NSW Aboriginal HEALTH

Information Guidelines

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NSW Aboriginal Health Resource Co-operative Ltd

the basis for a Memorandum of Understanding between
The Minister for Health of the State of New South Wales
The New South Wales Department of Health
The New South Wales Aboriginal Health Resource Cooperative Limited

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ISBN: 0 7313 4075 2
State Health Publication No. (AHB)980128

Further copies available from the Better Health Centre (02) 9954 1193

NSW Aboriginal Health Information Guidelines

1. Purpose of these Guidelines

The purpose of the NSW Aboriginal Health Information Guidelines is to ensure consistency and good practice in the management of health and health-related information about Aboriginal peoples in NSW.[1] This extends to issues surrounding the collection, ownership, storage, security, access, release, usage, reporting and interpretation of information, as well as issues of confidentiality and privacy.[2]

There are Commonwealth obligations associated with the collection, storage and release of information, which arise either through operation of Commonwealth law or through conditions imposed under funding or other agreements. Where such obligations arise, they must be complied with. However, such compliance should not generally prevent the adoption of the rigorous protection of information set out in these Guidelines.

These Guidelines are intended to supplement National and NSW State policies, protocols and guidelines associated with the management of health information. Specifically, they should be read in conjunction with the NSW Information Privacy Code of Practice, as updated from time to time. Reference should also be made to documents such as the National Aboriginal Health Strategy (1989), and the National Aboriginal and Islander Health Organisation (NAIHO) Report on Aboriginal Research Ethics (1987) appended to the NHMRC Ethical Guidelines in Aboriginal and Torres Strait Islander Research (1991).

2. Parties to these Guidelines

The parties to the NSW Aboriginal Health Information Guidelines are the members of the NSW Aboriginal Health Partnership, that is, the NSW Health Department and the NSW Aboriginal Health Resource Cooperative Limited (AHRC) representing Aboriginal Community Controlled Health Services in NSW.

At local levels these Guidelines will form the basis of local partnership agreements between Area Health Services and Aboriginal Community Controlled Health Services. Where such agreements do not exist, the Partnership is deemed to operate through the relevant Area Health Service Chief Executive Officer and local AHRC Executive member. Any agreements developed locally regarding the collection and use of health and health-related information about Aboriginal peoples must be consistent with the principles and terms outlined in these Guidelines.

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[1] While these Guidelines pertain specifically to health and health-related information about Aboriginal people, they also relate to information about Torres Strait Islanders in NSW.

[2] See Glossary for definitions of frequently used terms in this document.

These Guidelines and any related Subsidiary Agreements (as described in Part 6 below) require the signing of both the NSW Minister for Health and a nominated representative of the AHRC in order to take effect.

The NSW Aboriginal Health Partnership, at its highest level, is between the NSW Government, through its Health Portfolio, and the NSW AHRC. All state government agencies responsible for the management of Aboriginal health and health-related information should therefore be guided by the terms of these Guidelines. Individuals and organisations outside the Partnership who are involved in the management of information pertaining to Aboriginal peoples are also encouraged to adhere to the values, principles and other terms outlined in these Guidelines.

3. NSW Aboriginal Health Information Management Group (AHIMG)

The NSW Aboriginal Health Information Management Group (AHIMG) has been established through the NSW Aboriginal Health Partnership. The AHIMG has three primary aims:

- To ensure stakeholders work collaboratively to improve the quality and reliability of health and health-related information about Aboriginal peoples in NSW;
- To advocate improved access to, and use of, information that can support the planning and delivery of health services; and
- To build confidence in the use of information to improve health by ensuring appropriate consideration is given to cultural and ethical factors associated with the collection, privacy and use of information about Aboriginal peoples.

Under the direction of the NSW Aboriginal Health Partnership, the AHIMG is responsible for overseeing the implementation, monitoring and revision of these Guidelines and any related Subsidiary Agreements.

4. Agreed values

The parties to the NSW Aboriginal Health Information Guidelines support the holistic concept of health that embraces 'not just the physical well-being of the individual but the social, emotional, and cultural well-being of the whole community...' (National Aboriginal Health Strategy, 1989, p.x).

