

Can you keep a secret?

Amanda Cornwall

A new regulatory structure is required to protect health sector consumers.

When people go to the doctor they usually regard the information that is recorded about them as a secret which is shared only with those who are treating them. Yet, as discussed in 'Health On Line' (p.265 in this Journal), information technology is increasingly enabling personal health information to be much more widely shared. It is clear that a new regulatory infrastructure is required if consumers are to be adequately protected. This article considers some of the issues a fair regulatory infrastructure will need to address.

In an electronic world, Australians have grounds for increasing alarm about the type of information that is being kept about them, who is using it and how. Advances in information technology and health care mean that these concerns are just as applicable in health care as in any other area of life. New legal solutions are needed to meet these changes, but the courts and the Federal Government have been reluctant to introduce law reform. While England, New Zealand and most of Europe and the USA have had some level of health privacy laws for years, Australia has virtually none. Against this backdrop the Privacy Commissioner is expected to release a discussion paper proposing draft *National Health Privacy Principles* before the end of the year.

The problem

Information kept in health records is highly personal, containing a collection of some of the most intimate details of peoples' lives. There can often be information which, if disclosed inappropriately, may result in embarrassment or discrimination.

Advances in technology have made it possible to store, access and link data kept by health service providers in many exciting ways. Health care professionals can share patient information to provide a more co-ordinated approach to health care. Private health insurers and funders can use clinical information as part of assessing the efficiency of health care providers, to minimise duplications and check on over servicing. Managers and administrators can also use the information to monitor effectiveness and efficiency. Public health researchers can obtain access to information which helps to determine the causes of ill health and best possible treatments. There is clearly a public interest in allowing third party access to consumer health records for these purposes.

However, without regulation there is enormous potential for information leakage and uses of information which are not in the public interest. An example is the claim of life insurers that they should be able to access data in registries holding the results of genetic tests for cancer or other illnesses. If the data were released to insurers, people would be much less likely to subject themselves to the tests, detrimentally affecting early detection and prevention measures. This highlights the equally important public interest in ensuring management of personal information in a fair manner. Public confidence in the health system is essential to its effective operation. If people feel insecure about how

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their personal health information is kept they will be reluctant to use health services, and unlikely to openly discuss their condition.

Privacy laws offer a solution to these apparently conflicting demands. Privacy principles give the people who are the subject of a record some control over the information that is kept in the record, through a right to see it and to correct errors. At the same time, privacy principles require those who keep personal information to keep it confidential, but permit certain uses of the information if specified conditions are met.

Current law in Australia

There is no overarching protection of the privacy of personal health records in the public and private health sectors in Australia. A patchwork of laws across the country address some aspects of privacy in a fragmented and relatively ineffective manner.

Access to personal health records is available to consumers of public health services in Australia under Freedom of Information (FOI) laws. As a result, consumers of services such as public hospitals (including psychiatric hospitals) and community health centres, have a right to access their personal health records. They also have a right to seek correction of errors in the records and to appeal against a refusal of access or correction.¹ In practice, the exemptions to access under FOI have operated against the interests of consumers. The treating doctor's discretion remains the overriding factor in decisions about whether consumers obtain access to their records in many cases.²

In the private health sector the High Court said, in *Breen v Williams*, consumers have no right to access their records.³ The notes and records kept by private doctors, hospitals or clinics are regarded as their own. It is a matter for the doctor's discretion to decide what information a consumer needs to know. The Court also recognised doctors' legal obligations to keep the information in medical records confidential. Under this duty it is, once again, a matter for the doctor's discretion to decide if other people can have access to information in the records.

In NSW, regulations on private hospitals, nursing homes and day procedure centres give patients and their representatives a right of access and confidentiality in relation to 'clinical records'. Residents of nursing homes and hostels also have rights in relation to their records under Commonwealth and State laws.⁴

The confidentiality of health records is traditionally protected by ethical duties of doctors and other health professionals. In the public sector this ethic is reinforced by legislation, but the emphasis is on the circumstances of disclosure rather than privacy.⁵ As a result, the exemptions in these provisions have been criticised for promoting a culture of disclosure rather than emphasising the privacy of the person who is the subject of the information.⁶

Hopes of law reform

National law reform to protect personal privacy in the health sector has been recommended in a string of public inquiries over the past five years.⁷ The Federal Attorney-General, Daryl Williams, released a discussion paper on extending the *Privacy Act* to the private sector in September 1996.⁸ The proposed reforms were to be based on Australia's obligations as a party to the International Covenant on Civil and Political Rights (Article 17 prohibits arbitrary and unlawful

interference with a persons' privacy). It would also have implemented the 1980 OECD *Guidelines on the Protection of Privacy and Transborder Flows of Personal Data*, which set minimum standards for protection of privacy.

