

Appendix 2. Data Tables

Table 1. National population health data collections that include Indigenous status and age

Data Collection	Data Collected	Time Periods
Aboriginal and Torres Strait Islander Access to Major Health Programs ¹	Data collected related to trends in use of health services among Indigenous Australians especially Medicare Benefits Schedule (MBS) & Pharmaceutical Benefits Scheme (PBS).	Single study – conducted between November 2005 and March 2006.
Australia and New Zealand Dialysis and Transplant Register (ANZDATA) ²	Data collected on the type of kidney treatment including age, gender, racial origin etc.	Ongoing data collection. analysed and published annually.
Australia's Health 2006 ³	Collation of broad population health data by AIHW, includes focus on Indigenous children; birth weight, mortality, morbidity, disability, hospitalisations, vaccinations.	Ongoing, Periodic – Biennial.
ABS Birth Registration Data ⁴	Births registered sex of child, age and nuptiality of parents.	Ongoing data collection - analysed and published annually.
Bettering the Evaluation And Care of Health (BEACH) ⁵	Data on primary care consultations through surveys of random sample of 20 GPs each week. Details on patients seen, reasons people seek medical care, problems managed, treatments provided. Cross-sectional data.	Ongoing weekly data collection. Periodic – analysed and published annually.
National Hospital Morbidity Database (NHMD) ⁶	National Minimum Data Set for Admitted Patient Care; includes length of stay, diagnosis, procedures carried out and any external cause.	Ongoing data collection - analysed and published annually.
National Non-admitted Patient Emergency Department Care Database (NAPEDCD) ⁷	Public hospital emergency department care and waiting times; type and duration of visit and demographic data. Cross-sectional data.	Ongoing data collection - analysed and published annually.
National Cancer Statistics Clearing House (NCSCCH) ⁸	Data collected from the eight State and Territory cancer registries on cancer diagnosed in residents of Australia. The data provided to the NCSCCH enable record linkage to be performed and the analysis of cancer by site and behaviour.	Ongoing, Continuous registration of cases. Periodic – no set regular reporting time.
National System for Monitoring Diabetes including National Diabetes Register and	Data on all aspects of diabetes, including incidence. APEG focuses on diabetes in 0-14 year olds. Population based incidence data.	Ongoing data collection. Periodic - no set regular reporting time.
National Injury Surveillance Unit (NISU) ¹⁰	Collation of data from sources such as hospital separations data on injury.	Administrative data collected continuously and then specific analysis carried out by NISU over time. Periodic - no set regular reporting time.
National Mortality Database ¹¹	All deaths registered, includes cause of death. Population based incidence data.	Ongoing collection – analysed and published annually.
National Notifiable Diseases Surveillance System (NNDSS) ¹²	Mandatory reporting of >50 communicable diseases. Dataset includes disease code, postcode of residence, date of onset of the disease, death. Population based incidence data.	Continuous legally required notifications, published online (updated 3 times a week), quarterly in Communicable Diseases Intelligence, and annual report.
HIV/AIDS Surveillance - National AIDS/HIV Registry ¹³	National notifications. Year of Diagnosis, HIV exposure category, survival data, and other HIV/AIDS disease details. Population based incidence data.	Ongoing notification process – analysed and published annually.
National Influenza Surveillance Scheme ¹⁴	Laboratory reporting surveillance and sentinel surveillance by GPs and Emergency departments. Population based incidence data.	Ongoing data collection. Periodic - Fortnightly published updates.
OzFoodNet ¹⁵	Data on cases and outbreaks of foodborne diseases. Population based incidence data.	Ongoing data collection. Reports published quarterly and annually.