The parties affirm the guiding principles of the NSW Aboriginal Health Partnership Agreement, namely self-determination and community control. Aboriginal peoples have the right to control their destiny and make decisions about their health and the health services they receive.

The parties recognise that information is a resource, the value of which is determined by the contribution it makes to the ultimate goal of improving Aboriginal health and the priorities of the health system in addressing that goal. In this context, accurate, reliable and meaningful health information fulfils an important role in the planning and delivery of health services for Aboriginal peoples.

5. Guiding principles

There are eleven guiding principles underlying the NSW Aboriginal Health Information Guidelines. It is recognised that these principles are new. Existing processes and policies may not be consistent with these principles, and a process of change will be needed to instil these principles into practice.

Principle 1	The management of health and health-related information about Aboriginal peoples must be ethical[3], meaningful and useful to Aboriginal peoples, based on an agreed view negotiated between the relevant parties to the Partnership, and consistent with the guidelines in the National Aboriginal Health Strategy (1989), and the NAIHO Report on Aboriginal Research Ethics (1987). Such determinations may be made at State or local level, as appropriate.
Principle 2	Information about the health of Aboriginal peoples and the services they receive must be used to support improved health and better planning and delivery of health services.
Principle 3	The analysis, interpretation and reporting of Aboriginal health and health-related information should occur collaboratively between the parties to the Partnership.
Principle 4	The privacy and confidentiality of Aboriginal peoples and health service providers must be protected in accordance with the NSW Health Information Privacy Code of Practice, as endorsed by the Privacy Committee of NSW, and any other legislation or guidelines pertaining to the NSW health sector.
Principle 5	Health service providers should obtain free and informed consent from Aboriginal peoples about how and why their information is collected and used.
Principle 6	While health service providers have common information needs, there is also diversity among them which generates unique information requirements.
Principle 7	The cost of the resources required to collect and use information must be outweighed by the value added in supporting services which can lead to improvements in Aboriginal health.
Principle 8	Information should be collected as a by-product of service delivery, or as part of the ongoing operation of a service, or in the context of surveys and research agreed to by the relevant parties to the Partnership. The burden of data collection to Aboriginal peoples and service providers should be minimised.
Principle 9	The utilisation, rather than the collection, of information should be maximised.
Principle 10	The parties should be encouraged to share information that may assist in planning, management and delivery of health services for Aboriginal peoples.
Principle 11	Information collections require regular review and refinement by the parties to ensure relevance to service delivery and compliance with agreed information requirements.

[3] See Part 6.4 below.

6. Subsidiary Agreements

The AHIMG will develop Subsidiary Agreements to the NSW Aboriginal Health Information Guidelines in negotiation with the parties to the NSW Aboriginal Health Partnership. These Agreements will address issues such as ownership, sharing and use of information, performance measures, ethical issues and other relevant matters that may arise. Until Subsidiary Agreements are developed, the following broad guidelines will apply.

6.1 Consent

The collection of health information about an individual requires that person's informed consent. The recording of consent must be documented either electronically or on paper.

Consent should be obtained from Aboriginal communities or Aboriginal Community Controlled Health Services for the collection and use of health and health-related community information if one or more of the following apply:

- Aboriginality is a key determinant;
- data collection is explicitly directed at Aboriginal peoples;
- Aboriginal peoples, as a group, are to be examined in the results;
- the information has an impact on one or more Aboriginal communities;
- Aboriginal health funds are a source of funding.

Such consent should be documented and should be dependent on adherence to the principles and terms outlined in the NSW Aboriginal Health Information Guidelines, and appropriate involvement of, and negotiation with, relevant Aboriginal community representatives including the provision of adequate time-frames.

A written consent agreement should include:

- an explanation of why the information is being collected and how it will be used;
- assurances that additional consent will be sought if there are any changes in the specified use of the information;
- identification of who will, or is likely to, have access to the information; and
- advice regarding the right to withdraw consent.

Consent is not required if the collection of information is mandatory (for example, under legislation) however individuals should nonetheless be informed.