However, in March 1997 the Prime Minister announced that promised law reform would not proceed. Voluntary industry codes were regarded as more appropriate.

In the wake of the Commonwealth Government's announcement, the Privacy Commissioner initiated a process of consultation for *National Principles for Fair Handling of Personal Information*. The primary focus of the consultations was on the financial and communications sectors. Consumer and privacy groups refused to participate in the consultations officially, protesting that any principles which are not enforceable are a waste of time. The *National Principles*, published in February 1998, have the potential to be adopted as part of a legislative scheme but only if the Federal Government changes its policy.

In the meantime, State and Territory governments have started introducing laws to protect the privacy of health records. The Australian Capital Territory introduced the *Health Records (Privacy and Access) Act 1997* after extensive public consultation. It provides comprehensive protection of privacy in the public and private health sectors, enforceable through complaints to the Health Complaints Commissioner and the courts.

The Victorian Government also appears likely to introduce special privacy provisions for the health sector as part of a promised *Data Protection Bill*. The proposed Bill provides for the adoption of industry specific codes which would be enforceable under the umbrella data protection law. It suggests an approach similar to the New Zealand model. The *Privacy Act 1993* (NZ) applies generally to the public and private sectors, with provision for industry specific codes, including the *Health Information Privacy Code* (1994). Complaints about non-compliance with the obligations in this Code can be dealt with by the Privacy Commissioner, who can impose enforceable sanctions.

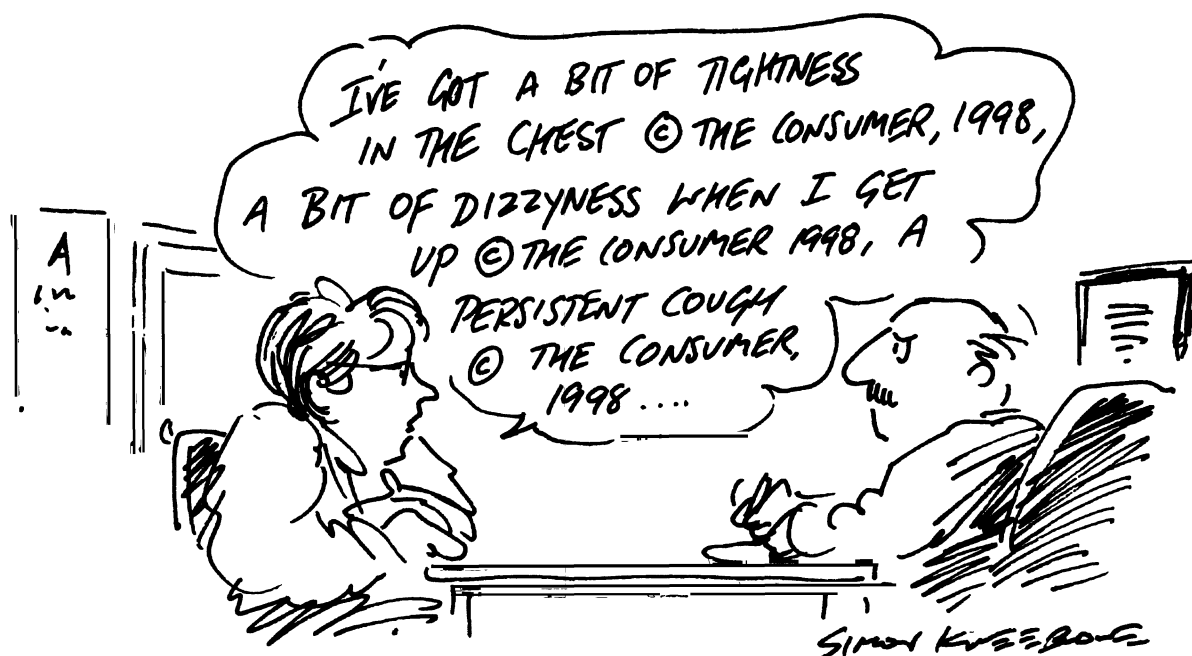
The issues

Consumer access to records

Consumers want access to their health records and are concerned about the accuracy of the information in the records. Research on personal health records in Australia and the USA has found high levels of factual inaccuracies in health records, as well as prejudicial or derogatory comments about patients.⁹

A fundamental principle of privacy protection is that people who are the subject of a record should be able to see it. Information Privacy Principle 6 in the *Privacy Act* (C'th) sets out this right. However, consumer access to health records goes against the traditional culture and practice of the medical profession. This is reflected in the policies of the Australian Medical Association, the Royal College of Psychiatrists and the Insurance Council of Australia, which strenuously oppose consumers having a right of access to their health records.¹⁰ The objections are couched in terms of doctors' expertise in making the best judgments about what consumers need to know, but they belie a professional bias.

