

Appendix 1: A history of data element changes

Presented below is specific information on the changes made to the data elements each year.

2009–10 changes

- *Country of birth*
 - change to using the 2nd edition of the Standard Australian Classification of Countries.

2008–09 changes

No changes were made.

2007–08 changes

The following changes were incorporated into version 13 of the *National health data dictionary* (HWI 88) and are a consequence of re-engineering the data elements for inclusion in AIHWs metadata repository METeOR. It is important to note that these changes do not alter the way data are collected for the AODTS–NMDS.

- *Australian state/territory identifier*
 - change of name from state/territory identifier to Australian state/territory identifier.

Supporting items

- *Cessation of treatment episode for alcohol and other drugs*
 - change from data element concept to glossary item
- *Commencement of treatment episode for alcohol and other drugs*
 - change from data element concept to glossary item
- *Episode of treatment for alcohol and other drugs*
 - change of name from Treatment episode for alcohol and other drugs to Episode of treatment for alcohol and other drugs
 - change from data element concept to object class
- *Service delivery outlet*
 - change from data element concept to object class

2006–07 changes

- Preferred language
 - change from using the ABS 2-digit ASCL codes to the 4-digit version 2 ASCL codes.

2005–06 changes

No changes were made.

2004–05 changes

The following changes were incorporated into the version 12 supplement of the *National health data dictionary* (HWI 72).

- *Establishment sector*
 - additions to Guide for use to clarify distinctions between definitions of Public and Private.
- *Main treatment type for alcohol and other drugs*
 - additions to Guide for use to assist clinicians coding to these Data domains.
- *Number of service contacts within a treatment episode for alcohol and other drugs*
 - this data element no longer used in AODTS–NMDS.
- *Other drugs of concern*
 - additions to Data domain and Guide for use describing two new supplementary ASCDC codes.
- *Other treatment type for alcohol and other drugs*
 - additions to Guide for use to assist clinicians coding to these Data domains.
- *Principal drug of concern*
 - additions to Data domain and Guide for use describing two new supplementary ASCDC codes.
- *Reason for cessation of treatment episode for alcohol and other drugs*
 - changes to Guide for use to clarify the correct use of the existing Data domains.
- *Source of referral to alcohol and other drug treatment service*
 - changes to Guide for use and refinement of Data domains to add clarity.
- *Treatment delivery setting for alcohol and other drugs*
 - rewording of Definition to clarify purpose of this Data element.
- *Treatment episode for alcohol and other drugs*
 - minor change to Definition and further clarification added to Guide for use.
- *Service contact*
 - this data element concept no longer used in AODTS–NMDS.

2003–04 changes

The following changes were incorporated into version 12 of the *National Health Data Dictionary* (HWI 43).

- *State/territory identifier*
 - change of name from State identifier to State/territory identifier.
- *Sex*
 - change to Data domain.

- *Indigenous status*
 - change to Definition and Context to more accurately reflect what is being collected
 - change to Data domain and Guide for use to bring more clarity to the codes used
 - change to Collection methods, Source document and Comments for clarification purposes.
- *Client type – alcohol and other drug treatment services:*
 - change to Definition and Context to reflect treatment episode
 - removal of code three in Data domain
 - modification to Guide for use and Collection methods to ensure consistency.
- *Injecting drug use:*
 - revision of Data domain
 - additional information included in Collection methods and Related data.
- *Principal drug of concern:*
 - revised Data definition, Data domain, and Guide for use
 - additional information added to Collection methods and Related data.
- *Other drugs of concern*
 - slight change to title and revised Data definition, Data domain, and Guide for use additional information added to Collection methods and Related data.
- *Source of referral to alcohol and other drug treatment service*
 - the Data domain and the Guide for use revised to more accurately capture the most common sources of referral and to make the categories more mutually exclusive
 - the separation of codes into Agency and Non-agency categories reflects the approach taken in the NCSDD data element 'Referral source'.
- *Service delivery outlet*
 - a new data element concept has been developed and it is designed to be generic so that it can apply to other community health areas, while still adequately covering AODTS outlets.
- *Geographic location of service delivery outlet*
 - a new derived data element has been developed to provide the geographic location of each AODTS outlet
 - this data element has also been designed to be generic so that it can apply to other community health areas
 - it is intended to function as a replacement for Geographical location of establishment in the AODTS-NMDS.

2002–03 changes

The following changes were incorporated into version 11 of the *National Health Data Dictionary* (HWI 36).

- *Client type – alcohol and other drug treatment services*
 - change of title to include term – alcohol and other drug treatment services
 - minor change made to context
 - change to Data domain with the removal of Code 9
 - change to Collection methods
 - inclusion of Related data.
- *Number of service contacts within a treatment episode for alcohol and other drugs*
 - change to Definition
 - change to Guide for use
 - change to Collection methods.

