

Confidentiality of Medical Records and Medical Research

Terms of Reference

In 1987 the Commission was asked to review the law relating to the use of patients' medical records for the purpose of medical research.

The reference was directed towards a specific area of privacy, under the general privacy reference,¹ which was agreed between the Commission and the Attorney-General in 1986.

Background of Reference

The Health Department had become increasingly concerned that the developing law of confidentiality would unduly restrict or obstruct medical research in Western Australia. Unlike the legislation of the Commonwealth² and some other Australian states,³ there is no specific statutory provision in Western Australia regulating the use of medical records for research purposes.

Given the absence of statutory authority, it was feared that a hospital's disclosure of medical records to a researcher, in a form that identified individual patients, was a breach of a legal duty of confidence. The breach would only be avoided if the patients had consented to the disclosure. Researchers claimed that in many cases it was impracticable to obtain such patient consent.

The Commission issued a discussion paper in March 1989 for the purpose of obtaining public comment. The Commission's report⁴ was delivered in August 1990.

Nature and Extent of Consultation

The Commission received 32 comments upon the discussion paper from a variety of sources including research organisations, hospitals, doctors and private individuals.

Recommendations

The Commission made the following recommendations:

1. The law should be clarified to ensure that the disclosure to researchers of patient-identifiable information without patient consent does not involve a breach of the legal duty of confidence, provided the research has been approved by a prescribed Institute Ethics Committee (IEC) in accordance with specified criteria.
2. Prescribed IEC's should be those of the teaching hospitals, WA universities and the state Health Department and of any other body prescribed by the Minister for Health which have consented to being prescribed.
3. In giving its approval the IEC should be satisfied that:
 - (a) The research project has as its purpose the advancement of medical knowledge or the improvement of health services in Western Australia;
 - (b) Access to patient-identifiable information is necessary for the scientific validity of the project;
 - (c) Access to that information without patient consent is justified having regard to specified factors; and that
 - (d) The public interest in undertaking the project outweighs the public interest in maintaining confidentiality.

1 Law Reform Commission of Western Australia, *Privacy*, Project No 65(l) (referred 1976, withdrawn 1993).

2 *Privacy Act 1988* (Cth); *Epidemiological Studies (Confidentiality) Act 1981* (Cth).

3 *Health Administration Act 1982* (NSW); *Privacy and Personal Information Act 1998* (NSW); *Health Act 1937* (Qld); *Health Commission Act 1976* (SA); *Health Services Act 1988* (Vic).

4 Law Reform Commission of Western Australia, *Confidentiality of Medical Records and Medical Research*

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- 8 Office of the Federal Privacy Commissioner, 'Good Privacy, Good Business: Privacy in Australia', October 2001, <<http://www.privacy.gov.au/publications/pia.doc>>.
- 9 *Privacy and Personal Information Protection Act 1998* (NSW).
- 10 See <<http://www.dhs.vic.gov.au/privacy/index.htm>>.
- 11 Above n 8.
- 12 See <<http://www.justice.tas.gov.au/legpol/privacy/index.htm>> for the full text of the Tasmanian Information Privacy Principles.
- 13 On 22 April 1999 the Northern Territory Chief Minister issued a Ministerial Statement to the Northern Territory Legislative Assembly on Access to Information and Privacy, above n 8.
- 14 'The Privacy Situation in Western Australia', 29 October 2001, <<http://www.ecc.on3n Aw8s3964.25 0 T.Be f ejx.htm>>.