HOUSE OF REPRESENTATIVES
STANDING COMMITTEE ON LEGAL AND CONSTITUTIONAL AFFAIRS

PRIVACY AMENDMENT (PRIVATE SECTOR) BILL 2000

AMA

SUBMISSION BY THE AUSTRALIAN MEDICAL ASSOCIATION

This submission is made by the Australian Medical Association, a professional organisation representing more than 26,000 Australian doctors.

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Introduction

The AMA welcomes the opportunity to present a submission on the proposed *Privacy Amendment (Private Sector) Bill 2000*. The AMA has previously submitted to the Attorney General's Department (21 January 2000) on the proposed privacy legislation for the private sector.

The AMA has long been a vigorous advocate for patient privacy. Current AMA policies seek to protect confidential patient information from third party interference, promote a beneficial health partnership through cooperative access to medical records and the free exchange of clinically relevant information between medical practitioners and their patients in the interests of optimum patient care.[1]

The AMA recognises that it is established Commonwealth policy to extend existing statutory public sector privacy protection to the private sector. The AMA appreciates the opportunity to contribute to the consultative process. The AMA participates in a number of forums dealing with privacy issues in the health sector.[2] Protection of the privacy and confidentiality of personal health information is vital to the maintenance of public trust in health industry systems. It is settled AMA policy to participate in discussions with the Federal Government on the development of systems to ensure the privacy and confidentiality of personal health information is maintained.

The AMA would, however, make the point that medical practitioners are already under legal and ethical duties to maintain accurate medical records, keep patient confidentiality and share clinically relevant information with patients. Effective enforcement procedures already exist to safeguard the rights of aggrieved patients. Accordingly, the AMA is concerned that the proposed legislation will be seen as doing little more than imposing an unduly onerous and costly compliance regime on medical practitioners without significantly enhancing the current legal mechanisms for the protection of patient privacy.

Publicising Privacy Protection

In order to realise the benefits of the proposed legislation, the AMA believes an adequately funded educational program is vital to explain these important changes to the profession and the public. The implications for the health sector alone warrant such a program.

In May 1999, the Attorney-General announced a national education campaign to accompany private sector privacy legislation which would include:

- a public relations campaign to establish awareness within the community including consumer and privacy groups, that privacy protection is an important element of the new legislation;
- seminars for the business community aimed at building stronger consumer confidence in electronic commerce without adding unnecessary compliance costs on business; and

[1] Code of Ethics, Position Statements on Use of Hospital Medical Records and Clinical Information for the Purpose of Non-Clinical Audit, Guidelines for Doctors on Providing Patient Access to Medical Records, Certificates Certifying Illness, Access to Medical Records by Doctors Who Are Not Treating the Patients Concerned, Genetic Issues. Attached as Annexure 1.

[2] National Health Information Management Advisory Council, Electronic Health Records Taskforce and forums associated with the General Practice Computing Group.

- information kits, and an Internet home page.[3]

Although the AMA is supportive of such a campaign, it is submitted that the proposed funding of an additional $3 million over 3 years on top of current resources to finance a campaign for the entire private sector is inadequate. The AMA strongly suggests that a campaign for the health sector be properly resourced. The recent GST Roll-Out campaigns provide an excellent example of what can be achieved with adequate funding and industry sector involvement.

The AMA has had an opportunity to consider the *Guide to Health Information Privacy* produced by the New Zealand Privacy Commissioner.[4] This publication provides a good model for the presentation of information to the medical profession and the public. The AMA would strongly urge that this *Guide* be referred to in the preparation of materials for the Australian health sector.

Access to Medical Records

The AMA notes with concern that the Bill, through the Access Provisions in National Privacy Principle (NPP) 6, seeks to overturn the common law with respect to patient access to medical records as stated by the High Court in *Breen v Williams* (1995) 186 CLR 71.

The High Court in *Breen v Williams* based its decision that there was no patient right to access medical records in part on the grounds that copyright attaches to the notes made by medical practitioners in the course of their professional practice. The Court was also strongly supportive of a professional's right to privacy in his/her working notes.

The copyright issue has implications for the entire private sector not just the health sector.

The AMA submits that the legal question of whether or not the proposed Bill is sufficient in law to override rights attaching to copyright owners as set out in the Commonwealth's *Copyright Act* is clarified prior to the passage of the Bill. One of the rights of a copyright owner is to control access to the work. This right would appear to be compromised by the statutory right of access in NPP 6. The right to alter, correct or delete information in NPP 6.5 also comprises copyright.

Further comments regarding access to medical records by patients and third parties are made under comments relating to the National Privacy Principles.

Specific Comments on the Bill

Definitions

Health information

The AMA's concerns regarding the definition of health information are as follows:

1. The definition of *health information* must recognise the different categories of information concerning an individual's health.

