



## IPP2.1(ca)(iv) & section 86(1)(a)(iv) Use and disclosure of health information

### Information Act Guideline

#### **Use and disclosure of health information for research and statistical purposes**

Section 86(1)(a)(iv) of the *Information Act* (the Act) enables the Information Commissioner to develop and issue a guideline to public sector organisations about the use and disclosure of health information necessary for research, or the compilation or analysis of statistics in the public interest. Information Privacy Principle (IPP) 2.1(ca)(iv) requires a public sector organisation to comply with any guideline made by the Commissioner under s86(1)(a)(iv) of the Act.

#### **Publication of the guidelines**

This guideline is issued by publication on the website of the Office of the Information Commissioner. If you require hard copies of this guideline, please contact the Office by telephone on 08 8999 1500 or send an email to [infocomm@nt.gov.au](mailto:infocomm@nt.gov.au).

#### **Privacy and Research**

An individual's right to privacy is a fundamental human right. This is recognised in a number of international instruments, in particular, the *International Covenant on Civil and Political Rights (Article 17)* and the *OECD Guidelines on the Protection of Privacy and Transborder Flows of Personal Data*. Australia adopted the OECD guidelines in 1984 and the principles in those guidelines are reflected in the Northern Territory *Information Act*. The IPPs deal with personal information privacy protection, a component of the broader concept of privacy.

However, the right to privacy is not an absolute right. In some circumstances, it must be weighed against the equally justified rights of others and against matters that benefit society as a whole. The conduct of human research represents one of these circumstances. Research is important for providing information to help the community and government make decisions that impact on the health and welfare of individuals and the community. However, it should be carried out in such a way as to minimise the intrusion on people's privacy. Ideally, this is done by obtaining the informed consent of participants prior to accessing their personal information. Where this is not practicable, de-identified information should be used. Where neither of these options is available, it may be that identifiable information must be used without consent in order for the research to proceed. In these latter cases, there is a need to balance the public interest in the research outcomes against the public interest in privacy.<sup>1</sup>

<sup>1</sup> From: *Guidelines Under Section 95 of the Privacy Act 1988* – published on:  
[http://www.nhmrc.gov.au/files\\_nhmrc/file/publications/synopses/e26.pdf](http://www.nhmrc.gov.au/files_nhmrc/file/publications/synopses/e26.pdf)

# The use and disclosure of health information

## GUIDELINE

### Use and disclosure of health information for research and statistical purposes

A public sector organisation may use or disclose health information about an individual if the following conditions are met:

- It is necessary for research, or the compilation or analysis of statistics;
- It is in the public interest;
- The research, compilation or analysis will not be published in a form that identifies the individual;
- It is impracticable for the organisation to seek the individual's consent before the use or disclosure;
- In the case of disclosure – the organisation reasonably believes the recipient of the information will not disclose the information;
- A Human Research Ethics Committee has reviewed the proposed activity and is satisfied that the public interest in the activity outweighs the public interest in maintaining the level of privacy protection provided by the *Information Act*.

The Human Research Ethics Committees must be constituted in accordance with, and act in compliance with:

- the *National Health and Medical Research Council Act 1992 (Cth)*;
- the *National Statement on Ethical Conduct in Research*; and
- the *Australian Code for the Responsible Conduct of Research*

as in force from time to time.

It is also recommended that researchers and relevant bodies consult the following guidelines if appropriate:

- *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*; and
- *Keeping research on track: a guide for Aboriginal and Torres Strait Islander peoples about health research*.



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Information Commissioner



# The use and disclosure of health information

## Definitions of relevant words

The following words and expressions, which can be found in this guideline, are defined in section 4 of the *Information Act*.

**Health information** means:

- (a) personal information about:
  - (i) the physical or mental health of a person; or
  - (ii) a person's disability; or
  - (iii) the provision of a health service to a person, including the person's expressed wishes about that provision; or
- (b) personal information connected with the provision of a health service; or
- (c) personal information connected with the donation or intended donation by a person of his or her body parts, organs or bodily substances; or
- (d) personal information that is genetic information about a person in a form that is, or could be, predictive about the person's health at any time.

**Personal information** means government information from which a person's identity is apparent or is reasonably able to be ascertained.

**Government information** means a record held by or on behalf of a public sector organisation and includes personal information.

**A record** means recorded information in any form (including data in a computer system) that is required to be kept by a public sector organisation as evidence of the activities or operations of the organisation, and includes part of a record and a copy of a record.

**Sensitive information** is defined in the Act and includes **health information**.

The *Information Act* does not contain a definition of the word "research" for the purpose of this guideline. The definition contained in the National Statement on Ethical Conduct in Human Research has been adopted.

## Application of the *Information Act* to use and disclosure of health information for the purpose of research

The *Information Act* sets up a regime for the responsible handling of personal information. The IPPs are the principles laid down for collecting and handling personal information by public sector organisations and these are set out in Schedule 2 of the *Information Act*. If there is an inconsistency between an IPP and another provision of the Act, to the extent of the inconsistency, the other provision applies and the IPPs do not apply. A public sector organisation interferes with a person's privacy if the organisation contravenes an IPP.



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This guideline is produced by the Information Commissioner to promote awareness and understanding about the *Information Act*. It is not a substitute for the Act. You should read the relevant provisions of the Act to see how it applies in any particular case. Any views expressed in this guideline about how the Act works are preliminary only. In every case, the Commissioner is open to argument by a member of the public or a public sector organisation that a different view should be taken.