

Electronic Health Records in Canada

Ethical and legal aspects

R.D. Speers, D.D.S.



To the extent that medical data contains some of the most intimate details of our existence, the necessity for controlling this data is essential to controlling our new identity in the digital age.

JRI Health Law Institute.

Personal Information Protection
and
Electronic Documents Act
(PIPEDA) Canada

PIPEDA

- Based on ten point Canadian Standards Association Model Privacy Code.

3. Consent

The knowledge and consent of the individual are required for the collection, use or disclosure of personal information, except where inappropriate

4. Limiting Collection

The collection of personal information must be limited to that which is necessary for the purposes identified by the organization.

Item 7 Everyone has the right to life, liberty, and security of person and the right not to be deprived thereof.....

Item 8 Everyone has the right to be secure against unreasonable search and seizure.

Canadian Charter of Rights and Freedoms

"The patient's interest and control of the information will continue.."

"the information revealed remains, in a fundamental sense, one's own for the individual to retain or communicate as he or she sees fit"

McInerney v McDonald
Supreme Court of Canada, 1992

Seven percent of respondents admitted they had forgone medical treatment so as not to jeopardise their employment status or insurability.

CMA sponsored Harris Poll, 1993

“If patients do not believe we can protect their privacy, and that we may be forced to share the information they confide in us, they will stop telling us everything we need to know to make the right diagnosis and provide the right care.”

Alberta Medical Association: Alberta Physicians Oppose Bill 52,
February, 2009

A breakdown in the relationship of trust and confidence between the person and the provider can result in the individual failing to follow up on health care and treatment needed in the future.

HealthConnect, 2002

Only with the strictest respect for the right of the patient to medical secrecy will patients feel free to confide with their physician.

**Confidentiality and Electronic Files,
H Roscam Abbing**

Primary and Secondary Uses
of
Health Information

Primary

That which occurs for the benefit of a
particular patient

Canadian Medical Association,
Health Information Privacy Code, 1998

Secondary Use

Uses not directly related to the benefit of the particular patient for whom the information has originated.

Canadian Medical Association,
Health Information Privacy Code, 1998

Secondary Use

Include: Employment medicals
Insurance medicals
Health Research,
Surveillance,
Etc.

Health Order - Encrypt Your
Mobile Devices, Do It *Now*:
Commissioner Cavoukian

Order HO-007, January 2010

Health Research

An exercise in benevolence or self interest?

The voluntary consent of the human subject is absolutely essential.

The Nuremberg Code, 1946

The right of the research subject to safeguard his or her integrity must always be respected.

The physician should obtain the subject's freely given consent, preferably in writing.

World Medical Association, Declaration of Helsinki

**...concern for the interests
of the subject must always prevail
over the interests of science and
society.**

World Medical Association, Declaration of Helsinki

Human studies may be undertaken without consent or *altered consent* if it “involves no more than minimal risk... or it does not involve therapeutic intervention”.

Tri Council Policy Statement: Ethical Research
Involving Humans: August, 199

The Research Ethics Board

The REB should recognize the need to minimize harms to ensure the harms are proportionate to the benefits....from the study.

Tri-Council Policy Statement for
Research Involving Humans, Can.

Human Research Ethics Committees

The primary role of an HREC is to protect the welfare and rights of participants in research, and each member.....is to decide independently....

National Statement on Ethical Conduct
Involving Humans, Australia, 1992

**“..that the patient’s right to privacy ..
be balanced against the patient’s privilege
to participate in research for the benefit of
society.”**

Rothman: The Epidemiologists Lament:1981
Am J. Pub. Health

Medical research rarely serves the interest of the research participant.

Research output measured in terms of papers published, patents granted, rather than in public health outcomes.

Freedom of medical research within restraints, Roscam Abbing,

**Putting researchers in charge of
(protecting) patients is like putting Colonel
Saunders in charge of the chicken coop.**

Privacy Commissioner: 1998 –99 Report to
Parliament

The electronic health record

Differing directions

Before this principle (control) is abolished I think it is incumbent on those who want to abolish it to clearly state why it should be done away with...

Frank Work, Information and Privacy Commissioner,
January 2009

By negating ‘expressed wish’,
Alberta Health and Wellness
would be under no obligation to
...respect a patient’s *expressed
wish*

- Alberta Information and Privacy Commissioner, Bill 52

Albertans will no longer have the
right to obtain a listing of who
has accessed their information
through Netcare

Information and Privacy Commissioner, Bill 52

HealthConnect recognized the issues of harm, embarrassment, and discrimination that may result from the misuse of health information

We may turn our backs on
technology and return to paper
records or keep hidden records...

Alberta Medical Association, Bill 52

“Widespread public fear is that of being socially or medically labelled or stereotyped in a way that leads to bias and prejudice and the loss of benefits -- such as a job, a loan, insurance or access to unbiased medical care...”

- Consumers Association of Canada, Alberta

If a victim cannot mask his or her information...their physical or emotional security may be put at risk because the abuser will have an easier time tracking them down

Chumir Foundation For Ethics, Bill 52

Bill 52 creates the ripest
environment for a constitutional
challenge in the country

Chumir Foundation for Ethics, Bill 52

With electronic health records, the scale of risk is much greater and the damage potentially more widespread, if something goes wrong.

HealthConnect: Discussion Paper

"The collection of personal information by private organizations should pose no problems since it is in the individual's best interest to consent.....
If such uses are legitimate, the individual will undoubtedly consent to them."

Implications of Bill C 54 (C6) on Medical
Information: 1999
M. Raymond Doray

Many people at our townhalls feared that those who want to violate our privacy for their own economic gain, exercise too much control over the nature of privacy legislation.

Privacy: Where do we draw the line?, 1997
House of Commons Standing Committee
on Human Rights and the status of persons
with disabilities.

Disclosure of Health Information

We have only to read the headlines on the papers in the grocery store check-out line to see what uses can be made of this (health) information.

Tom Wright, Information and Privacy

Commissioner of Ontario: December, 1995