References:

1. Aboriginal and Torres Strait Islander Access to Major Health Programs 2006. Urbis Keys Young – November, 2006. <http://www.health.gov.au/>
2. ANZDATA Registry Report 2007. Australia and New Zealand Dialysis and Transplant Registry Adelaide, South Australia. ISSN 1329-2870.
3. Australia's Health 2006. Australian Institute of Health and welfare. AIHW cat. No. AUS 73. Canberra: AIHW.
4. ABS, Births, Australia, 2006. Cat No. 3301.0, ABS, Canberra.
5. Britt H, Sayer GP, Miller GC et. al. 1999. BEACH: Bettering the Evaluation And Care of Health. A study of general practice activity, six-month interim report. AIHW cat. no. GEP 1. Canberra: Australian Institute of Health and Welfare (General Practice Series no. 1). ISSN 1442-3022.
6. National Hospital Morbidity Database (NHMD). Canberra: AIHW. http://www.aihw.gov.au/hospitals/nhm_database.cfm
7. National non-admitted patient emergency department care database (NAPEDCD). Canberra: AIHW. http://www.aihw.gov.au/hospitals/napedc_database.cfm
8. National Cancer Statistics Clearing House (NCSCH). Canberra: AIHW. <http://www.aihw.gov.au/cancer/ncsch/index.cfm>
9. Dixon T and Webbie K 2006. The National System for Monitoring Diabetes in Australia. AIHW Cat No. CVD 32. Canberra: AIHW.
10. Berry JG and Harrison JE 2007. Hospital separations due to injury and poisoning, Australia 2003–04. Injury research and statistics series no. 30. AIHW cat. no. INJCAT 88. Adelaide: AIHW.
11. Dunn C, Sadkowsky K, Brockway I 2007. The AIHW Mortality Database documentation. Canberra: AIHW.
12. National Notifiable Disease Surveillance System (NNDSS). Department of Health and Aging. Canberra. <http://www.health.gov.au/internet/main/publishing.nsf/Content/cda-surveil-nndss-nndssintro.htm>
13. HIV/AIDS, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2007. National Centre in HIV Epidemiology and Clinical Research, The University of New South Wales, Sydney, NSW; Australian Institute of Health and Welfare, Canberra, ACT. 2007.
14. Yohannes K, Roche P, Hampson A, Miller M, Spencer J 2003. Annual report of the National Influenza Surveillance Scheme. Surveillance and Epidemiology Section, Australian Government Department of Health and Ageing, Canberra.
15. OzFoodNet: enhancing food borne disease surveillance across Australia: quarterly report, January to March 2004. The OzFoodNet Working Group. OzFoodNet, Australian Government Department of Health and Ageing, Canberra.

