

Indigenous child health: urgent need for improved data to underpin better health outcomes

Emily Fremantle, Yvonne A Zurynski, Deepika Mahajan, Heather D'Antoine and Elizabeth J Elliott

The poor health and comparatively low life expectancy of Indigenous Australians are not disputed.^{1,2} Indigenous children have lower birthweights and higher rates of infection, injury and death than non-Indigenous children.¹⁻³ Mortality rates are also higher than those of Indigenous people in Canada, the United States and New Zealand.¹

Forty per cent of Australia's Indigenous population is aged under 14 years — more than twice the proportion in the total Australian population.⁴ Targeting child health will likely improve the long-term health of the Indigenous population, because many adult diseases originate in childhood.

Accurate documentation of the current state of Indigenous child health is vital. Continuous data collection allows us to monitor trends in disease and death rates, which inform clinical service needs and service development. These data may also identify the need for public health initiatives and provide a baseline to monitor improvements in health outcomes. Accurate data also help guide development of national health policy and future research, and data dissemination helps raise health professional and community awareness about discrepancies between Indigenous and non-Indigenous health outcomes.

With this in mind, we recently attempted to identify national, or nationally representative, data on Indigenous child health outcomes and to investigate how these data are used.

Data collections currently available

We searched electronic literature databases and Internet sites. Search strategies and process are available from the authors (Appendix 1; <http://www.apsu.org.au/index.cfm?objectid=D7D66872-E4E9-7BAF-6DAD4181360B635E>). Our search revealed a paucity of data collections published in or after 2000 with national scope (or state/territory collections from which national estimates may be determined) that report Indigenous status and include information about health outcomes in children aged under 15 years.

We identified 15 national data collections that include Indigenous status, age and health outcomes; six specific to Indigenous health; and 12 specific to child health. We also identified three important state-specific collections of Indigenous child health data. These collections are summarised in Box 1, with details available from the authors (Appendix 2; URL as above).

Although many collections provide useful information, most have significant limitations.

Limitations of existing data collections

Unreliable collection of Indigenous status

Inaccuracy and inadequacy in reporting of Indigenous status is a limitation of many collections.⁵⁻⁷ Only data from Western Australia, the Northern Territory, South Australia and Queensland were considered of sufficient quality for inclusion in the most recent national analysis of hospital separations for Indigenous

ABSTRACT

- Accurate data about Indigenous child health is vital to enable us to understand its current state, to acknowledge achievements, and to determine how to reduce inequalities between Indigenous and non-Indigenous children.
- We have identified a paucity of national, or nationally representative, data relating to Indigenous child health outcomes, and significant deficiencies in available data.
- A coordinated national approach will help address current data limitations, including lack of identification of Indigenous status, lack of currency, and lack of information about specific health disorders affecting Indigenous children.
- To ensure that health data collected are relevant and useful, Indigenous communities must have a role in data collection and management.

MJA 2008; 188: 588–591

people.⁸ The same problem is reported in birth and death collections,⁹ emergency department admissions,⁷ other child health data collections,⁴ and the national mortality dataset.¹⁰ Despite efforts to improve reliability of reporting of Indigenous status, consistent under-reporting is likely,^{6,11,12} hindering meaningful analysis of Indigenous health outcomes.

Lack of national data specific to Indigenous child health

Few national data collections are specific to the health of Indigenous children. Most use cross-sectional data from multiple sources to provide a "snapshot" of Indigenous child health at a specified time. There are no ongoing collections to underpin policy development, or to track the effect of interventions or long-term changes in child health.

The Australian Government's Longitudinal Study of Indigenous Children (LSIC) commenced in April 2008.¹³ It will follow 2200 young children from 11 sites for at least 4 years. Indigenous people were involved in developing the project, and data are to be collected by Indigenous research officers. Its data will not be nationally representative due to the small sample size, but will inform health providers and policymakers about family, community and other factors influencing health. LSIC will not collect disease-specific clinical information from health services.

A number of national data collections include child health outcomes; however, few provide reliable identifiers for Indigenous children. The Australian Paediatric Surveillance Unit (APSU) facilitates data collection on uncommon childhood conditions,¹⁴ but Indigenous children are under-represented in its data, most of which are provided by paediatricians based in urban and regional centres. The APSU is exploring ways to enhance access to data from clinicians working in Aboriginal Community Controlled Health Services (ACCHSs), Aboriginal Medical Services (AMSSs), and other rural and remote health services.