2001–02 changes

The following changes were incorporated into version 10 of the National Health Data Dictionary (HWI 30)

- *Establishment identifier*
- *Establishment number*
- *Establishment sector*
- *Country of birth (now uses latest ABS classification)*
- *Date of commencement of treatment episode for alcohol and other drugs.*

Appendix 2: Members of the IGCD AODTS– NMDS Working Group

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Current April 2009

Appendix 3: Australian Standard Geographical Classification

The Australian Standard Geographical Classification (ASGC) is a tool for collecting and disseminating geographically classified statistics. These are statistics with a 'where' dimension. The classification has been updated annually during the period the AODTS-NMDS has been operating. The ASGC is a hierarchical classification system consisting of six interrelated classification structures:

- Main Structure
- Local Government Area Structure
- Statistical District Structure
- Statistical Region Structure
- Urban Centre/Locality Structure
- Section of state Structure.

These structures are hierarchical, and are made up of geographical spatial units. The statistical local area (SLA) is a general-purpose spatial unit. It is the base unit used to collect and disseminate statistics other than those collected from the population censuses. In non-census years, the SLA is the smallest unit defined in the ASGC. In census years, a SLA consists of one or more whole census collection district. In aggregate, SLAs cover the whole of Australia without gaps or overlaps.

SLAs are identified by four-digit codes. These codes are unique only within a state or territory. For unique Australia-wide identification the four-digit SLA code must be preceded by the unique one-digit state/territory code. For example:

Barraba 10400 (in New South Wales) (S/T code 1)

Barcaldine 30400 (in Queensland) (S/T code 3)

Note that for the data element *Geographical location of service delivery outlet* the location is reported using a five-digit code, which comprise the unique one-digit state/territory code and the four-digit SLA.

The correct version of the ASGC to use for the 2009–10 AODTS-NMDS data is 2008 (please advise the AIHW if you use a different year).

The National Localities Index (NLI) was previously used to identify a locality or address in Australia to an SLA. This index has not been updated beyond the 2007 version of the ASGC. Instead, the ABS will provide a 'Locality to SLA Correspondence'. Check the ABS website for details or contact the AIHW for assistance.

The ABS has reviewed the ASGC and intends to replace it with a new classification, the Australian Statistical Geography Standard. The implementation of the ASGS will begin in 2011.

Appendix 4: Standard Australian Classification of Countries

The Standard Australian Classification of Countries (SACC) has been developed by the Australian Bureau of Statistics (ABS) for use in the collection, storage and dissemination of all Australian statistical data classified by country. It provides a single classification framework for both population and economic statistics. Unlike the ASGC, the SACC is not updated annually, but only as necessary. The latest version (at the time of writing) is the Second Edition released on 19 May 2008.

The SACC is a classification of countries essentially based on the concept of geographic proximity. In its main structure it groups neighbouring countries into progressively broader geographic areas on the basis of their similarity in terms of social, cultural, economic and political characteristics.

The SACC has a three-level hierarchical structure. The third, and most detailed level (used in the AODTS-NMDS), consists of the base units, which are countries. The classification consists of 244 third-level units including five 'not elsewhere classified' categories, which contain entities that are not listed separately in the classification. A four-digit code represents each country. The second level of the main classification structure comprises 27 minor groups, which are groups of neighbouring countries similar in terms of social, cultural, economic and political characteristics. Each minor group lies wholly within the boundaries of a geographic continent. A two-digit code represents each minor group. The first, and most general level of the classification structure comprises nine major groups which are formed by aggregating geographically proximate minor groups. A single-digit code represents each major group.

The 2009-10 AODTS-NMDS collection period will be the first to use the Second Edition of the SACC. Based on previous years' data, the AIHW has identified the following codes that were valid for the first edition of the SACC but will no longer be valid in the second edition (for the 2009-10 collection).

- 1100 - Australia (includes External Territories), nfd
- 2101 - Channel Islands
- 3213 - Yugoslavia, Federal Republic of
- 4199 - North Africa, nec
- 7200 - Central Asia (Caucasus)

There may also be other codes that need updating, depending on each jurisdiction's data.

Correspondences between the first and second editions of the SACC are available on the ABS website for those jurisdictions needing assistance with new codes in the 2009-10 AODTS-NMDS collection.

Appendix 5: Australian Standard Classification of Languages

The ABS developed the Australian Standard Classification of Languages (ASCL) in response to a wide community interest in the language use of the Australian population and to meet a growing statistical and administrative need. The Australian Standard Classification of Languages is intended for use whenever demographic, labour and social statistics are classified by language. The ABS uses the classification in its own statistical work, for example, in the Census of Population and Housing. The ABS urges its use by other government agencies, community groups, and academic and private sector organisations collecting, analysing, or using information relating to language use. This will improve the comparability of data from these sources.

In the ASCL, languages are grouped into progressively broader categories on the basis of their evolution from a common ancestral language, and on the basis of the geographic proximity of areas where particular languages originated. This results in a classification that is useful for the purposes of Australian social analysis by allowing populations of language speakers that are similar in terms of the ethnic and cultural origin to be grouped in a manner that is intuitively meaningful in the Australian context.

The ASCL has a three-level hierarchical structure. One-, two- and four-digit codes are assigned to the first-, second- and third-level units of the classification respectively. The first digit identifies the Broad Group in which each Language or Narrow Group is contained. The first two digits taken together identify the Narrow Group in which each Language is contained. The four-digit codes represent each of the Language or third-level units. The Australian Standard Classification of Languages Second Edition (2005-06) is the latest release at the time of writing. This version should be used for the 2009-10 collection period.

