

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