



COMMONWEALTH OF AUSTRALIA

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Commonwealth Department of
Health and
Aged Care

The Secretary
House of Representatives Standing Committee
on Legal and Constitutional Affairs
Parliament House
CANBERRA ACT 2600

Dear Sir/Madam

Inquiry into the Privacy Amendment (Private Sector) Bill 2000

Please find attached the Department of Health and Aged Care's submission to the Standing Committee on Legal and Constitutional Affairs regarding the *Privacy Amendment (Private Sector) Bill 2000*. I look forward to hearing of the outcomes of the Committee's review of this important legislation.

Yours sincerely

A. S. Podger
Secretary
May 2000

**COMMENTS FROM THE DEPARTMENT OF HEALTH AND AGED CARE
REGARDING THE *PRIVACY AMENDMENT (PRIVATE SECTOR) BILL 2000***

General comments

The Department of Health and Aged Care strongly supports the *Privacy Amendment (Private Sector) Bill 2000* and considers that this legislation will make a very important contribution to the protection of privacy in Australia. The Department is of the view that the proposed legislation is both sensible and workable and that it strikes an appropriate balance between the rights of the individual with respect to privacy and other public interests, such as research and the compilation and statistical analysis of health information. As such, the comments in this submission are intended to provide some clarification of particular issues relating to health information which the Department believes will enhance the operation of the Bill.

The introduction of the *Privacy Amendment (Private Sector) Bill 2000* represents an essential step forward in improving the privacy of personal information held in the private sector, including health information. The proposed Bill will, for the first time, extend general privacy protection to the private sector and set minimum benchmark standards for the appropriate handling of personal information in the private sector — this is particularly important within the context of the rapidly expanding 'information economy'.

Health information can often be both particularly sensitive and personal by nature. As such, inappropriate disclosure and use of an individual's health information can have a devastating impact on his or her life and circumstances. While consumers and the general community currently have a high level of trust in the way in which such sensitive health information is handled within the health sector, the capacity for emerging information and communications technologies to assemble, store and transfer information in unprecedented amounts has understandably raised concerns that individuals' health information privacy might be reduced in the electronic age. Providers, likewise, have expressed concerns that their privacy could be eroded as electronic information exchange increases across the health sector.

The Department of Health and Aged Care has worked closely with the Attorney-General's Department and the Office of the Federal Privacy Commissioner to ensure that the views of a wide range of stakeholders in the health sector have been obtained and considered when it comes to the application of the *National Principles for the Fair Handling of Personal Information* to health information held in the private sector. As a result, the Department is confident that the Federal Privacy Commissioner has been able to consult with a sufficiently representative range of stakeholders, enabling him to successfully negotiate an appropriate balance between competing interests and deliver the most optimal solution in the form of this Bill.

Overall, the Department of Health and Aged Care is strongly supportive of both the intentions of the Bill in providing adequate coverage to health information and the specific modifications that have been made to the National Principles incorporated in the Bill to accommodate the special needs of the health sector. While the Bill in its present format is eminently workable, there are a number of operational issues that the Department believes could be considered further to ensure that the legislation will fully meet consumers' and providers' interests in its application to health information.

Development of health sector guidelines

In particular, the Department would like to emphasise the need for guidelines — such as those issued by the Privacy Commissioner with respect to the Information Privacy Principles in Section 14 of the Privacy Act — to assist with the practical implementation of the proposed legislation in the private sector and ensure appropriate handling of health information. While the National Principles provide an overarching framework for the appropriate handling of health information, work still needs to be done to assist stakeholders to interpret the legislation as it will operate 'on the ground'.

The health sector comprises a diverse range of stakeholder groups, all of whom need to exchange health information about individuals in the everyday delivery of health care. Both providers and consumers need to have a clear understanding of how the legislation will apply to ensure that there is both consistency and transparency in the way in which information is handled across the health sector.

In the absence of such direction there may be confusion and lack of confidence among consumers and providers. It could also potentially result in inconsistent health codes being developed by different stakeholder groups.

The Privacy Commissioner in his report on the application of the National Principles for the Fair Handling of Personal Information to health information signalled his commitment to the development of detailed guidelines in several areas to assist in the interpretation of the National Principles. Currently, both National Principles 2 and 10 refer to guidelines approved by the Federal Privacy Commissioner under the proposed Section 95 A of the Privacy Act. The Explanatory Memorandum also refers to the issuing of guidelines by the Privacy Commissioner in relation to the application of sub-principle 2.1 (c) (direct marketing) in the health context and to the clarification of the 'directly related test' in the context of use and disclosure of sensitive information (NP 2.1 (a) (i)).

The Department has not yet seen mention of the making of general guidelines which would assist in the practical application of the legislation in other key areas. For example, in the area of consumers' access to their own health records, the Privacy Commissioner has previously stated his commitment to developing guidelines on access to health information. The Department feels that it is important that this commitment be made clear at this point in time. Health consumers and providers will require information on the level of access permitted (which could range from discussions between the doctor and the individual consumer to viewing the medical record itself), whether it involves obtaining a copy of the treating doctor's notes, access to additional materials contained within the record (such as letters from other doctors) or only a summary. While the Bill partly addresses the issue of access to records, how that access affects copyright and the intellectual property rights of doctors may need to be clarified.

