



Privacy & Public Health: Ensuring Public Trust

Electronic Health Information Privacy Conference
Ottawa, ON
03 November 2008

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Definition of Privacy



“the ability to determine for ourselves when, how, and to what extent information about us is communicated to others”

- Alan Weston, 1967

Why Privacy?



- essential to human dignity and autonomy
- key component of free speech and democracy
- underpins relations of mutual trust & confidence, healthy social fabric

Why is health privacy important?



- Particularly sensitive information
 - subject to prejudice; labelling; redlining
 - consequences for:
 - social status; human relations
 - employment opportunities
 - access to insurance
 - access to credit
 - access to government services
 - marketplace options
 - identity theft/fraud

The Importance of Trust



- Patient willingness to confide, without fear that personal information will be:
 - used to discriminate re: insurance, employment, credit....
 - accessed by others, causing embarrassment
 - accessed by one who poses a threat
 - used in a manner that is not for the health benefit of the patient (e.g., commercial use)
- Harris surveys show high levels of concern about medical privacy; some people avoid care due to data sharing concerns

The Right to Privacy



- *Nuremberg Code (1947)*:
 - “the voluntary consent of the human subject is absolutely essential”
- *Universal Declaration of Human Rights (1948)*:
 - “everyone has the right freely to participate inscientific advancement and its benefits” (Art.27)
 - “no one shall be subjected to arbitrary interference with his privacy....” (Art.12)

- *European Convention on Human Rights* (1950):
 - “everyone has the right to respect for his private and family life...there shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society.....for the protection of health....” (Art.8)

- *International Covenant on Civil and Political Rights (1966):*
 - “no one shall be subjected to arbitrary or unlawful interference with his privacy...” (Art.17)
 - “no one shall be subjected without his free consent to medical or scientific experimentation” (Art.7)

- World Medical Association, *Helsinki Declaration* (1964, as amended):
 - “the right of the subject to safeguard his integrity must always be respected. Every precaution should be taken to respect the privacy of the subject...” (1975)
 - “It is the duty of the physician in medical research to protect the life, health and **privacy** and dignity of human subjects” (2000)

- World Medical Association, *Statement on the Use of Computers in Medicine*:
 - “it is not a breach of confidentiality to release or transfer confidential health care information required for the purpose of conducting scientific research...provided the information released does not identify, directly or indirectly, any individual patient in any report of such research....or otherwise disclose patient identities in any manner...” (1973, amend.1983)

- Council of Europe, Recommendation on the Use of Medical Data (1997):
 - Scientific Research (s.12)
 - Whenever possible, use anonymous data
 - Where impossible (+ legit purposes), must have:
 - “free, express, informed consent” of data subject; or
 - defined project, important public interest, authorization of legally designated body, impractical to get consent, and data subject doesn’t object; or
 - the research “is provided for by law and constitutes a necessary measure for public health reasons”

Canadian Privacy Law



- *Canadian Charter of Rights and Freedoms*
- Public sector data protection statutes
- Private sector data protection statutes
- Health info privacy statutes: *Ont. PHIPA, Man. PHIA, Alta. HIA, Sask. HIPA*

SCC – health data privacy



- Supreme Court of Canada, *McInerney v. MacDonald* (1992):
 - “Information about oneself revealed to a doctor acting in a professional capacity remains, in a fundamental sense, one’s own....is held in a fashion somewhat akin to a trust....gives rise to an expectation that the patient’s interest in and control of the information will continue.”

Cdn Privacy Statutes



- Consent if possible
- Anonymous or de-identified if possible
 - (*minimal impairment*)
- Otherwise, balancing test:
 - Public benefit of collecting/using/disclosing PHI vs. individual privacy violations

Charter of Rights



- s.7: *“Everyone has 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”*
 - emerging privacy right
- s.8: *“Everyone has the right to be secure against unreasonable search or seizure”*
 - protects an individual’s “reasonable expectation of privacy”
 - protects “core biographical data” that tends to “reveal intimate details of the lifestyle and personal choices of the individual”
 - REP = normative, not descriptive, concept

Limits on Privacy Rights



- s.1: *Charter* rights are subject to “*such reasonable limits as can be justified in a free and democratic society*”
 - Impugned law/measure must deal with “pressing and substantial” concerns
 - Proportionality test:
 - Rational connection
 - Minimal impairment
 - Proportionality: effects not so harmful as to outweigh potential benefits of measure

Cdn AIDS Society v. Ontario



- Mandatory release of tainted blood records to public health authorities (1995)
 - CAS challenged as breach of privacy under ss,7 and 8 of *Charter*
- Ont. Court ruled violation was justified given:
 - severity of public health risk
 - mandatory release of data = rational approach
 - no other workable, less intrusive option
 - public health risk more serious than individual privacy violations

Health Info Research rules



- Consent if possible
- De-identification if possible
- Special body (eg: REB) must approve, s.t.:
 - Anonymous data won't suffice
 - Impractical to get consent (if none)
 - Adequate safeguards to protect confidentiality
 - No disclosure of personal data
 - Public importance of research outweighs individual privacy

Health Research



- rarely serves the interest of the research subject directly
- usually associated with third party (commercial) interests
- often driven by prospect of financial gain
- researchers often dependent on funding from private entities
- high stakes; heavy competition
- success measured in terms of number of publications or patents – not contribution to public health

Concerns



- Paternalistic approach (vs. individual consent)
 - Should individuals be forced to participate in research for benefit of future generations?
- Assumes properly constituted, well-functioning REBs
 - Resources, oversight of REBs?
- Assumes responsible, careful HICs

One expert view



- “No one has a duty to participate in medical research on behalf of the health of future patients and generations.”
- “Participation in medical research – through personal medical data...- is a gesture of altruism comparable to the donation of human biological material for other patients’ health care.”
 - Dr. Henriette Roscam Abbing, Univ. of Utrecht

What's changed?



- Technology – a double-edged sword:
 - Ever-increasing power to gather, store, analyse, monitor, track, share personal data

“The electronic computer is to individual privacy what the machine gun was to the horse cavalry”

But,

- Privacy-Enhancing Technologies (PETs) can help mitigate adverse effects on privacy:
 - De-identification; Anonymization of health data
 - Encryption; Access Controls
 - Tools to ensure informed consent

The Balancing Test



- Clash of values:
collective/public health vs. individual privacy?

OR

- Full accounting of social costs and benefits re: both public health and privacy?

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