6.2 Ownership/custodianship of information

The notion of 'ownership' holds special significance for Aboriginal peoples. For example, the ownership of land by Aboriginal peoples incorporates rights and responsibilities for its access and use. This includes the right to protect and care for the land, and the right to give permission to other parties about how it can be used.

The NSW Aboriginal Health Information Guidelines have been developed on the basis that Aboriginal peoples have the same rights and responsibilities of ownership regarding their health and health-related information. This includes the right to protect and care for the use of this information, the right to determine culturally appropriate forms for its reporting, and the right to grant or withhold permission from other agencies or organisations for its use.

When an agency or organisation creates a record containing information about a person, that agency or organisation is the custodian of that record. This is true of health information records created by health workers, doctors, and other service providers. Such records may be in the form of paper, electronic storage (digital), cassette or magnetic tape, or film.

Custodianship of information about Aboriginal peoples confers a number of responsibilities including:

- ensuring the information record is stored in a secure physical environment to prevent unauthorised access, destruction, use, modification or disclosure;
- maintaining the quality and accuracy of the information record;
- establishing and implementing appropriate levels of information protection; and
- determining when and where information disclosure and utilisation are appropriate, in accordance with the principles and terms of these Guidelines.

Health service providers who are custodians of information records about Aboriginal peoples share these responsibilities.

Custodians of information must also give consideration to appropriate destruction of information. Where legal requirements exist, they must be complied with. Otherwise it is preferable that consent agreements exist which include details regarding the destruction of data. Alternatively, identifying or potentially identifying information about individual, or discrete communities of, Aboriginal peoples should be destroyed as soon as there is no longer a research or operational requirement for such details.

6.3 Access to, and sharing of, information

A request by an Aboriginal person for access to his or her own health information can be made directly to the agency or organisation holding that information.

Requests by third parties for access to, and sharing of, Aboriginal health information must be determined with reference to the principles and terms of these Guidelines. Third parties making such requests must be provided with a copy of these Guidelines, and if access is granted, must formally acknowledge and agree in writing to adhere to the principles. These conditions apply to requests for access to individual information records, and to de-identified and aggregated information which includes Aboriginal sample or population groups.

Similarly, the release by the Custodian of information where Aboriginality is identified should be carried out consistent with the principles of these Guidelines. This applies whether the information pertains to individuals or groups. Authorised disclosure of potentially identifiable health information should include only those information items which are justifiable to carry out the intended use. Requests for access to personal information should be directed to the Custodian, and where applicable, to the relevant ethics committee/s.

In considering such requests, it is recognised that the value of collecting and recording Aboriginal health information is fully realised only when that information is shared and used to benefit Aboriginal peoples and communities. Furthermore, due regard must be given to how the information is analysed, and in particular how it is used and sensitively reported so that the information does not have unintended repercussions or consequences (see Part 6.4 below). Health professionals responsible for the care of Aboriginal peoples should be aware that information collection occurs in all types of clinical circumstances. The use of this

information in such settings as student or collegial teaching should comply with the principles of these Guidelines.

It is acknowledged that a mechanism for the resolution of disputes about access between the parties needs to be defined. This will be the subject of further work.

6.4 Ethical use of information

All requests for the use of health and health-related information about Aboriginal peoples must demonstrate compliance with all the terms of the NSW Aboriginal Health Information Guidelines.

Local and State Health Ethics Committees considering submissions involving the collection and use of health and health-related information about Aboriginal peoples should ensure compliance with all the terms of these Guidelines. In addition to consideration by local or institutional Ethics Committees, it is strongly recommended that proponents submit projects to the NSW Aboriginal Health Resource Cooperative (AHRC) Ethics Committee in association with the local community concerned, for consideration and advice if one or more of the following apply:

- Aboriginality is a key determinant;
- data collection is explicitly directed at Aboriginal peoples;
- Aboriginal peoples, as a group, are to be examined in the results;
- the information has an impact on one or more Aboriginal communities;
- Aboriginal health funds are a source of funding.

It is strongly recommended that the proponent of a submission which is considered but not endorsed by the AHRC Ethics Committee does not proceed with the project unless and until the difficulties identified by the AHRC Ethics Committee are resolved, regardless of endorsement by other ethics committees.