Appendix 6: Australian Standard Classification of Drugs of Concern

The Australian Standard Classification of Drugs of Concern (ASCDC) is the Australian statistical standard for classifying data relating to drugs that are considered to be of concern in Australian society. The ASCDC is essentially a classification of types of drugs of concern based on their chemical structure, mechanism of action and effect on physiological activity. The classification of type of drug is described as the 'main classification structure' throughout the ASCDC document. Because many collectors and users of drug-related data also require information on the form in which drugs are encountered and the method of drug use, the ASCDC also includes classifications for these elements of drug-related information. The ASCDC is intended for use in the collection, classification, storage and dissemination of all statistical, administrative and service delivery data relating to drugs of concern.

The ASCDC will assist government planners, policy analysts and social researchers by providing a consistent framework for the classification of drug-related data. The use of the standard definitions, classifications and coding procedures detailed in the ASCDC will help to ensure the comparability and compatibility of data derived from a range of different statistical, administrative and service provision systems at both the state and national level.

The main classification of the ASCDC has a three-level hierarchical structure.

The third and most detailed level of the classification consists of the base units which are separately identified drugs of concern, aggregate groups of drugs of concern and residual categories of drugs of concern. The classification comprises 153 third-level units including 10 aggregate groups of drugs and 32 residual 'not elsewhere classified' (nec) categories.

The 10 third-level aggregate units comprise drugs that do not support individual identification but which are aggregated to form single base-level units as they are chemically similar and, when grouped, represent useful categories.

The 32 nec categories contain drugs which are not sufficiently significant, in the current Australian context, to support separate identification or representation as an aggregate base-level unit. All drugs which have been identified as drugs of concern, but which are not listed separately or contained within one of the aggregate base-level units, are included in the nec category of the narrow group to which they relate.

The second level of the classification consists of 33 narrow groups that contain base-level units that are similar in terms of the classification criteria. Included in the 33 narrow groups are 6 residual 'Other' categories. These residual categories contain base-level units that do not belong in any of the alternative narrow groups contained within the broad group on the basis of the classification criteria.

The first and most general level of the classification comprises 7 broad groups. The broad groups are formed, in the main, by aggregating narrow groups that are broadly similar in terms of the classification criteria. The classification has one 'Miscellaneous' broad group which comprises narrow groups of drugs which were considered to be of sufficient importance to be included in the classification structure but which do not fit into any of the other 6 broad groups on the basis of the classification criteria.

TYPE OF DRUG CLASSIFICATION: BROAD GROUPS, NARROW GROUPS AND DRUGS OF CONCERN

The main classification structure is presented below. For detailed information, supplementary codes and the full version of the coding index, see Australian Standard Classification of Drugs of Concern (ABS 2000).

- 1 ANALGESICS
 - 11 Organic Opiate Analgesics
 - 1101 Codeine
 - 1102 Morphine
 - 1199 Organic Opiate Analgesics, not elsewhere classified.
 - 12 Semisynthetic Opioid Analgesics
 - 1201 Buprenorphine
 - 1202 Heroin
 - 1203 Oxycodone
 - 1299 Semisynthetic Opioid Analgesics, n.e.c.
 - 13 Synthetic Opioid Analgesics
 - 1301 Fentanyl
 - 1302 Fentanyl analogues
 - 1303 Levomethadyl acetate hydrochloride
 - 1304 Meperidine analogues
 - 1305 Methadone
 - 1306 Pethidine
 - 1399 Synthetic Opioid Analgesics, n.e.c.
 - 14 Non Opioid Analgesics
 - 1401 Acetylsalicylic acid
 - 1402 Paracetamol
 - 1499 Non Opioid Analgesics, n.e.c.
- 2 SEDATIVES AND HYPNOTICS
 - 21 Alcohols
 - 2101 Ethanol
 - 2102 Methanol
 - 2199 Alcohols, n.e.c.

22	Anaesthetics
	2201 Gamma-hydroxybutyrate
	2202 Ketamine
	2203 Nitrous oxide
	2204 Phencyclidine
	2299 Anaesthetics, n.e.c.
23	Barbiturates
	2301 Amylobarbitone
	2302 Methylphenobarbitone
	2303 Phenobarbitone
	2399 Barbiturates, n.e.c.
24	Benzodiazepines
	2401 Alprazolam
	2402 Clonazepam
	2403 Diazepam
	2404 Flunitrazepam
	2405 Lorazepam
	2406 Nitrazepam
	2407 Oxazepam
	2408 Temazepam
	2499 Benzodiazepines, n.e.c.
29	Other Sedatives and Hypnotics
	2901 Chlormethiazole
	2902 Kava lactones
	2903 Zopiclone
	2999 Other Sedatives and Hypnotics, n.e.c.
3	STIMULANTS AND HALLUCINOGENS
31	Amphetamines
	3101 Amphetamine
	3102 Dexamphetamine
	3103 Methamphetamine
	3199 Amphetamines, n.e.c.
32	Cannabinoids
	3201 Cannabinoids