Table 2. National data collections and reports specific to Indigenous health

Data Collection	Population covered	Data Collected	Data Collected by	Time periods	Limitations
Aboriginal and Torres Strait Islander Health Performance Framework 2006 ¹	Theoretically national coverage, although for many indicators data are only available from a few jurisdictions	Collation of data which measures the impact of the National Strategic Framework for Aboriginal and Torres Strait Islander Health against a set of indicators, including birth weight, infant mortality, hospitalisation, children's hearing loss, social and emotional wellbeing, determinants of health. Cross-sectional data.	Australian Health Ministers' Advisory Council (Australian Government Department of Health and Ageing)	Ongoing, Periodic – Biennial.	Much of the data presented are for some but not all jurisdictions: not truly national. Data limited by quality, availability of source data.
Footprints in Time: Longitudinal Study of Indigenous Children (LSIC) ²	National sample (11 sites; all States/Territories apart from Tasmania; 1/3 urban, 1/3 regional, 1/3 remote). 2,200 children aged 6-18 months to be recruited.	Will include quantitative and qualitative information about family, culture, historical events, community, environment and other significant life events in the early years.	Department of Families, Community Services, Housing and Indigenous Affairs (FaCSHIA). Input from Indigenous people in planning and collection phase to ensure relevance.	Data collection to commence April 2008. Longitudinal study: children to be followed at least annually for at least 4 years.	Small sample size: data not nationally representative and not ongoing. Potential to provide useful information about how Indigenous children are raised and the importance of the family and the social context on health and wellbeing. Data will be made publicly available for service providers, researchers and policy makers.
National Aboriginal and Torres Strait Islander Health Survey, 2004-05 (NATSIHS) ³	National sample of the Indigenous population covering approximately one in 45 of the Indigenous population.	Survey of self-assessed health status, risk factors and actions, and socio-economic circumstances. Details of long term conditions, health services used and social and emotional wellbeing. Data collected for children for some but not all aspects of the survey. Cross-sectional data.	Australian Bureau of Statistics	Ongoing, Periodic – analysed and published every six years.	Snapshot national data. Potential for sampling error, because it only covers a proportion of the population, and only those in private dwellings. Potential for bias due to self reporting of health status, interaction with an interviewer.
Overcoming Indigenous Disadvantage. Key Indicators Report 2007 ⁴	National coverage providing data on indicators of Indigenous disadvantage. Includes case study and community level data.	Collation of data on wide range of social indicators, to provide strategic background for policy development. Child health data includes infant mortality, birth weight, hospitalisation for communicable diseases, hearing impediments. Deliberately limited to indicators considered most useful with focus on <i>prevention</i> of disadvantage.	Steering Committee for the Review of Government Service Provision	Ongoing, Periodic – Biennial.	Health data focuses on children aged 0-4 only. Potential problems with incomplete Indigenous identification, sampling error, and being unable to provide nationally representative picture.
Overview of Australian Indigenous Health 2007 ⁵	Gathers national information to provide broad picture of Indigenous health status.	Collation of data is largely from published information including birth weight, infant mortality, hospitalisation. Some disease specific data also included.	Indigenous Health Infonet	Ongoing - analysed and published annually.	Data quality limited by data sources many of which are not nationally representative.
The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2005 ⁶	Report draws together information from different sources to give a "comprehensive overview".	Include Population Census data and information from a range of administrative data held by the Australian Institute of Health and Welfare. Contains wide range of health and welfare data: population, education, health, housing, disability, ageing, community services, risk behaviours. Chapter on Mothers and children, general data - morbidity and mortality data, cause categories and non-specific conditions. For the first time the report includes information on disability in the Indigenous population.	Australian Bureau of Statistics (ABS) and Australian Institute of Health and Welfare (AIHW)	Ongoing, Periodic – Biennial.	Broad national picture limited by the sources it uses. Most child health data in this report is not national.

References:

1. Australian Health Ministers' Advisory Council, 2006, Aboriginal and Torres Strait Islander Health Performance Framework Report 2006, AHMAC, Canberra. ISBN: 1741861357.
2. Footprints in Time: A Longitudinal Study of Indigenous Children (LSIC). Research Overview. Research and Analysis Branch Department of Family, Community Services and Indigenous Affairs (FaCSIA). <http://www.facsia.gov.au/>
3. National Aboriginal and Torres Strait Islander Health Survey 2004 – 05. Australian Bureau of Statistics, Cat no. 4715. 0
4. SCRGSP (Steering Committee for the Review of Government Service Provision) 2007. Overcoming Indigenous Disadvantage: Key Indicators 2007, Productivity Commission, Canberra. <http://www.pc.gov.au/gsp/reports/rogs/2007>
5. Thomson N, Burns J, Hardy A, Krom I, Stumpers S (2007) Overview of Australian Indigenous health status 2007: Retrieved from http://www.healthinonet.ecu.edu.au/html/html_overviews/overview.pdf.
6. The Health and Welfare of Australia's Aboriginal and Torres Strait Islander Peoples 2005. ABS Catalogue No. 4704.0 AIHW Catalogue No. IHW14.

