This brochure outlines the main features of the Australian Institute of Health and Welfare’s (AIHW’s) confidentiality and privacy regime for those who use AIHW information or provide data to the AIHW. More detailed information on the confidentiality provisions of the AIHW’s Act and policies and procedures is available on request or from the AIHW website.

Introduction

The AIHW is a major national agency set up by the Australian Government under the Australian Institute of Health and Welfare Act 1987 (Commonwealth) (AIHW Act) to provide reliable, regular and relevant information and statistics on Australia’s health and welfare.

The AIHW has an exemplary record of protecting the data in its custody. Stakeholders can be confident that the Institute uses its data to create authoritative reports that benefit the public, while protecting the confidentiality of the data and minimising any risk of inappropriate use and access. The AIHW is supported by strong privacy policies and processes, which are underpinned by the AIHW Act and the Privacy Act 1988 (Commonwealth) (Privacy Act).

In accordance with its privacy obligations, the AIHW does not release any information outside the Institute which could potentially identify an individual or organisation, except with the permission of the data provider or for research purposes that have been approved by its Ethics Committee and which do not contravene any conditions placed by data providers.

Legislative framework

AIHW Act

Individuals with access to information protected by the AIHW Act are subject to secrecy requirements imposed by section 29 of the Act. They include:

- all AIHW staff, including those employed short term
- staff of other bodies, including collaborating units, contracted to undertake specific functions on behalf of the AIHW
- anyone outside the Institute, such as a researcher (including people under the control of that person), who is given access to information concerning a person with the approval of the Ethics Committee.
Section 29 of the AIHW Act:

- Prohibits individuals who acquire information, either arising from their employment or doing any act or thing under an arrangement with the Institute, from disclosing (or making a record of) information concerning a person where the disclosure is not made for the purposes of the AIHW Act. The AIHW Ethics Committee has authority to allow the release of information protected by section 29 for research purposes.
- Prevents individuals in receipt of information acquired under the AIHW Act from being required to divulge or communicate that information to a court.
- Provides for criminal penalties, including fines of up to $2,000 or imprisonment or both, for those who breach section 29.

Information concerning a person is any information about individuals, organisations, bodies politic (where the body is the information provider) and deceased persons (where the deceased person is the information subject).

Employees are required to sign an Undertaking of Confidentiality when they begin employment with the AIHW. In the undertaking, staff:

- are advised of the confidentiality requirements imposed upon them by the AIHW Act and Privacy Act.
- acknowledge that they may be subject to criminal penalties for breaching legislative requirements.

Contractors and any other third parties who may come into contact with identifiable information are also required to sign confidentiality undertakings. Researchers who receive identifiable data after a successful Ethics Committee approval process are also required to sign confidentiality undertakings. Depending on the circumstances of a case, the Institute may also require individuals who have received potentially identifiable data (that is, data that could potentially be linked to other sets and thus create identifiable data) to sign confidentiality undertakings or undertakings that they will not engage in data linkage with the provided information.

Freedom of Information Act

Freedom of Information (FOI) requests received by the AIHW are made under the Freedom of Information Act 1982 (Commonwealth) (FOI Act). Section 38 of the FOI Act exempts information from disclosure under Freedom of Information law where that information is protected by section 29 of the AIHW Act. Consequently, the Institute does not release personally identifiable information in response to FOI requests.

The Privacy Act

Personal information held by the Institute is also protected by the provisions of the Privacy Act. This includes information from which the identity of a living individual (not an organisation) can be reasonably ascertained. The Privacy Act applies to all personal information held by the AIHW, whether acquired for the purposes of the Act or for other reasons (for example, personnel records).

The Privacy Act and associated Information Privacy Principles (IPPs) set the rules for the collection, storage, use and release of all personal information in the Commonwealth public sector. Among other things, the IPPs:

- outline the various consent and advice requirements that apply when agencies collect personal information.
- require that all reasonable security measures are taken to protect personal information against loss and unauthorised access.
- prohibit the use of personal information for other than the purpose for which it was collected unless consent has been given for broader use.
- prohibit the disclosure of personal information to any other person, body or agency, except in specified circumstances.

Where data are to be used for medical research, the IPPs may be waived in limited circumstances under section 95 of the Privacy Act. Specifically, the Institute and parties applying for the data must ensure compliance with the Guidelines under Section 95 of the Privacy Act, which have been produced by the National Health and Medical Research Council (NHMRC) and approved by the Privacy Commissioner. The guidelines are at http://www.comlaw.gov.au/Details/F2008B00225.

For more information on the Privacy Act and Information Privacy Principles, visit www.oaic.gov.au.

Governance arrangements

AIHW Ethics Committee

The AIHW Ethics Committee is established under section 16(1) of the AIHW Act. The Australian Institute of Health and Welfare (Ethics Committee) Regulations 1987 (Commonwealth) set out the committee’s functions and role.

The regulations give the committee the power to make determinations on the ethical acceptability of Institute activities, and activities engaged in by external parties under arrangements with the Institute. They also allow the committee to make decisions on the acceptability of the release of identifiable information to researchers for research purposes.

The committee reviews all projects, including internal proposals, involving the release of identifiable information, the creation of new data sets and data linkage. In forming its opinion, it considers relevant NHMRC guidelines, such as the National Statement on Ethical Conduct in Human Research.

Before agreeing to the release of identifiable data, data linkage activities or establishment of new data sets, the Ethics Committee requires that those involved with a project – both within and external to the AIHW – sign a confidentiality undertaking. This includes undertakings that:

- unit record files will not be matched, in whole or in part, with other information for the purposes of attempting to identify individuals, and that no other attempt to identify an individual will be made.
- the person/organisation receiving the information will not disclose or release the information to any other person or organisation, except as statistical information that does not identify an individual.

For more information, see www.aihw.gov.au/ethics.

Policies, protocols and practices

The AIHW has a range of policies and protocols to ensure the confidentiality of its data. These include data custody and access policies, and protocols that limit access to data collections and protect identifiable data from being accessed or released inappropriately.

Data custody and governance

The AIHW maintains a central register of its data holdings. Each data set has a data custodian (a senior staff member) who is responsible for authorising any access to data in accordance with the AIHW’s confidentiality and privacy requirements and any requirements of data providers. Access is granted only when required by a staff member to carry out their duties and with the approval of the data custodian.

Independent audits of AIHW data collections are conducted regularly to ensure that their integrity and security are maintained. These audit reports are considered by the Audit and Finance Committee of the AIHW Board and subsequently reported in summary form to the board.

All of the AIHW’s statistical outputs are subject to rigorous quality control to ensure that an individual or organisation is not likely to be able to be identified from the data.

For more information, see the AIHW Guidelines for the Custody of Data.