33	Ephedra Alkaloids
	3301 Ephedrine
	3302 Norephedrine
	3303 Pseudoephedrine
	3399 Ephedra Alkaloids, n.e.c.
34	Phenethylamines
	3401 DOB
	3402 DOM
	3403 MDA
	3404 MDEA
	3405 MDMA
	3406 Mescaline
	3407 PMA
	3408 TMA
	3499 Phenethylamines, n.e.c.
35	Tryptamines
	3501 Atropinic alkaloids
	3502 Diethyltryptamine
	3503 Dimethyltryptamine
	3504 Lysergic acid diethylamide
	3505 Psilocybin
	3599 Tryptamines, n.e.c.
36	Volatile Nitrates
	3601 Amyl nitrate
	3602 Butyl nitrate
	3699 Volatile Nitrates, n.e.c.
39	Other Stimulants and Hallucinogens
	3901 Caffeine
	3902 Cathinone
	3903 Cocaine
	3904 Methcathinone
	3905 Methylphenidate
	3906 Nicotine
	3999 Other Stimulants and Hallucinogens, n.e.c.

- 41 Anabolic Androgenic Steroids
 - 4101 Boldenone
 - 4102 Dehydroepiandrosterone
 - 4103 Fluoxymesterone
 - 4104 Mesterolone
 - 4105 Methandriol
 - 4106 Methenolone
 - 4107 Nandrolone
 - 4108 Oxandrolone
 - 4111 Stanozolol
 - 4112 Testosterone
 - 4199 Anabolic Androgenic Steroids, n.e.c.
- 42 Beta2 Agonists
 - 4201 Eformoterol
 - 4202 Fenoterol
 - 4203 Salbutamol
 - 4299 Beta2 Agonists, n.e.c.
- 43 Peptide Hormones, Mimetics and Analogues
 - 4301 Chorionic gonadotrophin
 - 4302 Corticotrophin
 - 4303 Erythropoietin
 - 4304 Growth hormone
 - 4305 Insulin
 - 4399 Peptide Hormones, Mimetics and Analogues, n.e.c.
- 49 Other Anabolic Agents and Selected Hormones
 - 4901 Sulfonylurea hypoglycaemic agents
 - 4902 Tamoxifen
 - 4903 Thyroxine
 - 4999 Other Anabolic Agents and Selected Hormones, n.e.c.

- 51 Monoamine Oxidase Inhibitors
 - 5101 Moclobemide
 - 5102 Phenelzine
 - 5103 Tranylcypromine
 - 5199 Monoamine Oxidase Inhibitors, n.e.c.
- 52 Phenothiazines
 - 5201 Chlorpromazine
 - 5202 Fluphenazine
 - 5203 Pericyazine
 - 5204 Thioridazine
 - 5205 Trifluoperazin
 - 5299 Phenothiazines, n.e.c.
- 53 Serotonin Reuptake Inhibitors
 - 5301 Citalopram
 - 5302 Fluoxetine
 - 5303 Paroxetine
 - 5304 Sertraline
 - 5399 Serotonin Reuptake Inhibitors, n.e.c.
- 54 Thioxanthenes
 - 5401 Flupenthixol
 - 5402 Thiothixene
 - 5499 Thioxanthenes, n.e.c.
- 55 Tricyclic Antidepressants
 - 5501 Amitriptyline
 - 5502 Clomipramine
 - 5503 Dothiepin
 - 5504 Doxepin
 - 5505 Nortriptyline
 - 5599 Tricyclic Antidepressants, n.e.c.
- 59 Other Antidepressants and Antipsychotics
 - 5901 Butyrophenones
 - 5902 Lithium
 - 5903 Mianserin
 - 5999 Other Antidepressants and Antipsychotics, n.e.c.

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VOLATILE SOLVENTS

- 61 Aliphatic Hydrocarbons
 - 6101 Butane
 - 6102 Petroleum
 - 6103 Propane
 - 6199 Aliphatic Hydrocarbons, n.e.c.
- 62 Aromatic Hydrocarbons
 - 6201 Toluene
 - 6202 Xylene
 - 6299 Aromatic Hydrocarbons, n.e.c.
- 63 Halogenated Hydrocarbons
 - 6301 Bromochlorodifluoromethane
 - 6302 Chloroform
 - 6303 Tetrachloroethylene
 - 6304 Trichloroethane
 - 6305 Trichloroethylene
 - 6399 Halogenated Hydrocarbons, n.e.c.
- 69 Other Volatile Solvents
 - 6901 Acetone
 - 6902 Ethyl acetate
 - 6999 Other Volatile Solvents, n.e.c.

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MISCELLANEOUS DRUGS OF CONCERN

- 91 Diuretics
 - 9101 Antikaliuretics
 - 9102 Loop diuretics
 - 9103 Thiazides
 - 9199 Diuretics, n.e.c.
- 92 Opioid Antagonists
 - 9201 Naloxone
 - 9202 Naltrexone
 - 9299 Opioid Antagonists, n.e.c.
- 99 Other Drugs of Concern

Appendix 7: Steps for protecting privacy

The following extract from the Office of the Privacy Commissioner's website summarises the privacy obligations of organisations such as drug treatment agencies. For more detailed information please refer directly to the website.