[3] May 11 1999 Attorney-General
[4] Annexure 2

Some information is best termed *aides memoire* or working notes. These often do not represent the considered therapeutic opinion of the medical practitioner.

Example 1.
Practitioners will make notations in a file as reminders or as triggers to consider matters further or as professional communications to other practitioners in a multi practitioner practice. These notations ensure continuity of care. A short note indicating there is an unresolved question of abuse or other highly sensitive matter is clinically relevant to other practitioners, but could prove to be extremely damaging to the therapeutic relationship if seen by the patient or, in the case of minors, a parent or other family member/guardian. Exclusion of these notes from the file would compromise patient care as other practitioners would not be aware of clinically relevant concerns.

Example 2.
A practitioner may include a clinically relevant notation in language which may be distressing to a patient. The term 'habitual abortion' is a clinically accurate and meaningful term to describe recurrent miscarriage. Read without explanation, it has the capacity to cause unnecessary distress.

The AMA submits that the definition of ***health information*** must be amended **to include the words " information or a considered therapeutic opinion**".

Health information means:
(a) information or a considered therapeutic opinion about:

Other information contained in a medical file is the property of third parties. Reports containing the health information about an individual are prepared for third parties for legal purposes (litigation and compensation) and insurance purposes. The consent of the individual is required in these cases. It should be noted that in some instances the medical practitioner preparing these reports is not in a therapeutic (doctor/patient) relationship with the individual, but is in a contractual relationship with the party requesting the expert medical opinion.

The AMA submits that the definition of ***health information*** must be amended **to include a new section (d) "but not information concerning an individual that is prepared for or on behalf of third parties".**

2. The definition is inadequate to protect genetic information. The definition, although sufficiently broad to cover personal communications concerning an individual's health, is not sufficient to include genetic information. The construction of the Bill is such that protection is provided for "health information" and then in turn "sensitive information", but neither definition affords an adequate degree of protection for genetic information, perhaps among the most sensitive of personal information. Genetic information may not always concern the health of an individual.

Example 1.
Genetic information is collected through DNA sampling for legal proceedings. This information would not fall within the current definition.

Example 2.
Genetic information is collected for medical research purposes. This information would not fall within the current definition.

The AMA submits that the definition of ***health information*** must be amended **to include a new section (e) "genetic information collected about an individual".**

The AMA further submits that these issues are far too important to be left to Guidelines and must be addressed in the legislation itself.

Exempt acts and exempt practices of organisations

The AMA submits that the exemptions provided for journalists and employers should not extend to personal health information, including genetic information. To exclude it, would make a mockery of the privacy protection afforded in other parts of the legislation.

Specific Comments on the National Privacy Principles

The AMA makes the general comment that much of the conduct described in the National Privacy Principles (NPPs) reflects what occurs at present in medical practice. However, there is a real risk that the proscriptive and in cases imprecise language of the NPPs will result in the proposed legislation being seen as an unwarranted bureaucratic interference in current medical practice without any obvious or significant gain to either patients or practitioners.

The AMA submits that the NPPs must be the subject of detailed Guidelines which clarify their effect and application to the health sector, particularly in the case of the collection (NPP 1 and 10) and access and correction provisions (NPP 6).

NPP 1. Collection

No specific comments save to say that the terms "reasonable and practicable" would need to be supported by detailed Guidelines.

NPP 2. Use and Disclosure

NPP 2.1 (d)

The AMA submits that the onus should not be on individuals to 'opt out' of secondary use of their personal information. The onus should be on collecting organisations to seek individuals' consent to 'opt-in'.

The AMA is concerned that this provision will allow third party payers such as health insurers to gain access to personal health information. The AMA does not oppose ethical medical research conducted in accordance with appropriate guidelines, but urges caution in allowing statutory rights of access to third parties in the absence of a requirement for specific patient consent.

NPP 2.1 (e)

The AMA submits that this be amended to remove the word "imminent" to ensure consistency with the provision in NPP 6.1(b).

NPP 2.4

The AMA is concerned that individuals such as minors, who are at law generally considered unable to give consent, may be disadvantaged by the right of disclosure to a family member. The legal capacity of a minor to give consent is subject to assessment in each individual case. NPP 2.4 has the capacity to erode the common law rights to privacy currently enjoyed by adolescents. The AMA is concerned that the fine points of law which arise in the medical treatment of minors and patients with impaired decision making ability may be ignored in a general right of disclosure which may be enforced by family members to the detriment of the patient.

The AMA submits that NPP 2.4 be amended to reflect that a practitioner is not required to disclose information concerning minors or patients with impaired decision making ability without the individual's consent if, in the reasonable opinion of the practitioner, such disclosure would not be in the best interests of the individual concerned.

NPP 3. Data Quality

No specific comment.