Table 3. National data collections and reports specific to Children

Data Collection	Population covered	Data Collected	Data Collected by	Time periods	Limitations
A Picture of Australia's Children 2005 ¹	Collates information from many data sources to describe key national indicators of health, development and wellbeing of Australia's children aged 0-14.	Health, development, wellbeing data; mortality; morbidity - some specific conditions/diseases although data often not available/not presented for Indigenous children.	Australian Institute of Health and Welfare (AIHW)	Ongoing - Periodic - analysed and published every three years.	Data missing for many key indicators for Indigenous children. Reliability of Indigenous identification in the data sources used is unclear.
Australian and New Zealand Neonatal Network (ANZNN) ²	All infants in the 29 Level 3 Neonatal Intensive Care Units who are born <32 weeks gestation, or have birth weight <1500g, or need major surgery, or need assisted ventilation for >4 hours.	60 variables including Indigenous status of the mother. Admission details, medical status, diagnoses, care received and outcomes. Population based incidence data.	Neonatal Intensive Care Units submit data to the ANZNN	Ongoing - analysed and published annually.	Voluntary data collection process. Only collects mother's ethnicity and has a high proportion of missing data: ethnicity not included in most recent analysis.
Australian and New Zealand Paediatric Intensive Care Registry (ANZPIC Registry) ³	All children admitted to the 15 ICU's across Australia and New Zealand.	Demographic details including Indigenous status, admission details, diagnosis, and medical care received outcome and discharge details. Population based incidence data.	Intensive Care Units who submit data to the ANZPIC Registry quarterly.	Ongoing - analysed and published annually.	Reliability of the voluntary data collection process; Very small population of patients admitted to PICU's each year.
Australian Childhood Immunisation Register (ACIR) ⁴	Children under 7 registered with Medicare are automatically registered with ACIR, and non-Medicare enrolled children are added when an immunisation is recorded. Providers including Aboriginal Health Services and Aboriginal Health Workers then record all immunisations administered.	Immunisations administered are recorded, monitoring immunisation status for each child. Records Indigenous status. Population based incidence data.	Healthcare providers, submit to Medicare Australia	Ongoing - analysed and published annually.	ACIR thought to underestimate immunisation coverage in Australia. Accuracy of Indigenous status reporting also challenged ⁵ .
Australian Paediatric Surveillance Unit (APSU) ⁶	Nationwide coverage, active surveillance of small number of specified rare conditions in children 0-15 year with monthly reporting by >95% paediatricians.	Notifications of cases, their geographic distribution, clinical features, current management and short term outcome. Indigenous status is recorded.	APSU	Surveillance duration variable for different conditions. Biennial.	High monthly reporting and provision of de-identified data. Potential to miss cases in children seen in the Aboriginal health system unless serviced by paediatricians. Not suitable for common conditions.
Health of Children, 2004 ⁷	Data from the National Health Survey 2004 combined with other data for national coverage of Australian children's health.	Morbidity, disability, GP consultations, Hospitalisations, mental disorders and Mortality. Cross-sectional data.	ABS	Ongoing - Periodic - analysed and published every three years.	Does not highlight Indigenous child health statistics, possibly because of small numbers of Indigenous children.
Longitudinal Study of Australian Children (LSAC) ⁸	Project to survey two age groups over time; 5,000 babies aged <12 months and 5,000 four to five year olds. Indigenous children represented in LSAC in the same percentage as the general population (approx 350 children).	Looks at Family functioning, Health, Non-parental child care, Education and Cross-discipline services. Cross-sectional data.	Department of Families, Community Services and Indigenous Affairs (FaCSIA) and the Australian Institute of Family Studies (AIFS)	Ongoing - analysed and published annually.	Very small Indigenous sample included in this project – little meaningful national data.