1 Data collections reviewed for accurate data on Indigenous child health*

National population health data collections that include Indigenous status and age [†]	National data collections and reports specific to children [§]
Aboriginal and Torres Strait Islander Access to Major Health Programs	A picture of Australia's children 2005 (AIHW)
Birth registration data (ABS)	Australian and New Zealand Neonatal Network
Australia and New Zealand Dialysis and Transplant Registry	Australian and New Zealand Paediatric Intensive Care Registry
<i>Australia's health 2006</i> (AIHW)	Australian Childhood Immunisation Register
Bettering the Evaluation And Care of Health	Australian Paediatric Surveillance Unit
HIV/AIDS surveillance (NCHECR)	<i>Health of children 2004</i> (ABS)
National Hospital Morbidity Database (AIHW)	Longitudinal Study of Australian Children
National Non-admitted Patient Emergency Department Care Database (AIHW)	National Congenital Malformations and Birth Defects Data Collection; Australian Birth Anomalies System
National Cancer Statistics Clearing House (AIHW)	National Perinatal Data Collection
National System for Monitoring Diabetes (AIHW)	The mental health of young people in Australia
National Injury Surveillance Unit (AIHW)	The Australian Early Development Index: Building Better Communities for Children
National Mortality Database (AIHW)	Child protection Australia 2003–04 (AIHW)
National Notifiable Diseases Surveillance System	State-specific data collections on Indigenous child health [¶]
National Influenza Surveillance Scheme	Western Australian Aboriginal Child Health Survey
OzFoodNet	Study of Environment on Aboriginal Resilience and Child Health (New South Wales)
National data collections and reports specific to Indigenous health[‡]	Northern Territory Aboriginal Health Key Performance Indicators Information System
Aboriginal and Torres Strait Islander Health Performance Framework 2006	
<i>Footprints in Time</i> : Longitudinal Study of Indigenous Children	
National Aboriginal and Torres Strait Islander Health Survey, 2004–05	
<i>Overcoming Indigenous disadvantage: key indicators 2007</i>	
<i>Overview of Australian Indigenous health status 2007</i> (HealthInfoNet)	
<i>The health and welfare of Australia's Aboriginal and Torres Strait Islander peoples 2005</i> (AIHW, ABS)	

ABS = Australian Bureau of Statistics. AIHW = Australian Institute of Health and Welfare. NCHECR = National Centre in HIV Epidemiology and Clinical Research.

* For full details, see Appendix 2 <<http://www.apsu.org.au/index.cfm?objectid=D7D66872-E4E9-7BAF-6DAD4181360B635E>>. † Appendix 2, Table 1. ‡ Appendix 2, Table 2. § Appendix 2, Table 3. ¶ Appendix 2, Table 4.



Data unrepresentative of heterogeneous Indigenous communities

Indigenous people often have limited access to mainstream health services and are therefore under-represented in many data collections. Indigenous people are more likely to access ACCSs, but data collection is a low priority for these often under-resourced services.¹⁵ The NT Aboriginal Health Key Performance Indicators (NTAHKPI) project, currently under development, promises excellent coverage for data collection from remote AMSs and ACCSs.¹⁶

Primary care services are crucial, but poorly used, sources of information about Indigenous child health. Annual reports from the Bettering the Evaluation And Care of Health (BEACH) program make no reference to collecting data from ACCSs.¹⁷ The only national data routinely collected from ACCSs contribute to the annual Service Activity Reporting by the Office of Aboriginal and Torres Strait Islander Health and the National Aboriginal Community Controlled Health Organisation (NACCHO). These Service Activity Reports do not include specific child health outcomes data.¹⁸

Most Indigenous child health data (80/136 titles from our PubMed search) come from small, community-based studies in diverse Indigenous communities. Although these data are crucial for understanding health problems and needs in selected communities, they are not necessarily applicable elsewhere and cannot provide the comprehensive, ongoing data needed to support national policy. Conversely, national data are not relevant to all Indigenous communities. Regardless of the data collection, it is

crucial that Indigenous communities have a more active role in the collection and management of health data to ensure that information collected is available and useful.¹⁹

Small sample size and lack of timeliness

Indigenous children are under-represented in many national collections, precluding meaningful analysis. The BEACH program report of encounters with Aboriginal people did not include data about Indigenous children.²⁰ The Indigenous sample (about 350 children) in the Longitudinal Study of Australian Children is not representative of the total Indigenous child population.