NPP 4. Data Security

No specific comment.

NPP 5. Openness

No specific comment.

NPP 6. Access and Correction

The AMA submits that this NPP be the subject of detailed Guidelines approved by the Commissioner under section 95A. The AMA would require that these Guidelines reflect that the right of access is not available to information which is the property of third parties or opinion which is not *considered therapeutic opinion* (see comments under Definition of Health Information).

It is submitted that NPP 6 be amended to exclude the following from access without the express consent of the relevant parties:

- working notes, aides memoire and professional communications between treating doctors, which do not represent a considered therapeutic opinion;
- information prepared for, or relevant to, legal proceedings;
- information which is the property of third parties.

It is noted that in the case of commercially sensitive information, NPP 6.2 protects commercially sensitive information from disclosure.

NPP 6.1 (e)

The AMA acknowledges that NPP 6.1(e) has been modified to some extent following its earlier representations. However, the AMA is concerned that when an individual is either engaged in or contemplating legal proceedings the discovery and access provisions which are controlled under court rules should remain and not be overridden by a Privacy Principle. The current wording of NPP 6.1(e) only prevents a person from relying on the access requirements if they are in or contemplating legal proceedings against the collecting organisation. The AMA repeats its previous submission that the access provisions should not be available to the individual if they are engaged in, or contemplating, legal proceedings against **any person or**

organisation. The AMA repeats its submission that NPP 6.1(e) should be amended as follows:

> "… except to the extent that:
> (e) the information relates to existing **or contemplated** legal proceedings between the organisation **or any other person or organisation** and the individual …."

NPP 6.5

It should be noted that information in a medical file represents an ongoing contemporaneous record. Therapeutic opinion may change over a period of time. Test results such as blood pressure, may change over a period of time. It is submitted that, in the case of health information, any alteration must be apparent on the face of the record so as not to compromise patient care. In the case of disagreement, patients should have the ability to annex comments to a file, but information should not be removed. Deletions should not be permitted. There are sound clinical and legal reasons for preserving health information.

It is also submitted that there must be no ability for one practitioner to make alterations to the considered therapeutic opinion of another which may be contained in a medical file.

NPP 7 Identifiers.

It is noted that in all discussions with relevant government officers and agencies, the issue of unique patient identifiers has been specifically excluded. Accordingly, the AMA reserves its right to comment on the issue of patient identifiers at a later date, except to submit that specific legislation covering this subject may be necessary. It should also be noted that medical files contain a variety of patient identifiers used by organisations other than the treating practitioners such as hospital unit record numbers, workers' compensation claim numbers, Medicare numbers and private health insurance numbers.

NPP 8 Anonymity

No specific comment

NPP 9 Transborder data flows

No specific comment

NPP 10 Sensitive Information

NPP 10.1 (c)

The AMA submits that this be **amended to delete "imminent**" to ensure consistency with the provision in NPP 6.1(b) and the inclusion of "imminent" is unduly restrictive.

NPP 10.2

The AMA is concerned that the current wording of NPP 10.2 would hamper the provision of health care to patients. The general exemption allowing the collection of sensitive information (which includes health information) in NPP 10.2(a) is linked to a requirement that the information is collected **EITHER**, as required or authorised by law (NPP 10.2(b)(i) **OR** in accordance with rules established by competent health or medical bodies that deal with obligations of professional confidentiality which bind the organisation (NPP 10.2 (b)(ii)).

Neither of the contemplated scenarios in NPP10.2 (b) appears to recognise the practical realities of established medical practice. Learned medical colleges do not generally issue

detailed guidelines or advice on what medical records should contain. There is no organisation which issues legally binding guidelines dealing with the obligations of professional confidentiality. As stated above, medical practitioners' obligations of confidentiality and patient privacy arise from legal and ethical duties.

NPP 10.3

The AMA's chief concern is that NPP 10.3 may allow third party payers for health care to collect sensitive health information without the consent of the patient. The AMA submits that third parties, such as health payers, seeking to use patient health information should be restricted to the use of de-identified data unless identified data is necessary, such as for the payment of rebates or claims.

The AMA further submits that in any case where a third party payer seeks to use, collect or in any way handle personal health information in a patient identifiable form, the patient's express specific consent be obtained. The AMA would not agree that a general consent to disclosure clause would satisfy this obligation.

Final Comments

The AMA is not opposed to the intent of the proposed legislation to protect the privacy of patient information from the unreasonable and unlawful intrusion of third parties. However, the AMA would be opposed to a regime which placed onerous, costly and unreasonable compliance obligations on medical practitioners in private practice and failed to respect and recognise practitioners' rights to privacy in their professional records.

The AMA is concerned that a properly funded educational program, developed in conjunction with the profession, must accompany the application of the National Privacy Principles to the private practice sector.

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