (*Canadian Aids Society v. Ontario*)
- Would obtaining consent of the individual be impractical, impossible or defeat the legitimate public health objective?
- Does the collection, use or disclosure infringe on the privacy of the individual to the least extent required to achieve the legitimate public health objective?

Privacy Best Practices

- Designate a person who is accountable for ensuring privacy compliance and provide their name/contact information to your clients
- Implement policies, procedures and practices to protect personal health information and communicate these policies, procedures and practices to clients
- Communicate to clients the purposes for which their personal health information is routinely collected, used or disclosed prior to collection, use or disclosure
- Collect, use or disclose personal health information with consent unless the collection, use or disclosure is permitted or required to be made without consent

Privacy Best Practices (cont'd)

- Do not collect, use or disclose personal health information if other information will serve the legitimate public health purpose
- Where personal health information is required, limit its collection, use or disclosure to that reasonably necessary to meet the legitimate public health purpose
- Collect, use and disclose non-identifiable or aggregate information whenever possible
- Limit access to personal health information to those who “need to know”
- Develop guidelines and implement procedures with respect to the retention of personal health information

Privacy Best Practices (cont'd)

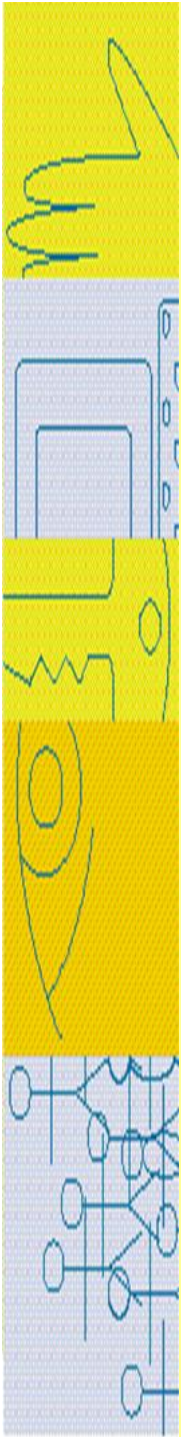
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- Collect, use and disclose non-identifiable or aggregate information whenever possible
- Limit access to personal health information to those who “need to know”
- Develop guidelines and implement procedures for the retention and disposal of personal health information

Privacy Best Practices for Health Information Technologies

- Build privacy into the design specifications
- Minimize collection and use of identifiable information
- Whenever possible use non-identifiable, aggregate or coded information and implement encryption, anonymization or pseudonymization
- Institute authentication and access control measures
- Implement detailed audit monitoring systems
- Conduct privacy impact assessments

Security Best Practices

- Implement safeguards to ensure personal health information is protected against theft, loss and unauthorized use, disclosure, copying or modification
- Ensure personal health information is retained, transferred and disposed of in a secure manner
- Implement administrative, technical and physical safeguards to protect personal health information
- Conduct privacy impact assessments on health information systems, technologies or programs



Implementation of Administrative, Technical and Physical Safeguards

Administrative Safeguards

- Require execution of confidentiality agreements
- Provide training on privacy of personal health information
- Require registration of users of health information technology
- Limit persons with access based on the “need to know”
- Develop, monitor (audit) and enforce privacy and security policies

Technical Safeguards

- Implement encryption, pseudonymization, anonymization
- Institute strong authentication measures (computer password protection and unique log on identifications)
- Implement detailed audit monitoring systems

Physical Safeguards

- Access cards to enter location of personal health information
- When not in use, records of personal health information should be stored in a secure area and locked
- Deploy routine surveillance



Privacy Impact Assessments

1. Review impact an information system, technology or program may have on individuals' privacy
2. Identify, address and mitigate actual or potential risks to privacy
3. Ensure collection, use or disclosure of personal health information is compliant with legislation



Final Thought

“ Anyone today who thinks the privacy issue has peaked is greatly mistaken...we are in the early stages of a sweeping change in attitudes that will fuel political battles and put once-routine practices under the microscope.”

Forrester Research, March 5, 2001



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