1. Only collect information that is necessary.

Make sure individuals know what personal information your organisation or agency collects and why. Consider if each piece of information is necessary for any of the functions or activities of the organisation or agency and if the information is required in the circumstances. It may be the case that in some circumstances you can carry out your activities without collecting personal information, allowing individuals to interact with your organisation anonymously.

2. Do not collect personal information about an individual just because you think that information may come in handy later.

You should only collect information that is necessary at the time of collection, not information that may become necessary or useful at a later date. If the need arises later, collect the information then.

3. Tell people what you are going to do with the personal information you collect about them.

You should let individuals know why you need to collect the information, how you plan to use it and if you intend disclosing it. You should provide details about how they can contact you and, if they want to, how they can gain access to their personal information.

4. Consider whether you should be using personal information for a particular purpose.

Organisations often begin using personal information for a secondary purpose unrelated to the main purpose they collected the information. Unless you have consent from the individual concerned or authorisation under law, you should normally only use personal information if it is related to the purpose you collected it for and within the reasonable expectations of the individual.

5. Consider whether you need to disclose personal information.

In some cases, organisations and agencies disclose personal information that they do not need to disclose or disclose information without thinking about whether the disclosure is authorised. Consider whether you can achieve your purpose without disclosing personal information. It is often best practice to seek consent from the individual concerned if you wish to disclose their personal information for a reason beyond the reason for which you collected it. The Privacy Act allows disclosures in some circumstances.

6. If people ask, give them access to the personal information you hold about them.

Organisations and Australian and ACT Government agencies have a general duty to provide individuals with access to their personal information. You should be as open as possible by providing individuals with access to their own personal information in the form they request. If you wish to deny an individual access to personal information you should provide reasons, consistent with the Privacy Act, as soon as you can. Agencies should also be

mindful of their obligations under the Freedom of Information Act 1988 (Cth) which also provides some grounds for denying access.

7. Keep personal information secure.

It is important that you keep personal information safe and secure from unauthorised access, modification or disclosure and also against misuse and loss. The steps you should take should be proportionate to the sensitivity of the information you hold. Methods might include checking that all personal information has been removed from computers before you sell them, installing firewalls, cookie removers and anti-virus scanners on work IT systems, keeping hard copy files in properly secured cabinets, training staff in privacy procedures and allowing file access to staff on a 'need to know' basis only. You could also regularly monitor your information handling practices to ensure they are secure and consider the adequacy of existing security measures. Depending on the size of the organisation and the information it collects, you may wish to consider having an external privacy audit conducted.

8. Don't keep information you no longer need or are no longer required to retain.

If you no longer need personal information and there is no law that compels you to retain the information, then destroy it. You should shred, pulp or destroy the paper on which the personal information is recorded, place the files in a security garbage bin and securely delete any electronic record or file from computer systems to ensure it cannot be retrieved.

9. Keep personal information accurate and up to date.

Personal information can change. This is why you need to take reasonable steps to keep the personal information your organisation or agency holds current. If the personal information of someone changes amend your records to reflect those changes and make sure both hard copy and electronic files are updated. If you know that some personal information is likely to change regularly, then periodically go through the files to ensure the records are accurate and up to date.

10. Consider making someone in your organisation or agency responsible for privacy.

This could be a designated person (often called a Privacy Contact Officer or Chief Privacy Officer) who is aware of your organisation or agency's responsibilities under the Privacy Act and who is willing and able to handle complaints and enquiries about the personal information handling practices of your organisation or agency. The person may also be responsible for implementing a complaints handling process, staff training program and promoting Privacy Act compliance.

Source: <www.privacy.gov.au/publications/ten_steps/ten_steps_org.pdf>. Accessed 19/02/09.

Appendix 8: Privacy and the AIHW

The AIHW's functions are to:

- identify and meet the information needs of government and the community to enable them to make informed decisions to improve the health and welfare of Australians
- provide authoritative and timely information to the Australian Government, state and territory governments and non-government clients through the collection, analysis and dissemination of national health, welfare, housing assistance and community services data, and
- develop, maintain and promote, in conjunction with stakeholders, information standards for health, welfare, housing assistance and community services data.

As a Australian Government agency, the AIHW must comply with the IPPs set out in the *Privacy Act 1988*. The AIHW is also bound by its own legislation, the *Australian Institute of Health and Welfare Act 1987*, which contains a section on confidentiality (s29).

In summary s29 states:

- A person who holds any information concerning another person, due to their employment at the AIHW, or due to the fact they are performing a duty or function for the AIHW, or doing any act as a result of any arrangement entered into by the AIHW, shall not directly or indirectly:
 - divulge that information to any person
 - give a document containing that information to any person
 - be required to divulge that information to a court.
- Nothing prohibits a person holding information concerning another person (as stated above) from:
 - divulging information to the Minister if it does not identify the information subject
 - divulging information to the information provider
 - divulging information to a person specified in writing by the Ethics Committee if to do so is not contrary to the written terms upon which the information was divulged initially by the information provider (only applies to health related statistical information)
 - publishing conclusions based on statistics derived from the work of the AIHW if to do so is not contrary to written terms upon which the information provider divulged the information directly to the AIHW.

AIHW policy and procedures on information security and privacy

(Excerpt from *AIHW Information Security and Privacy Policy and Procedures* document).