In summary, the Department is of the view that general guidelines (in addition to those issued under the proposed Section 95A of the Privacy Act) to assist with the practical application of the legislation are essential for the health sector to ensure that there is a consistent approach to applying the National Principles and to reduce potential duplication of effort (and the potential for confusion) in developing health codes in respect of the new provisions. The Department envisages that such health information privacy guidelines would be presented in a practical and user-friendly format, similar to the excellent guidelines produced by the Office of the Privacy Commissioner for the National Principles for the Fair Handling of Personal Information and the

Information Privacy Principles.

Furthermore, the Department would urge that, in order to gain stakeholder trust and confidence, the Federal Privacy Commissioner be asked to lead the development of health specific guidelines in close consultation with key stakeholder groups. The Department of Health and Aged Care would be keen to support and contribute to this process and would envisage working closely with the Privacy Commissioner and the Attorney-General's Department to this end. It is important that government take the lead in development of guidelines to cover personal health information — if left to the health sector there is a risk that different interpretations of the National Principles could emerge.

Extension of time for small businesses

The exemption of small businesses with an annual turnover of \$3m or less from the operation of the legislation for a period of 12 months after its commencement will mean that much of the health sector will not be affected by the legislation until 1 July 2002 at the earliest. While this exemption provides time for small businesses to adjust to the new environment, it may be questioned by consumers to whom access to medical records is a pressing issue.

According to Australian Bureau of Statistics figures for 1994-95, around 5% of medical practices had a gross income of more than \$1m. This would mean in effect that the majority of medical practices and other health providers in the private sector will have a very long lead time before the right of consumers to access their own records will come into effect. Moreover, given the many activities currently being undertaken in the health information management/information technology area, the Department's view is that the legislation should be applied to the health sector as soon as is practicable. Consumers and providers want assurance that health information being exchanged will be given appropriate privacy protection as soon as possible.

Definition of journalism

While the Department of Health and Aged Care acknowledges the importance of balancing the public interest in providing safeguards for the handling of personal information and the public interest in allowing a free flow of information to the public through the media, it could be argued that the definition of journalism is unnecessarily broad. The risk is that this could legitimise a whole range of publication methods that might not be generally accepted as 'journalism' eg newsletters, information, promotional material or other publications produced by an organisation for public circulation where that material could be said to have the "character of news, current affairs, documentaries and other information to the public". The definition may be more capable of being interpreted as being restricted to the generally accepted concept of 'journalism' if the word 'information' were omitted from paragraphs (a)(i) and (a)(ii) of the definition, although this would still seem to leave it fairly broad. It is just that the Department is concerned that there are appropriate safeguards/codes of practice in place to prevent the disclosure of sensitive health information under such circumstances.

Approving guidelines for use and disclosure of health information

The proposed Subsection 95 A (2) of the Privacy Act states that, for the purposes of subparagraph 2.1(d)(ii) of the National Principles, the Commissioner may, by notice in the Gazette, approve guidelines that relate to the use and disclosure of health information for the purposes of research, or the compilation or analysis of statistics, relevant to public health or safety. As the term 'research' is not defined in the Bill, the Department is concerned that this could be interpreted too narrowly. While the Department would want to see adequate safeguards in place, Governments need and use personal health information to ensure the availability, effectiveness and efficiency of health services and the health system more generally — that is, legitimate activities carried out in the interest of the public, and ultimately, of the individual health consumer. Accordingly, further consideration could be given to this issue.

Collection Principles

Clarification may be required of what constitutes a 'competent health or medical body' referred to in National Principle 10.3. One way of doing this is for the legislation to require that the Privacy Commissioner approve which organisations are 'competent'. Alternatively, 'competent health or medical bodies' could be prescribed in regulations made under the Act.

Disclosure of health information in health care settings

It is current practice for the reception areas of hospitals and other health care services to provide updates of an individual's condition to friends and relatives without discussing actual details. The Department's understanding is that National Principle 2.1 (a) would not prevent this current practice from taking place. It may be useful for purposes of clarification to have it specified in the Bill (using similar wording to the New Zealand Health Privacy Code) that: a health organisation that holds health information as defined in the Privacy Act, can use or disclose information in general terms concerning the presence, location, and condition and progress of the patient in a hospital where the individual would reasonably expect the organisation to use or disclose the information for that purpose; and where the use or disclosure is not contrary to the express request of the individual or his or her representative.

Identifiers - National Principle 7.2

The Department understands that additional issues concerning the use of government assigned identifiers have been raised during the earlier consultations conducted in relation to this legislation — particularly with respect to identifiers being used in the interests of individuals to identify information being exchanged between the private and public sectors. This may require further consideration as to whether National Principle 7.2 should be amended to accommodate current practices in the use of health identifiers by States and Territories by allowing a government agency to specify the purposes for which its own identifier can be used. Limitations could be placed on such purposes by ensuring that they are subject to approval by the Federal Privacy Commissioner.

Genetic information

Clearly, genetic information is a type of 'health information' and as such falls within the scope of the legislation to the extent that such information identifies individual. However, it must be recognised that there are unique privacy and other issues associated with genetic information that require additional consideration. The Attorney-General and the Minister for Health and Aged Care intend to jointly pursue further policy consideration of these important and complex issues.