National Congenital Malformations and Birth Defects Data Collection/ Australian Birth Anomalies System ⁹	Number of infants with malformations diagnosed within the first 28 days of life, as well as congenital malformations detected during fetal life by prenatal screening. Information on terminated pregnancies also included.	Mother's and infant details - gestational age, sex, birth weight, outcome, method of prenatal diagnosis, codes for each congenital malformation, date of death. Population based incidence data.	State and Territory perinatal data systems, birth defect registers and hospitals report to the National Perinatal Statistics Unit (NPSU), a collaborating unit of AIHW	Ongoing data collection. Periodic - no set regular reporting time.	Report in 2004 criticised the quality of data received by NPSU and made recommendations for development of an Australian Birth Anomalies System using standard definitions and reporting. Indigenous status is collected and independently published by some states/territories against mortality rates: no national data.
National Perinatal Data Collection (NPDC) ¹⁰	Data on all births in Australia, based on notifications by midwives or other staff to the perinatal or midwives data collection in each state and territory. Information is included in the NPDC for all births of at least 400 grams birth weight or at least 20 weeks gestation.	The National Perinatal Minimum Data Set includes characteristics of the mothers and their babies including Indigenous status.	State/territory collections report to National Perinatal Statistics Unit (NPSU)	Ongoing - analysed and published annually.	Limitations in accuracy of data about Indigenous status. Unknown numbers born outside the notification system.
National Survey of Mental Health and Wellbeing (Child and Adolescent Component) 2000 ¹¹	Survey of a representative national sample of 4500 children and adolescents aged 4-17.	Number of young people with mental health problems; the nature of these problems; treatment received and services used. Indigenous status collected. Cross-sectional data.	Commonwealth Department of Health and Aged Care	Last carried out in 1998 - published 2000	Indigenous children in the survey representative of the proportion in the general population, but felt to be too small a sample to guarantee a true reflection of the status of mental health for Indigenous children as a whole. A more culturally sensitive method of questioning may be required to establish a true Indigenous picture. Data is now quite old, unclear of any plans for a repeat.
The Australian Early Development Index (AEDI): Building Better Communities for Children ¹²	Nationwide: communities can apply to take part in the AEDI. In 2004 the first sites were selected. After three years it is anticipated that around 420 schools (12,500 children) will have been involved in the project.	Data on physical health and wellbeing, social competence, emotional maturity, language and cognitive skills, and communication skills and general knowledge.	Centre for Community Child Health, Melbourne, in partnership with the Telethon Institute for Child Health Research. [Funded by the Australian Government Department of Family and Community Services and supported by Shell Company of Australia Limited.]	Ongoing - analysed and published annually.	Community Indigenous data not linked with development in analysis of results. Small samples - focus on benefit in individual communities rather than giving a broad picture; Possibly subject to teacher reporting bias; Provides only information about the very early years. National data, although no communities in NT and very few in QLD and SA included. Any community can join, but less likely to represent very remote communities.
Child protection Australia ¹³	All children who come into contact with the community services departments for protective reasons. A limited amount of data is collected on intensive family support services.	Data collected from the community services departments in each state and territory. Data on trends in child protection also included.	AIHW	Ongoing data collection. Periodic - no set regular reporting time.	Each state and territory has its own legislation, policies and practices in relation to child protection, which accounts for some of the differences between jurisdictions in the data provided. Quality of the data on Indigenous status varies between states and territories.

References:

1. Australian Institute of Health and Welfare 2005. A picture of Australia's children. AIHW cat. no. PHE 58. Canberra: AIHW.
2. Evans N, Hutchinson J, Simpson J M et. al. 2007. Prenatal predictors of mortality in very preterm infants cared for in the Australian and New Zealand Neonatal Network. Arch Dis Child Fetal Neonatal Ed; 92(1):F34-F40.
3. Christie Turton, Lynda Norton, Anthony Slater (2005) Report of the Australian and New Zealand Paediatric Intensive Care Registry. ISBN: 1876980184.
4. Australian Childhood Immunisation Register. List of reports available from the secure internet site. Medicare Australia. <http://www.medicareaustralia.gov.au/public/services/acir/index.shtml>
5. Menzies R, McIntyre P, Beard F 2004. Vaccine preventable diseases and vaccination coverage in Aboriginal and Torres Strait Islander people, Australia, 1999 to 2002. Commun. Dis Intell; 28(2):127-59.
6. Australian Paediatric Surveillance Unit (APSU). A Unit of the Royal Australasian College of Physicians, Division of Paediatrics and Child Health, The University of Sydney. ISSN: 1443-3524.
7. Health of Children, 2004. ABS Cat no. 4829.0.55.001.
8. Growing Up in Australia: The Longitudinal Study of Australian Children: 2005-06 Annual Report, November 2006. ISBN: 0642395446.
9. AIHW NPSU: Birch et al. 2004. Recommendations for development of a new Australian Birth Anomalies System: a Review of the Congenital Malformations and Birth Defects Data Collection. AIHW Cat. No. PER 23.
10. Laws PJ, Abeywardana S, Walker J, Sullivan EA 2007. Australia's mothers and babies 2005. Perinatal Statistics series no 20. Cat no. PER 40. Sydney: AIHW National Perinatal Statistics Unit.
11. Sawyer MG, Kosky RJ, Graetz BW et. al. 2000. The National Survey of Mental Health and Wellbeing: the child and adolescent component. Aust N Z J Psychiatry; 34(2):214-20.
12. Australian Early Development Index: Building Better Communities for Children Project Final Evaluation Report March 2007. Centre for Community Child Health Royal Children's Hospital, Melbourne. http://www.rch.org.au/...inal_Evaluation_Report_March_07.pdf
13. Australian Institute of Health and Welfare (AIHW) 2005. Child protection Australia 2003–04. AIHW cat. no. CWS 24. Canberra: AIHW (Child Welfare Series no. 36).