A survey of Australian doctors in 1988 revealed that doctors did not recognise the benefits of consumer access to their records, and almost unanimously disapproved of consumer access to records. They rejected the notion that



access to records would lessen consumer anxiety, help consumers make more informed decisions or improve the quality of the record.¹¹ These views are directly opposite to the evidence from medical research, which shows that these are the very areas where major benefits occur.¹²

Underlying these arguments is a fear of *legalisation* of the doctor-patient relationship. Doctors claim they fear legal proceedings will occur if patients are routinely able to access their records. Yet failure to allow access in the absence of legal proceedings is, if anything, likely to provoke rather than prevent such proceedings. The only way that people are able to obtain access to their medical records at present is through litigation, through the discovery process. It makes far more sense to allow the records to be obtained and subjected to expert advice on the standard of professional care before litigation commences. This is the practice in countries such as the UK. It is also the practice supported by the Medical Defence Union, which insures a large proportion of doctors in Australia.¹³

The need to ensure that access is dealt with sensitively is recognised in all laws on consumer access to medical records. Under FOI laws and the ACT law on access to medical records the doctor can refuse access where giving a consumer access to their medical records is likely to put the safety of the consumer or another at risk. This is a modification of Information Privacy Principle 6 in the *Privacy Act* which provides that the subject of a personal record has a right to access the record. However, the obligation is on the health practitioner to justify any decision to refuse access, rather than the consumer to prove why they should have it.

Disclosure to others

People want to be assured that the information in their medical records is being properly managed, kept secure, up to date and relevant. This means that only those who need to know information for treatment purposes, or for other public interest purposes, should have access to it.

These values are reflected in Information Privacy Principles (IPP) 10 and IPP 11, in the *Privacy Act* (Cth). IPP 10 requires information in personal records to be used only for the purpose for which the record was created. IPP 11 requires

that information cannot be disclosed to others without the consent of the person who is the subject of the record. Strict application of IPP 10 and 11 would prohibit provision of relevant information to members of a health care team, or to family members in emergency situations. They would also inhibit use of data in health records for research purposes in the public interest by requiring individual consent to use of information for research in each case. The alternative, to exempt health services from the obligation to obtain consent, for example, would be equally unacceptable. This would be the effect of extending the current exemption in the *Privacy Act* for health research using personal records held by Commonwealth Government agencies.

Consumers' Health Forum has recently advocated strong measures to prevent researchers being able to use information in the personal health records without the consumer's consent. On the basis of the views expressed in the consultation undertaken as part of their Consumers' Health Information for Research Purposes Project, they argue that individuals should be able to veto the inclusion of their medical records in computer databases.

A middle ground might allow consumers to provide general consent to use of information in their files for certain types of research only. This would allow consumers some measure of control over the use of information, but would not be as costly and onerous as requiring consent for every specific research proposal.

A plethora of voluntary codes

A major objection to voluntary codes to deal with privacy in the health sector is that they have been unsuccessful to date in effecting change. The greatest obstacle to change in the health industry is the traditional attitude that *doctor knows best*, and that the doctor's discretion must override any notion of consumer rights. Without changing the law there is little likelihood that these attitudes on the part of health professionals will alter.

The worst outcome from the Commonwealth Government's policy in favour of voluntary codes is the piecemeal development of policies and codes in different corners of the health sector. Such fragmentation may be worse than no action at all as the plethora of codes and guidelines raise

expectations which cannot be met, creating confusion and disillusionment.

State and Territory Health Departments, which are responsible for delivery of the majority of acute care health services in Australia, have developed their own privacy codes and policies. NSW Health adopted an *Information Privacy Code of Conduct* in 1997, consolidating and updating a number of existing protocols on confidentiality, disclosure and consumer access to records. NT Health has developed a similar code. In Victoria the *Department of Human Services (DHS) Information Privacy Principles* were released in August 1998. The Principles cover personal information held by the Department and any agencies funded to provide services on its behalf — DHS incorporates health, aged care, housing, Aboriginal affairs, youth and community services.

The Royal College of General Practitioners have an *Interim Code of Practice for Computerised Medical Records in General Practice* (1997) based on information privacy principles. It says that General Practitioners should provide consumers with access to their personal medical record on request, except in unlikely circumstances where it is likely to cause serious harm or distress. In contrast, the Australian Medical Association's *Guidelines for Doctors on Providing Access to Medical Records* (1997) provides that providing consumers with access to their record is entirely at the discretion of the doctor who prepared the clinical notes. It also provides a broad discretion for doctors to release personal information without the consumer's permission. Another privacy code has been produced by the Australian Pharmaceuticals Advisory Council as part of their 1997 report, *Addressing Privacy Issues Relating to Use of Medication Data*.