All Ethics Committees should monitor the conduct of approved studies to ensure ongoing adherence to agreed protocols and methods.

6.5 Performance measures

Performance measures associated with Aboriginal health, and services delivered to Aboriginal peoples via the public health sector, must be developed in consultation and negotiation with the relevant parties to the Partnership, and respecting the rights of Aboriginal self-determination and community control. The performance measures must comply with the NSW Aboriginal Health Information Guidelines.

7. Cooperation between the Parties

The parties of the NSW Aboriginal Health Information Guidelines will cooperate with each other in order to achieve the objectives and purposes of these Guidelines, and the performance of their respective commitments as set out in these Guidelines.

8. Future of these Guidelines

The NSW Aboriginal Health Information Guidelines will be reviewed 12 months after implementation. Key issues to be considered will include implementation of the Guidelines, and identification of strengths, deficiencies and necessary changes.

Urgent matters arising as a result of the implementation and functioning of these Guidelines, which require consideration before the 12-month review, should be referred to the NSW Aboriginal Health Partnership via the NSW Aboriginal Health Information Management Group secretariat:

AHIMG Secretariat
c/- Aboriginal Health Branch
NSW Health Department
73 Miller Street
North Sydney NSW 2059

Tel: (02) 9391.9502
Fax: (02) 9391.9480

Glossary

Within the context of the NSW Aboriginal Health Information Guidelines the following definitions apply:

Aboriginal community information - information that can be linked to an identifiable Aboriginal community, whether that community is identified directly or indirectly.

Aboriginal Health Resource Cooperative Limited (AHRC) - the peak body representing Aboriginal Community Controlled Health Services in NSW.

confidentiality - the restricted disclosure of personal information to authorised persons, entities and processes at authorised times and in an authorised manner.

custodian (of information) - a person or agency with day-to-day responsibility for the protection of individual client records including those held within data collection systems.

custodianship (of information) - day-to-day responsibility for the protection of individual client records including those held within data collection systems.

de-identified information - information which has been stripped of details such as individual names, addresses, dates of birth, death or other events, or in certain circumstances Aboriginal community identifiers; or where such details have been sufficiently altered to render the identification of individuals or communities unlikely. (There are cases where aggregated data, apparently stripped of identifiers, may permit individuals or communities to be identified, eg. an uncommon medical condition. Special consideration should be given to ensuring the privacy of individuals and communities in such circumstances.)

health services - all services provided by the parties of the NSW Aboriginal Health Partnership. Such services include administrative and support services.

information - details collected about individuals, groups and communities, as well as those compiled through general population collections.

management (of information) - includes issues such as collection, ownership, storage, security, access, release, usage, reporting and interpretation of information.

ownership (of information) - the right to control the dissemination and use of personal information. Ownership of Aboriginal health and health-related information may be on an individual or collective community basis. (These special ownership rights are recognised for the purpose of these Guidelines, but it is noted that current legislation does not recognise this type of ownership.)

personal information - information about an individual whose identity is known, or whose identity can be reasonably ascertained from the information.

potentially identifiable information - information from which names, addresses and precise dates have been removed, but from which it might still be possible to identify an individual.

privacy (of Aboriginal community information) - the right of an Aboriginal community to exercise appropriate control over the availability of Aboriginal community information to others.

privacy (of information) - the right of an individual to exercise appropriate control over the availability of personal information to others.

third party - a person, being neither the subject of the information to be disclosed nor the subject's health care provider at the time access occurs.

References

National Aboriginal Health Strategy (1989) Department of Aboriginal Affairs, Canberra.

National Aboriginal and Islander Health Organisation (NAIHO) (1987) Report on Aboriginal Research Ethics - see National Health and Medical Research Council (NHMRC) (1991) Ethical Guidelines in Aboriginal and Torres Strait Islander Research.

National Health and Medical Research Council (NHMRC) (1991) Ethical Guidelines in Aboriginal and Torres Strait Islander Research.

NSW Health Information Privacy: Code of Practice (1st edition, May 1996), NSW Health Department.

developed as part of the

Aboriginal Health Information Strategy