PRIVACY IN A CONSUMER CENTRED HEALTHCARE SYSTEM

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Privacy law in Australia

- Numerous federal and state Acts; common law
Privacy law in Australia

- Focus on relationship between doctor and patient
- Patient autonomy, individual rights, and privacy, confidentiality
Health Records Act 2001 (Vic)

- "An organisation must not do an act, or engage in a practice, that is an interference with the privacy of an individual" (s 21).

- An act or practice is "an interference with the privacy of an individual" if it "... breaches ...a Health Privacy Principle ..." (s 18).
Particularly ...

- The *Collection* principle
- The *Use and Disclosure* principle
Health Records Act 2001 (Vic)
Health Privacy Principle 1.1(a):
"An organisation must not collect health information about an individual unless the information is necessary for one or more of its functions or activities and ... the individual has consented".
Health Records Act 2001 (Vic)
Health Privacy Principle 2.2:

An organisation must not use or disclose health information about an individual for a secondary purpose unless …

(b) the individual has consented to the use or disclosure; or …
Requiring individual consent raises problems

- Clinical testing and interventions
- Research
Treatment: “high risk” families
(Prof Graham Giles)
Research

Linking patients’ health info with other health info and other kinds of info reveals correlations:

– Medical conditions
– Diet
– Residence
– Lifestyle
– Occupation
– Environmental hazards
– Drug use …
However, the objects of Health Records Act 2001 (Vic) include:

- section 6 (b): to balance the public interest in protecting the privacy of health information with the public interest in the legitimate use of that information; ...

- section 6(d): to promote the provision of quality health services, disability services and aged care services.
How does this balance operate in practice?

Individual

Community
1.1 Treatment: collection of information

- family histories!
- Privacy Commissioner issued Public Interest Determinations to make it clear that drs can obtain and record information about third parties when compiling family histories.
NHMRC Guidelines for Genetic Registers 1999
Register staff may use identified family information, obtained from the registrant, to search the register’s database. … If a link is identified, there may be immediate benefits to the registrant and his/her close relatives. For example, if the mutant gene responsible for the disorder in the family has already been identified in another branch of the family, predictive testing can be offered immediately, and without duplicating the process of mutant gene identification.
1.2 Treatment: disclosure of information

Do probands have a right of *veto* so drs & genetic counsellors can’t

- discuss informally with colleagues?
- warn close blood relatives of genetic risk?
- test tissue for relatives’ benefit?
- record info in genetic register?
Have your say about protecting human genetic information

Public meeting
Thursday 22 November 2001
6pm - 8pm
(Tea/coffee will be served from 5.30pm)

Ella Latham Theatre
1st Floor
Murdoch Children’s Research Institute
Royal Children’s Hospital
Flemington Road
Parkville VIC 3052
Health Records Act 2001 (Vic)
Health Privacy Principle 2.2(h)

An organisation may disclose health information if it reasonably believes that it is ‘necessary to lessen or prevent—
(i) a serious and imminent threat to an individual's life, health, safety or welfare; …’
ALRC-AHEC, Essentially Yours, Report 96, 2003
The Commonwealth should amend the Privacy Act 1988 (Cth) to permit a health professional to disclose genetic information about a patient to a genetic relative where the disclosure is necessary to lessen or prevent a serious threat to an individual’s life, health or safety, even where the threat is not imminent.

Rec 8.4 also obtain access to tissue for test in similar circs
Privacy Act 1988 (Cth) now amended: s 95AA, NPP 2.1 (ea)

s 95AA (2) Commissioner may approve guidelines relating to use and disclosure of genetic information for lessening or preventing a serious threat to the life, health or safety (whether or not the threat is imminent) of genetic relative
Organisation *may disclose* genetic information if -

(i) it reasonably believes use or disclosure is necessary to lessen or prevent a **serious threat** to the life, health or safety (**whether or not the threat is imminent**) of a genetic relative ...
But ...

- Limited to serious risks, however defined.
- Federal Privacy Act may not apply in situations covered by state law eg where information is held by state institution.
Also no provision protecting privacy later - cf Genetic Privacy and Non-discrimination Bill 1998 (Cth) (not passed) Clause 8(2)

(2) The person to whom genetic information has been disclosed may disclose the information only to the extent reasonable in the exercise of judgment for professional medical consultation for the direct benefit of a patient or with the written authorisation of the individual.
What should the law be?
Recognise that genetic information is familial (mutation in the family); person’s own status (+ve or –ve) is personal.
Law should focus on wrongful use of personal information.

In April 2008, the U.S. Senate passed the Genetic Information Nondiscrimination Act (GINA). Became law in May 2008.
2. Research: more ‘lenient’ approach

- Privacy legislation
- NHMRC National Statement on Ethical Conduct in Human Research 2007
Health Records Act 2001 (Vic) HPP 2.2(g): may use info in research w/o consent if:

- impracticable to seek individual's consent
- identification necessary
- use accords with guidelines of Health Services Commissioner
Privacy Act 1988 (Cth)

- NPPs 2.1(d), 10.3: may use or disclose info w/o consent where necessary for
  - research,
  - compilation or analysis of statistics
  - management, funding or monitoring of a health service
- relevant to public health or public safety
HREC may waive need for consent if:

- benefits justify risks of harm of research w/o consent
- impracticable to obtain consent (eg due to quantity, age or accessibility of records)
- sufficient protection of privacy; confid’y of data
- plan for making information arising from research available to them
- participants not deprived of possible financial benefits due to them
NHMRC Statement 2007

New chapter on databanks

- Consent requirements for collection of information into databanks, including
  - ‘specific consent’ for specific project
  - ‘extended consent’ to use info in future, closely related, projects
  - ‘unspecified consent’ to use info for any future research.
- Ethical review body may approve collection without consent
ALRC: Many health information data bases in Australia (ch 66)

- Medicare, Pharmaceutical Benefits Program databases.
- cervical cancer register
- ANZ Dialysis and Transplant Registry
- Menzies Centre for Population Research - genealogical data, genetic samples, health information supplied by donors, to search for genetic causes of disease.
Concern about personal info being used in research

Australian Consumers Association “when consumers go to the doctor, they provide health information on the basis that it will be used only for the purposes of their clinical care. They don’t expect that third parties will be trawling through their health records; even if it is in de-identified form. In this sense third party access to data without the consumers’ knowledge is something of a breach of trust”.
But NHMRC research:

- considerable support among the general public (66%) and health consumers (64%) for approved researchers to match information from different databases.

- Even more support if information identified by unique number rather than name (ALRC Privacy Report, 64.21).
ALRC recommends: (ALRC Privacy Report 65.16)

- Unified Privacy Principles (UPPs)
- ‘Collection’ and ‘Use and Disclosure’ principles should permit research using *identified* or *identifiable* personal information without consent.
- subject to HREC review
- Privacy Commissioner to issue ‘Research Rules’ for review