Standards Australia have also addressed health privacy issues by developing an Australian Standard *Personal Privacy Protection in Health Care Information Systems* — AS 4400-1995. The standard is compatible with the Commonwealth *Privacy Act* and the principles in the OECD Guidelines. It has been used as the basis for development of health privacy codes, such as the NSW Health *Information Privacy Code of Conduct*.

Commonwealth government activities

Although the Commonwealth Government does not provide primary health services, such as hospitals, privacy issues are significant within the jurisdiction of the Minister for Health and Family Services. The Minister is responsible for regulation of private health insurers, funding and administration of the National Health and Medical Research Council and the Health Insurance Commission (Medicare), and regulation of pharmaceuticals.

It is therefore not surprising that the Department of Health and Aged Care is attempting to provide a level of leadership despite the fact that national health privacy legislation remains off the agenda. The Department is encouraging the development of national standards and specifications for electronic formats for personal health records and for the electronic linkages between health service providers. This was announced in the 1997-1998 budget (known as the *National Health IT Standards Project* and was the subject of a high level process mid 1998 to be followed by broader consultation later this year. The Project is divided into four areas of work:

- Health Commerce
- Digitalisation and Consolidation of Personal Information

- Aggregation and Feeding back information to the Health System, and
- Privacy, Security and Access.

Other relevant initiatives are a \$12.4 million package to strengthen the statistical evidence base of public health decision making, and the development of the National Public Health Information Plan, announced in the 1998-99 budget.

Future prospects for reform

Some of these activities have reinforced the need for national law reform with regard to privacy in the health sector. The need for a clear framework for protecting privacy and public confidence in the health sector seems overwhelming. Health care providers and managers, researchers and others are increasingly convinced. However, the major obstacle to reform seems to be the intransigence of the AMA and the insurance industry, which to date appears to be more effective than the support of other interest groups.

The Privacy Commissioner cannot, of course, make a commitment to legislation while government policy remains committed to voluntary codes. This leaves organisations such as the Public Interest Advocacy Centre, along with other consumer and privacy groups, only able to offer conditional support for the *Health Privacy Principles* the Commissioner aims to develop. However, the process of developing the Principles may demonstrate to the AMA and the Commonwealth Government that an absence of coherent legislative reform is no longer tenable. The public will not accept the risks and the industry cannot operate effectively without it, given the realities of technological change.

References

1. For example, *Freedom of Information Act 1989* (NSW), ss.16 and 31; *Freedom of Information Act 1982* (Vic.) ss.13 and 33; *Freedom of Information Act 1982* (Cth) ss.11 and 41.
2. Australian Law Reform Commission (ALRC) Report, 'Freedom of Information?' No 75, 1977.
3. *Breen v Williams* (1996) 138 ALR 259.
4. *Nursing Homes Regulation 1996* (NSW), *Day Procedure Centre Regulations 1996* (NSW) and *Private Hospitals Regulation 1996* (NSW).
5. For example, s.135A *National Health Act 1953*; *Health Administration Act 1982* (NSW); *Public Health Act 1991* (NSW); *Health Services Act 1988* (Vic.); and *Health Insurance Act 1973* (Cth), s.130.
6. Carter, M., *Public Health Law and Privacy, Public Health Law in Australia: New Perspectives* (in publication), AIHLE, Chapter 6.
7. These include: the report of the HIV/AIDS Working Party, September 1992; the *Inquiry into the Use of Pituitary Derived Hormones in Australia and Creutzfeldt-Jakob Disease* in 1993 and 1994; the *Review of Professional Indemnity Arrangements for Health Care Professionals*, Final Report, AGPS, 1995; *Open Government: A Review of the Federal Freedom of Information Act 1982*, ALRC Report No.77 and ARC Report No.40, 31 December 1995, p.207; and the Senate Community Affairs References Committee *Inquiry Into Access to Medical Records*, 1997.
8. Attorney General's Department (Cth), Discussion Paper, *Privacy Protection in the Private Sector*, October 1997, AGPS.
9. Public Interest Advocacy Centre (PIAC), *Whose Health Records?*, 1996, chapter 3.
10. See submissions to the Senate Community Affairs References Committee *Inquiry into Access to Medical Records*, 1997.
11. Westbrook, J. and Nugent, M., 'Patient Access to Medical Information, Part 2: A Survey of Medical Practitioners' Views', (1988), 18(2) *AMR Journal* 52 at 57. The sample included 107 medical practitioners, with specialities which included surgeons, physicians, anaesthetists, rehabilitation medicine, general practice, and interns.
12. See PIAC, above, ref. 9, chapter 4.
13. Aders, H., 'Should Doctors Let Patients See their Own Files?', (1998) *Journal of the MDU*, April 5.