

La Trobe University
Research and Graduate Studies Office
Human Research Ethics

Summary
Information Privacy Legislation

This section details the following legislation/guidelines:

1. Information Privacy Act 2000 (Vic)
2. Health Records Act 2001 (Vic)
3. Health Commissioner's Statutory Guidelines on Research
4. Privacy Act 1988 (Cth)
5. Privacy Amendment (Private Sector) Amendment Act 2000 (Cth)
6. NHMRC Guidelines under Section 95 of the Privacy Act
7. NHMRC Guidelines under Section 95A of the Privacy Act

1. Information Privacy Act 2000 (Vic)

The *Information Privacy Act* establishes a regime for the responsible collection and handling of *personal information* by Victorian public sector organisations and bodies established for a public purpose, such as universities. Personal information is defined in s. 3 to mean –

information or an opinion (including information or an opinion forming part of a database), that is recorded in any form and whether true or not, about an individual whose identity is apparent, or can reasonably be ascertained, from the information or opinion,...

The Act came into effect on 1 September 2001. Agencies must be fully compliant with the Act by 1 September 2002.

The Information Privacy Principles (IPPs) are central to the Act, and prescribe how personal information is to be collected, used, disclosed and stored. Investigators must comply with the IPPs in carrying out their research. While investigators should familiarise themselves with all of the IPPs. IPP 2.1 and IPP 10.2. are of particular relevance to research where it is *not* proposed to obtain the individual's *consent* to the use, disclosure or collection of personal information.

IPP 2.1 (c) provides that an organisation may *use or disclose* personal information about an individual for a secondary purpose without that individual's consent if the use or disclosure is necessary for research, or the compilation or analysis of statistics, in the public interest, other than for publication in a form that identifies any individual, and:

- (a) it is impracticable for the organisation to seek the individual's consent; and
- (b) in the case of disclosure, the organisation reasonably believes that the recipient of the information will not disclose the information.

IPP 10.2 provides that an organisation may *collect sensitive information** about an individual without that individual's consent if:

- (a) the collection is necessary for research, or the compilation or analysis of statistics, relevant to government funded targeted welfare or educational services; and
- (b) there is no reasonably practicable alternative to collecting the information for that purpose; and
- (c) it is impracticable to seek the individual's consent to the collection.

* *Sensitive information* is personal information that is information or an opinion about an individual's racial or ethnic origin, political opinions, membership of a political association, religious beliefs or affiliations, philosophical beliefs, membership of a professional or trade association or trade union, sexual preferences or practices, or criminal record.

Investigators should note that in most instances, the individual's consent to the collection, use or disclosure of personal information should be obtained. Mere inconvenience is not a sufficient reason not to obtain an individual's consent.

Further information about the Act and the IPPs can be found on the La Trobe University Legal Services homepage under For Staff – Legal Services – Privacy and on the Victorian Privacy Commissioner's website at www.privacy.vic.gov.au/

2. Health Records Act 2001 (Vic)

The *Health Records Act* establishes a regime for the responsible collection and handling of personal information that is *health information* by health service providers and others who handle health information. *Health information* is information about the health of an individual or about the provision of health services to him/her.

The Act will be fully operational from 1 July 2002. The Act applies when health information is being handled by a Victorian public sector organisation, by a body established for a public purpose by a Victorian Act, or by an organisation that provides a health service in Victoria. The *Health Records Act* also applies to any person or body that collects, holds or uses health information within Victoria.

The Health Privacy Principles (HPPs) are central to the Act, and prescribe how health information is to be collected, used, disclosed and stored. Investigators must comply with the HPPs in carrying out their research. While

investigators should familiarise themselves with all of the HPPs, HPP 1.1 and HPP 2.2 are of particular relevance to research where it is *not* proposed to obtain the individual's consent to the collection, use or disclosure of health information.

HPP 1.1 (e) provides that an organisation may *collect* health information about an individual without that individual's consent if the collection is necessary for research, or the compilation or analysis of statistics, in the public interest, and:

- i.* that purpose cannot be served by the collection of de-identified information; and
- ii.* it is impracticable to seek the individual's consent to the collection; and
- iii.* the information is collected in accordance with guidelines issued by the Health Services Commissioner.