Even Indigenous-specific surveys have potential for sampling error. The National Aboriginal and Torres Strait Islander Health Survey, 2004–05 (NATSIHS) collected data from a small proportion of Indigenous people, and only those in private residences.¹

One-off, targeted surveys (eg, the WA Aboriginal Child Health Survey [WAACHS]) are invaluable for their holistic approach to health and inclusion of data on determinants of health;²¹ however, they do not allow monitoring of trends. Data analysis in these projects is labour-intensive, often leading to delayed publication of outdated information. Attempts to use key indicator variables to model outcomes for Qld and the NT, to increase the national scope of survey results, have been unsuccessful.²²

Lack of data on conditions of particular significance

Indigenous children appear to have higher rates of vaccine-preventable diseases (VPD) and lower immunisation rates than

non-Indigenous children.²³ However, validity of national data on VPD is limited by inaccurate identification of Indigenous status such that notifications, hospitalisations and mortality data for VPD could not be included for all jurisdictions in the most recent summary report.²⁴ NACCHO claims it is impossible to comment on immunisation rates for Indigenous children "with any accuracy",¹⁵ making it difficult to monitor the effectiveness of vaccination programs.

Although otitis media is a common serious problem among Indigenous children there are no comprehensive national data on rates of ear infection and hearing loss in young children.²⁵ Estimates are made from hospital separation data, exclude children managed as outpatients, and have the problem of inadequate Indigenous identification. NATSIHS (which provides self-reported ear health data), the WAACHS, and small community-based research projects cannot reflect seasonal or temporal variation in disease.

Rheumatic fever occurs predominantly in Indigenous children and can cause rheumatic heart disease.²⁶ Mandatory reporting schemes in the NT and central Australia will enable estimation of the incidence of rheumatic fever among Indigenous children. In collaboration with the APSU and the National Heart Foundation of Australia, the Menzies School of Health Research is conducting surveillance of rheumatic fever to provide national data.

A key contributor to Indigenous health is the concept of social and emotional wellbeing. National child and adolescent mental health data are nearly 10 years old, and the Indigenous sample is too small to be meaningful.²⁷ The WAACHS provides the only data on Indigenous child mental health.²¹ The approach to addressing mental health must be informed by national data collected using a culturally sensitive approach.

Lack of coordinated national approach

Differences in reporting methods, data sources, clinical details, case definitions and data quality make it difficult to compile a national picture of Indigenous child health to inform strategies to improve outcomes. The Australian Indigenous HealthInfoNet (<http://www.healthinfonet.ecu.edu.au>) is a useful resource, but it relies on existing data collections and is limited by the quality of the original data (Appendix 2, Table 2).

What is needed, and how could it be achieved? (Box 2)

Accurate, relevant and timely national data on Indigenous child health are essential to inform service provision, resource allocation and policy development; to ensure accountability by governments and health services; and to enable comparisons with non-Indigenous and international outcomes.

An important first step will be to improve the national coverage, quality, availability and usefulness of existing data collections. This has been recognised by the Australian Government Department of Health and Ageing, which, at the recommendation of the Australian Health Ministers Advisory Council (AHMAC), established the National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data in 2001 (<http://www.aihw.gov.au/committees/nagatsihid/>). It aims to advise the AHMAC on ways to improve "the quality and availability of data" on Indigenous health, and to coordinate "the range of Indigenous health information management activities". The Advisory Group developed a strategic plan and a set of national data principles, but has not published any other recommendations.

2 Recommendations to improve Indigenous child health data collections

Improve existing data collections

- Improve national coverage
- Improve accuracy of Indigenous identification data
- Ensure collection of standardised minimum datasets of child health indicators
- Include details about medical conditions and health outcomes of specific significance to Indigenous children at community, regional and state/territory level
- Involve Indigenous communities and health services in the planning, management and use of data collections

Improve the usefulness of data

- Ensure data collected are available and applicable at the local community level
- Facilitate the translation of data into policy and clinical practice

Link datasets

- Link health outcome data with data about wider determinants of individual and community health, including education, housing, access to health care, and contact with community and legal services.

The Australian Bureau of Statistics and the Australian Institute of Health and Welfare developed a plan to improve identification of Indigenous status and the quality of Indigenous child health data, and to include mental health and primary care data.^{10,28} Improving Indigenous identification is also a priority of the community services sector,²⁹ while the Menzies School of Health Research is striving to improve translation of health data into policy and practice.³⁰ Work is also underway to improve the coverage of data collections in the NT through the NTAHKPI project.¹⁶

It may be more realistic and more meaningful to strive for collection of a standardised minimum set of child health indicators (similar to that proposed for the NTAHKPI project¹⁶), facilitated through appropriately resourced, state-based networks of Indigenous medical services and collated to provide a national picture.

