

## Feature chapter

### Security of data in the AIHW

Individual data collected by statistical agencies for statistical compilation, whether they refer to natural or legal persons, are to be strictly confidential and used exclusively for statistical purposes.<sup>1</sup>

Proposed new national privacy legislation (Privacy Amendment (Private Sector) Bill 2000) has been the catalyst for lively debate about the security of information. As well, the community is being included in discussions about opportunities to create an electronic health record.

The AIHW has an exemplary record of protecting the security of the data it holds on the health and welfare of Australians.

The functions of the Institute include the collection, coordination and production of health- and welfare-related statistics and information and the provision of assistance to other persons carrying out such activities, the development of specialised statistical standards and classifications relevant to health and welfare services and, subject to the confidentiality provisions in clause 29 of the *Australian Institute of Health and Welfare Act 1987*, allowing researchers access to statistics and other health-related information held by the Institute or its contractors.<sup>2</sup>

The security of data held by the AIHW has been of the highest importance since the Institute was established. The Explanatory Memorandum which accompanied the introduction of the *Australian Institute of Health Act 1987* stated: 'An important aspect of the Bill is the provision to protect the confidentiality of personal information given to the Institute. Any publications based on the work of the Institute may not identify an individual (including a deceased person...)'.<sup>3</sup> The Act's confidentiality provisions are contained in s. 29. (The AIHW Act is reproduced in Appendix 2.)

Section 29 of the AIHW Act prohibits disclosure or communication of information held under the Act even to a court of law. Section 29(4)(e) of the Act includes the requirement not to disclose even the source of the information or 'the whereabouts, existence or non-existence of a document concerning a person'. The AIHW can, however, inform the community that it is responsible for particular collections.

In 1988, the Commonwealth Privacy Act became law. The *Privacy Act 1988* contains 11 Information Privacy Principles (IPPs) which govern the conduct of Commonwealth agencies, including the AIHW, in their collection, management, use and disclosure of records containing personal information. The requirements of the Privacy Act supplement those of the AIHW Act.

In meeting its legislated function of producing health- and welfare-related statistics and information, the AIHW follows the high ethical standard laid down in its Act and the established practice of the Australian Bureau of Statistics (ABS) and the United Nations Principles of Official Statistics of protecting the security of personal information. However, the legislation allocates to the AIHW the additional function (subject to s. 29 of the Act) of enabling 'researchers to have access to health-related information and statistics held by the Institute or by bodies or persons with whom contracts or arrangements have been entered into by the Institute'. This function provides a degree of flexibility in addressing more complex requirements of researchers.

Section 95 of the Privacy Act contains special provision to allow access to identified or identifiable data for medical research purposes. Section 95 enables Commonwealth agencies to disclose identifiable records for medical research purposes in accordance with privacy guidelines issued by the National Health and Medical Research Council (NHMRC) and approved by the Privacy Commissioner. Essentially, s. 95 allows for an ethics committee to accept that an IPP may need to be breached to allow medical research to proceed, subject to a test of 'overriding public good'.

Section 16(1) of the AIHW Act requires the AIHW to appoint a Health Ethics Committee. The Committee may form an opinion as to the acceptability or otherwise, on ethical grounds, of health-related activities of the Institute or bodies with which it is associated. Section 29(c) of the Act permits release of data with the written authority of the Ethics Committee. The Australian Institute of Health Ethics Committee Regulations require the Committee in fulfilling its functions to have regard to any relevant ethical principles and standards formulated or adopted by the NHMRC (as prescribed by s. 95 of the Privacy Act). Following Ethics Committee consideration and clearance, researchers granted access by the Institute to identifiable data must sign an undertaking which binds them to the same confidentiality obligations (under s. 29 of the AIHW Act) as apply to AIHW staff. Monitoring compliance with the requirements of the undertaking is integral to the Ethics Committee process.