HPP 2.2 (g) provides that an organisation may *use or disclose* health information about an individual for a secondary purpose without that individual's consent if the use or disclosure is necessary for research, or the compilation or analysis of statistics, in the public interest, and:

- i.* it is impracticable to seek the individual's consent before the use or disclosure; and
- ii.* that purpose cannot be served by the use or disclosure of de-identified information; and
- iii.* the use or disclosure is in accordance with guidelines issued by the Health Services Commissioner.

Investigators should note that in most instances, the individual's consent to the collection, use or disclosure of health information should be obtained. Mere inconvenience is not a sufficient reason not to obtain an individual's consent.

Further information about the Act and the HPPs can be found on the La Trobe University Legal Services homepage under For Staff – Legal Services – Privacy and on the Health Services Commissioner's website at www.health.vic.gov.au/hsc/

3. Health Commissioner's Statutory Guidelines on Research

The Health Commissioner has issued Guidelines under the Health Records Act pursuant to HPP 1.1 (e) (iii) and HPP 2.2 (g) (iii). The Guidelines are on the Health Services Commissioner's website at www.health.vic.gov.au/hsc/

Investigators who are proposing to conduct research in circumstances where either of these HPPs apply, must submit to the UHEC the information required by those Guidelines. The UHEC will consider the proposal in accordance with the procedures set out in the Guidelines. In order to approve a proposed activity, the UHEC will need to be satisfied that the public interest in the

research or compilation or analysis of statistics substantially outweighs the public interest in the protection of privacy.

4. Privacy Act 1988 (Cth)

This Act regulates the handling of personal information by Commonwealth public sector agencies. The Act sets out eleven Information Privacy Principles (IPPs) governing the use, collection, storage and disclosure of personal information by those agencies. Information about the Act can be found at the Federal Privacy Commissioner's website <http://www.privacy.gov.au/>

5. Privacy Amendment (Private Sector) Amendment Act 2000 (Cth)

This Act came into effect on 21 December 2001 and extends the Commonwealth Privacy Act to protect personal information held by private sector organisations by requiring them to comply with ten National Privacy Principles (NPPs) regarding the use, collection, storage and disclosure of personal information. The NPPs apply to businesses (including non-profit organisations) with an annual turnover of over \$3 million, and to all health service providers, irrespective of turnover. The NPPs cover personal information, sensitive information and health information.

Information about the Act can be found at the Federal Privacy Commissioner's website <http://www.privacy.gov.au/>

6. NHMRC Guidelines under Section 95 of the Privacy Act

The Section 95 Guidelines provide a framework for the conduct of medical research using information held by Commonwealth agencies where identified personal information is proposed to be used without the consent of the individuals to whom the information relates. In these situations, a Commonwealth agency may collect or disclose personal information in identifiable form, for medical research purposes without infringing the Privacy Act if the proposed research has been approved by a Human Research Ethics Committee (HREC) in accordance with the Section 95 Guidelines. To approve a proposal, the HREC must decide that the public interest in the research outweighs, to a substantial degree, the public interest in privacy.

Investigators should note that in most instances, the individual's consent to the collection, use or disclosure of personal information should be obtained. Mere inconvenience is not a sufficient reason not to obtain an individual's consent.

The Guidelines can be found on the NHMRC's website at <http://www.nhmrc.gov.au/>

7. NHMRC Guidelines under Section 95A of the Privacy Act

The Section 95A Guidelines provide a framework for the conduct of research relevant to public health or public safety or the compilation of statistics, relevant to public health or public safety. The Section 95A Guidelines relate to the collection, use or disclosure of health information held by all private sector health service providers, and to private sector organisations with an annual turnover of more than \$3 million, where identified personal information is proposed to be used without the consent of the individuals to whom the information relates.

In these situations, an organisation may collect, use or disclose the personal information in identifiable form, without infringing the Privacy Act if the proposed research has been approved by a HREC in accordance with the Section 95A Guidelines. To approve a proposal, the HREC must decide that the public interest in the research outweighs, to a substantial degree, the public interest in privacy.

Investigators should note that in most instances, the individual's consent to the collection, use or disclosure of health information should be obtained. Mere inconvenience is not a sufficient reason not to obtain an individual's consent.

The Guidelines can be found on the NHMRC's website at <http://www.nhmrc.gov.au/>