More detailed data about specific diseases and health determinants could be collected and analysed by state/territory or region. If the characteristics of communities were collected, there would be potential for data modelling to predict outcomes in similar communities. It is important to acknowledge and address the significant barriers to collecting data in many communities, whether urban or remote. These include inadequate capacity and infrastructure, including technology and appropriately trained personnel, and reluctance to report data that might stigmatise individuals and communities.

Data collection will not in itself eliminate disparities between the health of Indigenous and non-Indigenous children, but is an important component in understanding and addressing the complex causal pathways to poor health.

Acknowledgements

The activities of the Australian Paediatric Surveillance Unit are supported by the Australian Government Department of Health and Ageing; NHMRC Enabling Grant No. 402784 and NHMRC Practitioner Fellowship No. 457084 (Elizabeth Elliott); the Discipline of Paediatrics and Child Health, University of Sydney; and the Royal Australasian College of Physicians.

Competing interests

None identified.

Author details

Emily Fremantle, BA(Hons), Research Assistant¹

Yvonne A Zurynski, BAppSc, MAppSc, PhD, Assistant Director,¹ and Senior Lecturer²

Deepika Mahajan, BSc(Hons), MSc, PhD, Research Fellow¹

Heather D'Antoine, BAppSc, MHEc, Senior Research Officer³

Elizabeth J Elliott, MD, FRACP, FRCPC, Director,¹ Professor of Paediatrics and Child Health,² and Paediatrician⁴

¹ Australian Paediatric Surveillance Unit, The Children's Hospital at Westmead, Sydney, NSW.

² Discipline of Paediatrics and Child Health, University of Sydney, Sydney, NSW.

³ Telethon Institute for Child Health Research, Perth, WA.

⁴ The Children's Hospital at Westmead, Sydney, NSW.