In the 5 years to June 2000, the Health Ethics Committee has agreed to 140 releases of records for research purposes, and has rejected 9 applications. The Ethics Committee also obtained amendments to a number of the proposals to ensure they met the guidelines.

The Ethics Committee's *Guidelines for the Preparation of Submissions for Ethical Clearance* have been endorsed by the Board and are available on the AIHW web site: at <http://www.aihw.gov.au>.

Fundamental to the AIHW's fulfilment of its mission are the processes established by national information agreements covering health, housing and community services

information. Each agreement contains a requirement that 'information will be collected, disseminated, used and secured in such a way as to protect the privacy and confidentiality of any individual to whom and/or organisation to which it may refer. In particular, all State/Territory and Commonwealth privacy and confidentiality legislation and established ethical guidelines and practices will be complied with under this Agreement.' The privacy provisions of the agreements require the parties to 'acknowledge that data holders will comply with the provision of the Commonwealth's *Privacy Act 1988* as amended, and any other Commonwealth, State or Territory legislation relevant to the confidentiality or privacy of the data'.<sup>4</sup> Thus data provided to the AIHW under the agreements is covered by an additional level of security.

The AIHW has a range of strategies in place to ensure the confidentiality of its data, including:

#### Undertaking of Confidentiality

Newly appointed Institute staff, including staff employed on a short-term basis and staff of collaborating units, are required to sign an Undertaking of Confidentiality as soon as they start work. Verbal and written information covering security of data is part of the induction material given to all new staff.

#### Datahound

There is a central corporate register of AIHW data holdings (Datahound) to support a standardised approach to their management.

#### Formal delegation of responsibilities to data custodians

Staff at Unit Head level have responsibility for particular data sets, including ensuring compliance with any security and confidentiality requirements. The Director has delegated responsibility for the custody of data holdings to those data custodians.

The Board has endorsed *Guidelines for Custody of AIHW Data* which describe the responsibilities of data custodians and the processes to be followed in carrying out those responsibilities. It also details the roles and responsibilities of other staff in monitoring data security and confidentiality. The Board requires regular data audits to ensure the soundness of practices regarding security of data.

#### Internet security

Because of its concerns regarding Internet security, the AIHW has adopted a cautious approach to incorporating use of the Internet into its working environment. The Institute's connection to the Internet follows Defence Signals Directorate (DSD) recommendations and has been certified by DSD to provide the high level of security required by the Institute.

## Policies and Guidelines

The Institute's Board and Executive have endorsed a range of policies and guidelines to ensure the secure handling of its data holdings:

- *AIHW Information Security and Privacy Policy and Procedures*
- *Guidelines for the Custody of AIHW Data*
- *Guidelines for the Preparation of Submissions for Ethical Clearance*
- *AIHW IT Security Manual*

The Information Privacy Principles and the requirements of the Australian Public Service Code of Conduct also apply.

The Institute will not permit its data to be linked for administrative or regulatory purposes.

The AIHW supports the principle that 'Official statistics provide an indispensable element in the information system of a democratic society, serving the Government, the economy and the public with data about the economic, demographic, social and environmental situation.'<sup>5</sup> Information collected by the AIHW is used only for statistical and research purposes. The framework of legislation, formal agreements, the requirements of its Board, and endorsed policies, principles, guidelines and practices guarantee the security of that information.

## Notes

1. Principle 6, Principles of Official Statistics, United Nations Statistical Commission, Report on the Special Session (11–15 April 1994), Economic and Social Council, Official Records, 1994, Supplement No. 9.
2. The Parliament of the Commonwealth of Australia, House of Representatives, Australian Institute of Health Bill 1987, Explanatory Memorandum (11264/87 Cat. No. 87 4080 2).
3. *ibid.*
4. National Housing Data Agreement, National Community Services Information Agreement, Agreement on National Indigenous Housing Information
5. Principle 1, Principles of Official Statistics, United Nations Statistical Commission, Report on the Special Session (11–15 April 1994), Economic and Social Council, Official Records, 1994, Supplement No. 9.