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House of Representatives Standing Committee on Legal and
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AIHW comments to the Inquiry into the Privacy Amendment (Private Sector) Bill 2000

The Australian Institute of Health and Welfare welcomes the opportunity to comment on the Inquiry into the *Privacy Amendment (Private Sector) Bill 2000*. This is an area of vital interest to the Institute. The Institute has operated for several years now under comprehensive privacy legislation, and there have been no reported complaints or identified inadequacies in our processes.

The Institute became concerned that debate over the new legislation might affect the current collection and dissemination of nationally relevant health information collected from both the public and private sectors for research purposes. The draft Bill proposes an extension of the current good practice based around the oversight of the NH&MRC's Australian Health Ethics Committee and the Privacy Commissioner.

In regard to information used for research purposes, it is important to distinguish the use of personal health information for clinical applications from research and statistical applications. The Institute uses health information for statistical purposes and strongly endorses the inclusion of the proposed section 95A to cover use of personal health information for research and statistical purposes. The current section 95 Guidelines have worked effectively and their use should cover personal health information collected by the private sector.

As the Institute's functions are conducted according to law (viz. *The Australian Institute of Health and Welfare Act 1987*), proposed amendments do not appear to inhibit the Institute's ability to carry out its functions. Bodies carrying out Institute functions under contract with the Institute are similarly acting according to law. Nevertheless, some specific issues are of concern:

Definitions for terms used in the National Privacy Principles relating to health information

9. health information

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The definition included in the draft might not unambiguously cover information collected in health surveys, e.g. risk factor information such as smoking status, alcohol consumption, sexual practice history.

The Institute suggests the following addition to paragraph (9) to address this issue:

9. **health information** means:
- (a) (iv) information which could be predictive of a person's current or future health.

10 health service

The definition in the draft does not seem to include unambiguously the situation where care only is provided, and not treatment. This would be the case for palliative care patients, and residential aged care residents, potentially.

The Institute suggests the following amendment to that definition:

- “10 health service means:
- (a) (iii) to treat or care for the individual's illness or disability or suspected illness or disability.”

Definition of disability

No definition is included of “disability” although the term is used in the definitions of both “health information” and “health service.” The Institute suggests that such a definition be included.

The following definition from the *Disability Discrimination Act 1992* defines disability very broadly and is suggested as an appropriate definition for inclusion in the Privacy Act:

Disability Discrimination Act 1992 (Commonwealth)

‘disability’, in relation to a person, means:

- (a) total or partial loss of the person's bodily or mental functions; or
- (b) total or partial loss of a part of the body; or
- (c) the presence in the body of organisms causing disease or illness; or
- (d) the presence in the body of organisms capable of causing disease or illness; or
- (e) the malfunction, malformation or disfigurement of a part of the person's body; or
- (f) a disorder of malfunction that results in the person learning differently from a person without the disorder or malfunction; or

- (g) a disorder, illness or disease that affects person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour;

and includes a disability that:

- (h) presently exists; or
- (i) previously existed but no longer exists; or
- (j) may exist in the future; or
- (k) is imputed to a person.

9 Transborder data flows

It is not clear from the draft that transfer of personal information to a foreign country can be done only if the requirements of the Privacy Act, principally those included in Principle 2 – Use and disclosure, are met.

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