The provisions of the *Privacy Act 1988* and the Information Privacy Principles establish the framework for the collection, storage, use and release of all personal information in the public sector. The AIHW policy complies with the requirements of the *Privacy Act 1988* and in addition, covers issues of specific relevance to the AIHW, including s29 on confidentiality contained in the *AIHW Act 1987*.

Privacy ethos

1. All AIHW and collaborating unit staff must have a knowledge of section 29 and a good understanding, in relation to the work they do, of the implications of:
 - The Australian Institute of Health and Welfare Act 1987, section 29
 - The Information Privacy Principles.
2. All AIHW and collaborating unit staff must sign the Institute's *Undertaking of confidentiality – Employees*.
3. The Institute will ensure that its various collaborating units maintain a consistent privacy and security ethos.
4. All work performed by consultants, contractors, seconded staff, visiting fellows and students working under supervision of the Institute which involves access to information collected under the AIHW Act and other identifiable information, must be authorised by contracts which impose information and privacy security requirements at least as stringent as those applying to Institute employees.

Information gathering and receipt

5. Information may only be collected and held for the purpose of AIHW activities.
6. Identifiable information may only be collected and held with the approval of the Institute's Ethics Committee.
7. Any information collected must be limited to that directly relevant to the aims and objectives of an approved project.
8. All data holdings containing identifiable information must be recorded and managed in accordance with the Institute's *Guidelines for custody of AIHW data*.
9. Except as outlined in paragraphs 10 and 11 below, the consent of information subjects for the use of their information should be obtained when the identifying information is in the form of identified records held indefinitely on registers used to contact the information source for research purpose (all such research must be approved by the Ethics Committee).
10. Otherwise, consent should not be required provided that appropriate guarantees are given that the information will be handled in a secure environment, the public good benefits of the research are clear and its use will have no impact on those individuals whose information is being used. As far as is possible, an opt out option should be provided.
11. Regardless of whether consent needs to be obtained, information subjects should be advised, by whatever mechanism is appropriate, why their information is being

collected, how it is to be used, who will be using it, the type of access that will occur and how it will be protected.

Information storage, retention and destruction

12. Data must be stored to meet the storage and archival requirements of the National Archives of Australia, and in accordance with the Institute's *Guidelines for custody of AIHW data*.
13. Data custodians are responsible for ensuring their data holdings are protected from unauthorised access, alteration or loss.
14. Paper-based identifiable information must be kept securely locked away when not in use. The minimum requirement is that, outside normal working hours, the information must be stored in locked drawers or cabinets.
15. Particular care must be taken regarding the print out and photocopying of paper-based information. Users must stand by printers and photocopiers while this material is being printed or copied.
16. Information users must follow normal practice for the use of IT systems (see the IT Security Manual) to ensure the security and privacy of in-confidence information stored on computer systems.
17. Identifiable information must not be copied to or held on workstation hard disks.
18. Wherever possible, identifiable information and associated attribute information should each be stored separately in databases to minimise any risk from unauthorised access.
19. Identifiable information must not be copied or removed from Institute premises without specific approval from the relevant Data Custodian.
20. Normally, data holdings used in support of the Institute's Work Program must be retained for a specified period in order to allow later verification of the research, and in accordance with undertakings given to data providers.
21. Decisions regarding retention of databases lies with Data Custodians, and must be taken in accordance with the Institute's *Guidelines for custody of AIHW data*.
22. The Institute will maintain a physical security system, which provides reasonable and properly enforced measures to protect both staff and its repositories of personal information.

Information transmission

23. If identifiable information is sent by post, registered or certified mail or safe hand delivery must be used.
24. The electronic transmission of identifiable information must apply procedures for the certification of transmission and the encryption of information which are at least commensurate with that used for transmission by post.

Information retrieval and use within the Institute

25. Rather than treating ownership (of data) as an indivisible entitlement, it should be treated as a 'basket of rights' in relation to the information concerned, and there

should be acceptance that different parties may have different entitlements. The 'basket of rights' would include the right to do the following, for statistical purposes:

- gain access to information
 - amend the information
 - use the information
 - disclose the information
 - control who can do these things and under what conditions.
26. Data Custodians may approve use, within the Institute, of identifiable information for purposes consistent with those for which it was collected, in accordance with the Institute's *Guidelines for the custody of AIHW data*.
27. In published tables, the amount of information in small cells should be reduced to minimise the potential for identification. Aggregations of data with small cell sizes, which may enable inferences about or identification of individual entities, should not be published.

Conditions applying to data linkage projects

28. Ethics Committee approval is required for record linkage projects. Before granting such approval, the Committee must be satisfied that:
- the 'public good' benefits to be reasonably expected from them will be significant
 - 'best practice' procedures will be adopted throughout the conduct of the studies.
29. It is not necessary for the Institute to obtain the consent of information subjects for the use of their information in record linkage studies if:
- their identity is irrelevant (except to facilitate the linkage process)
 - the objective is data analysis
 - no administrative action will be taken in relation to the individuals concerned.
30. The Institute will not permit its data to be linked for client management or regulatory purposes.