Correspondence: yonnez@chw.edu.au

References

- 1 Trewin D. National Aboriginal and Torres Strait Islander Health Survey, 2004–05. Canberra: Australian Bureau of Statistics, 2006. (ABS Cat. No. 4715.0.)
- 2 Ring IT, O'Brien JF. Our hearts and minds — what would it take for Australia to become the healthiest country in the world? *Med J Aust* 2007; 187: 447–451.
- 3 Helps Y, Harrison J. Hospitalised injury of Australia's Aboriginal and Torres Strait Islander people 2000–02. Adelaide: Australian Institute of Health and Welfare, 2006. (AIHW Cat. No. INJCAT 94.)
- 4 Australian Institute of Health and Welfare. A picture of Australia's children. Canberra: AIHW, 2005. (AIHW Cat. No. PHE 58.)
- 5 Australian Institute of Health and Welfare. Data quality of Aboriginal and Torres Strait Islander identification: seven community services data collections. Canberra: AIHW, 2004. (AIHW Cat. No. HWI 79.)
- 6 Australian Institute of Health and Welfare. Improving the quality of Indigenous identification in hospital separations data. Canberra: AIHW, 2005. (AIHW Cat. No. HSE 101.)
- 7 Thomas DP, Anderson IP. Use of emergency departments by Aboriginal and Torres Strait Islander people. *Emerg Med Australas* 2006; 18: 68–76.
- 8 Australian Institute of Health and Welfare. Australian hospital statistics 2004–05. Canberra: AIHW, 2006. (AIHW Cat. No. HSE 41.)
- 9 Australian Institute of Health and Welfare. Aboriginal and Torres Strait Islander health performance framework 2006 report: detailed analyses. Canberra: AIHW, 2007. (AIHW Cat. No. IHW 20.) <http://www.aihw.gov.au/publications/index.cfm/title/10429> (accessed Apr 2008).
- 10 Phillips A. Describing remote health and well-being in Australia. Health and well-being in remote Australia: public seminar; 2005 Nov 1; Canberra. Canberra: National Rural Health Alliance, 2005. <http://nrha.rural-health.org.au/seminars/?IntContId=101&IntCatId=18> (accessed Apr 2008).
- 11 Australian Institute of Health and Welfare. National Advisory Group on Aboriginal and Torres Strait Islander Health Information and Data: strategic plan 2006–2008. Canberra: AIHW, 2006. (AIHW Cat. No. IHW 19.)
- 12 Australian Institute of Health and Welfare; Australian Bureau of Statistics. Recent developments in the collection of Aboriginal and Torres Strait Islander health and welfare statistics 2005. Canberra: AIHW; ABS, 2006.
- 13 Research and Analysis Branch, Australian Government Department of Family, Community Services and Indigenous Affairs. 2006/07 directions for Footprints in Time. A Longitudinal Study of Indigenous Children. Developing research options. Canberra: FaCSIA, 2007.
- 14 Zurynski YA, Peardon E, Bower C, Elliott EJ. Impacts of national surveillance for uncommon conditions in childhood. *J Paediatr Child Health* 2007; 43: 724–731.
- 15 National Aboriginal Community Controlled Health Organisation. What's needed to improve child health in the Aboriginal and Torres Strait Islander population. Canberra: NACCHO, 2003.
- 16 Northern Territory Aboriginal Health Key Performance Indicators Information System [website]. <http://www.nt.gov.au/health/ahkpi/> (accessed Dec 2007).
- 17 Britt H, Miller GC, Charles J, et al. BEACH: Bettering the Evaluation And Care of Health. General practice activity in Australia 2005–06. Canberra: Australian Institute of Health and Welfare, 2007. (AIHW Cat. No. GEP 19.)
- 18 Office for Aboriginal and Torres Strait Islander Health; National Aboriginal Community Controlled Health Organisation. A national profile of Australian Government funded Aboriginal and Torres Strait Islander Primary Health services. Service activity reporting 2004–05 key results. Canberra: Commonwealth of Australia, 2008. [http://www.health.gov.au/internet/main/publishing.nsf/Content/109B161487EB5078CA25722B00834290/\\$File/service%20activity%20reporting%2004%2005%20key%20results.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/109B161487EB5078CA25722B00834290/$File/service%20activity%20reporting%2004%2005%20key%20results.pdf) (accessed Apr 2008).
- 19 Jamieson LM, Sayers SM. Indigenous health research — changes in 60 years. *Aust NZ J Public Health* 2006; 30: 385–387.
- 20 Charles J, Britt H, Knox S. Encounters with indigenous patients in Australian general practice. *Aust Fam Physician* 2005; 34: 810–811.
- 21 Zubrick SR, Silburn SR, Lawrence DM, et al. The Western Australian Aboriginal Child Health Survey: the social and emotional wellbeing of Aboriginal children and young people. WAACHS Vol. 2. Perth: Telethon Institute for Child Health Research, 2005.
- 22 Rawnsley T, Dexter S, Palin K. Synthesising estimates of Indigenous child health based on the WA Aboriginal Child Health Survey. Research paper. Canberra: Australian Bureau of Statistics Analytical Services Branch, 2005. (ABS Cat. No. 1352.0.55.071.)
- 23 Menzies R, McIntyre P. Vaccine preventable diseases and vaccination policy for indigenous populations. *Epidemiol Rev* 2006; 28: 71–80.
- 24 Menzies R, McIntyre P, Beard F. Vaccine preventable diseases and vaccination coverage in Aboriginal and Torres Strait Islander people, Australia, 1999 to 2002. *Commun Dis Intell* 2004; 28: 127–159.
- 25 Steering Committee for the Review of Government Service Provision. Overcoming Indigenous disadvantage key indicators 2005. Canberra: Australian Government Productivity Commission, 2005.
- 26 Maguire GP, Nelson C. Acute rheumatic fever and rheumatic heart disease: an insight into Aboriginal health disadvantage and remote Australia [editorial]. *Med J Aust* 2006; 184: 506.
- 27 Sawyer MG, Arney FM, Baghurst PA, et al. The mental health of young people in Australia. Canberra: Mental Health and Special Programs Branch, Commonwealth Department of Health and Aged Care, 2000.
- 28 Australian Institute of Health and Welfare. Quality of Aboriginal and Torres Strait Islander identification in community services data collections. Update on eight community services data collections. Canberra: AIHW, 2007. (AIHW Cat. No. HWI 95.)
- 29 Australian Bureau of Statistics. Improving statistics on children and youth — an information development plan, 2006. Information paper. Canberra: ABS, 2006. (ABS Cat. No. 4907.0.)
- 30 Dade Smith J. Educating to improve population health outcomes in chronic disease. A curriculum package to integrate a population health approach for the prevention, early detection and management of chronic disease when educating the primary health care workforce in remote and rural northern Australia. Darwin: Menzies School of Health Research, 2005.

(Received 28 Aug 2007, accepted 3 Mar 2008)