Table 4. Key state-specific data collections on Indigenous child health

Data Collection	Population Covered	Data Collected	Data Collected by	Time Periods	Limitations
Western Australia Aboriginal Child Health Survey (WAACHS) ¹	The first fully representative community survey of Aboriginal Child Health and wellbeing. Covered 5,289 ATSI children in Western Australia.	Health component of the survey included questions on household and environment, physical health, use of health services, and health risks. Survey also looked at socio-emotional wellbeing and education.	Telethon Institute for Child Health Research	Single study – conducted between May 2000 and June 2002.	Query as to whether findings can be applied to the rest of Australia. (4)
Study of Environment on Aboriginal Resilience and Child Health (SEARCH) ²	Cross-sectional study of 800 families (approx 2000 children) who attend Aboriginal Medical Services (AMS's) particularly in urban environments, to monitor the causes of health and illness in aboriginal children. Limited to NSW.	Data describes and investigates the causes of health and illness in Aboriginal children. Focus on healthy environments and selected child health problems.	Project run by the Aboriginal Health and Medical Research Council (AHMRC), Aboriginal Medical Services (AMS's), the Institute for Health Research and leading health researchers in NSW. Also involved are NSW Health, the Aboriginal Housing Office and the Rio-Tinto Aboriginal Foundation.	Ongoing	Study ongoing, no published data as yet. Sample limited to NSW.
Northern Territory Aboriginal Health Key Performance Indicators Information System (NTAHKPI) ³	All community based Aboriginal health services and Aboriginal community controlled health services in Northern Territory.	19 KPIs – include low birth weight babies, immunisation, underweight children <5 yrs of age, number of anaemic children, diabetes data. Potential for extension to further indicators.	The Northern Territory Aboriginal Health Forum (AHF) that comprises representatives from the Commonwealth Department of Health and Aging (DoHA), Aboriginal Medical Services Alliance (AMSANT) and Northern Territory Department of Health and Community Services (DHCS)	Under development: data delivery from all community health centres planned to commence in 2008.	Limited to Northern Territory. Limited child health indicators included.

References:

1. Zubrick SR, Lawrence DM, Silburn SR et. al. 2004. The Western Australian Aboriginal Child Health Survey: The Health of Aboriginal Children and Young People. Perth: Telethon Institute for Child Health Research. http://www.ichr.uwa.edu.au/files/user17/Volume1_Complete.pdf
2. Study of Environment on Aboriginal Resilience and Child Health (SEARCH): Coalition for Research to Improve Aboriginal Health. <http://www.saxinstitute.org.au/criahconference2005/criah.pdf>
3. Northern Territory Aboriginal Health Key Performance Indicators Information System (NTAHKPI): Department of Health and Aging. <http://www.nt.gov.au/health/ahkpi/home.shtml>