Information release and disclosure outside the Institute

31. The AIHW Act allows the Institute to release or disclose identifiable health information to third parties, subject to s29 of the AIHW Act.
32. Requests for access to or release of identifiable information from a database must be in writing. Any person or organisation wishing to access an Institute database for research purposes should prepare an adequate written proposal for the study following the Institute's *Guidelines for the preparation of submissions for ethical clearance*.
33. Any requests for release or disclosure of identifiable information must be scrutinised by the appropriate Data Custodian in accordance with the Institute's *Guidelines for custody of AIHW data*.
34. If the information requested can be provided under the information provider's constraints, and its release would not contravene s29 of the Act, but the information

cannot be provided under an existing Ethics Committee approval, then an opinion must be obtained from the Committee. In this case the appropriate Data Custodian should provide the information requested with documentation necessary for submissions to the Committee.

35. The Institute should endeavour to identify potential disclosure requirements at the commencement of a project and, where appropriate, to build these into the agreements with information providers and into submissions to the Institute's Ethics Committee. Such action can be used to obtain information provider and ethical approval in advance, thereby streamlining the release process.
36. Staff should take particular care to ensure that no release, publication or public presentation or discussion of individual records or results of research could breach the requirements of this Policy. Results shown in tables with small cell values often need special attention (see paragraph 25).

The Institute in an agency role

37. Data providers, such as Registrars of Births, Deaths and Marriages in states and territories, supply data to the Institute for the Institute's purposes. The Institute reformats these data and produces national data sets. These data sets may be returned to the Registrars.
38. Should Registrars wish to furnish the national lists of births and deaths to other agencies for their own purposes, Institute staff may assist the Registrars with these tasks, acting as the Registrar's agent.
39. At all times, it must be clear that the work is being undertaken as an agent of the Registrars.

Monitoring and audits

40. The Institute's Board requires that security audits be carried out as part of the Institute's audit program.
41. Compliance and quality control will be assessed by routine data audits. Results will be reported to the Board's Audit and Finance Committee.

Breaches and sanctions

42. The Institute relies on the diligence of all staff in preventing breaches of information security.
43. If a breach is thought to have occurred it should be reported immediately to the Director through normal divisional/collaborating unit reporting channels.
44. The Director may appoint a person to investigate the circumstances of a suspected breach. If a breach is proven the Director may initiate disciplinary or legal action under the relevant legislation.
45. Details of suspected breaches will be treated as STAFF-IN-CONFIDENCE information at all times.
46. The Institute's Fraud Control Guidelines and Plan (available to staff on the Intranet) are also relevant.

AIHW Ethics Committee

(Excerpt from Guidelines for the preparation of submissions for ethical clearance document)

The AIHW Ethics Committee (appointed under s16(1) of the Australian Institute of Health and Welfare Act) may, under strict conditions, allow the release of information to researchers proposing studies judged to have scientific merit and that meet the required data confidentiality standards. The following criteria upon which the submissions will be evaluated include:

Purpose of the proposal

- The Committee will only approve use of information for research purposes. A key criterion is that the research output is to be put in the public domain. Regulatory, legal and administrative purposes are not acceptable, unless there is an overriding public good and no detriment to the information subject.

Research focus of the proposal

- The Committee will only approve research that has recognition of relevant ethical considerations, including social and cultural factors, by all involved in the conduct of the activity, and their commitment to upholding ethical standards.
- The Committee will also take into consideration a project's overall value to society and the predicted outcome of activities in relation to possible risks such as the comfort and privacy of information subjects.

Scientific validity of the proposal

- The Institute has the responsibility only to submit to the Committee proposals that it considers as scientifically valid.
- The Committee has the right to raise queries about scientific validity if it sees fit, and to refer them to the Institute.
- The submission should be signed off by the responsible Data Custodian.

Approval by the applicant's own institutional ethics committee

- All applications other than applications by the Institute before the Committee need to be approved by the applicant's own institutional ethics committee.

Organisational framework of the researcher

- Consideration will be given to whether there is an established accountability mechanism, (e.g. an institutional ethics committee), that can impose sanctions if necessary.
- The Committee may approve an agreement between the Institute and other organisations for the use of the Institute's data in classes of research projects so that the organisation can release identifiable AIHW data subject to the approval of its own Ethics Committee.

Credentials and technical competence of the researcher

- The qualifications, competence and expertise of personnel engaged in the activities will be considered.

Extent to which privacy and consent issues have been addressed

- The Committee will take into account the privacy provisions contained in *Minding our own* business which is the privacy protocol for Australian Government agencies in the Northern Territory handling personal information of Aboriginal and Torres Strait Islander peoples.
- The Committee will only approve research projects where the protection of the wellbeing and privacy of the subjects, and also of persons who collect, communicate, work with or have access to the information about them is assured.
- The Committee will be mindful of legal requirements, in particular the pertinent sections of the AIHW Act, and the *Privacy Act 1988* and the current *Guidelines for the protection of privacy in the conduct of medical research* as approved by the Privacy Commissioner.
- If further information is needed from information subjects, the Committee will seek their consent to an approach by the principal investigator.
- The Committee will not require informed consent where this is not necessary.

Adequacy of researcher's data security protection mechanisms

- The Committee must be assured that the maintenance of adequate degrees of confidentiality of information about identifiable persons (and, in certain cases, of groups of persons) is enforced.
- The Committee must also be assured of the physical security of data, covering the security access system to the building, storage rules for hard copy of data, computer security procedures and the disposal of data when no longer required.

Commitment to, and method of publishing results of research

- The Committee considers it important that the results of research are disseminated to the appropriate groups, communities and individuals. Therefore, the dissemination plan will be carefully considered in each submission. The Committee requests that a copy of the published work be made available to it and may also request that a summary of the research be made available on the AIHW website.
- The Committee does not give approval to projects where there is no intention to publish results. The 'Undertaking' signed by researchers, allowing for legal disclosure of information by the AIHW, specifies that the AIHW must be acknowledged as the source of data in any publication, and that a copy of any published material must be supplied to the AIHW.

Transfer of data out of Australia

- This will not normally be approved, but can be on a case-by-case basis where the overseas data holder and their organisations are of undoubted quality.

For more information on the AIHW Ethics Committee, refer to:

<www.aihw.gov.au/committees/ethics/index.cfm>.

Data Custodians at the AIHW

(Taken from *Guidelines for custody of AIHW data*)

Whilst all staff at the AIHW share responsibility for maintaining the security of AIHW data, data custodians have overall responsibility for the security of specified data collections. Once the data custodian delegation instrument is signed, the custodians assume the responsibility of the director in regard to the data in their custody. The relevant unit head is given the responsibility of data custodian. The custodianship is vested in a position rather than a named person.

Data custodians ensure that data holdings within their unit are properly documented, maintained and controlled, and ensure an appropriate level of consultation with other units regarding the data resources within the Institute. This includes responsibility for:

- recognising and abiding by all limitations placed on data
- maintaining up-to-date documentation, including data catalogue entries, of the content and format of the data holding and of the constraints applying to its use and/or release
- authorising and recording users of the data within the AIHW, and providing advice and assistance to new users on any constraints which apply
- assisting potential users wishing to access identifiable data in the preparation of their proposals for submission to the Health and Welfare Ethics Committees (*see Guidelines for the preparation of submissions for ethical clearance*)
- following Ethics Committee approval, arranging for the secure transfer of data to recipients in accordance with constraints imposed regarding the use of data. Working with the Ethics Committee Secretariat with their monitoring processes
- ensuring, when required, the appropriate destruction (or return to the original information provider) of the data holding.

Appendix 9: National Aboriginal and Torres Strait Islander Health Data Principles

All organisations with significant responsibilities in Aboriginal and Torres Strait Islander health data should encourage the application of these principles and establish meaningful partnerships with Aboriginal and Torres Strait Islander Australians.

Mindful of Aboriginal and Torres Strait Islander peoples' understanding of ownership, including ownership of personal and community information, and any relevant agreements with various parties, including governments, these principles set out a culturally respectful foundation for the collection, storage and use of their health and health-related information.

Principle 1: The management of health-related information about Aboriginal and Torres Strait Islander persons must be ethical, meaningful, and support improved health and better planning and delivery of services.

Principle 2: The analysis, interpretation and reporting of Aboriginal and Torres Strait Islander health and health-related information should, where feasible, occur collaboratively with Aboriginal and Torres Strait Islander peoples.

Principle 3: The privacy and confidentiality of Aboriginal and Torres Strait Islander people will be protected in accordance with any relevant legislation and privacy codes.

Principle 4: Aboriginal and Torres Strait Islander peoples should be informed at the point of service that attendance/participation may contribute to administrative or mandatory data collections and that such data will be used to improve the quality, coverage and scope of health services and protect the public health. Data collection agencies and data custodians should have a policy that provides this information to people at the point of data collection and appropriate governance arrangements to review its implementation.

Principle 5: In general, free and informed consent should be obtained from Aboriginal and Torres Strait Islander peoples prior to any information management activities, except where mandatory reporting or legislative provisions apply. Otherwise, where there is a proposal to initiate an information management activity without the consent of Aboriginal and Torres Strait Islander peoples, it must be clearly demonstrated both that the activity will advance the interests of Aboriginal and Torres Strait Islander peoples and that it is impractical and infeasible to obtain further specific consent.

Principle 6: The value of the resources required to collect and use information should be assessed in the light of the potential benefit to Aboriginal and Torres Strait Islander peoples' health.

Principle 7: The collection, collation and utilisation of information should be conducted in the most efficient and effective manner possible and minimise the burden on Aboriginal and Torres Strait Islander people.

Principle 8: Systematic and ethical processes for sharing information should be encouraged to assist in policy, planning, management and delivery of health services to Aboriginal and Torres Strait Islander people.

Principle 9: Aboriginal and Torres Strait Islander communities should be provided with feedback about the results and possible implications arising from data analysis.

Principle 10: Information collections require regular review and refinement in order to ensure ongoing relevance to service delivery and the potential for improved health outcomes.

Principle 11: Cultural respect and security of data practices must be promoted across all collections. Aboriginal and Torres Strait Islander individuals and communities should be afforded the same ethical and legal standards of protection as are enjoyed by other Australians. This may require the development and application of methods that are different to or in addition to those in mainstream data collections.

Endorsed by AHMAC October 2006.

Source: <www.aihw.gov.au/committees/nagatsihid/nagatsihid_data_principles.doc>

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