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# **Thematic list of projects using linked data relating to Aboriginal and Torres Strait Islander people**

Australian Institute of Health and Welfare  
Canberra

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# Abbreviations

ABS	Australian Bureau of Statistics
ACIR	Australian Childhood Immunisation Register
ACT	Australian Capital Territory
AEDI	Australian Early Development Index
AGE	acute gastroenteritis
AHLO	Aboriginal Health Liaison Officers
AIHW	Australian Institute of Health and Welfare
ALRI	acute lower respiratory infection
AMI	acute myocardial infarction
ANZDATA	Australian and New Zealand Dialysis and Transplant Registry
APDC	Admitted Patients Data Collection
APOCC	Aboriginal Patterns of Cancer Care
BBV	blood borne virus
CALD	culturally and linguistically diverse
CHC	Child Health Check
CHCI	Child Health Check Initiative
CHD	coronary heart disease
CHeReL	Centre for Health Record Linkage
CMI	Client Master Index
CRIAH	Coalition for Research to Improve Aboriginal Health
DOB	date of birth
DoHWA	Department of Health Western Australia
DRUID	Darwin Region Urban Indigenous Diabetes Study
DSC	Western Australian Disabilities Services Commission
GAA	Growth Assessment and Action dataset
HMDC	Hospital Morbidity Data Collection
HRN	Hospital Registration Number

HSC	Health Statistics Centre, Queensland Health
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification
ICP	invasive coronary procedures
ID	intellectual disability
IDEA	Intellectual Disability Exploring Answers Dataset
IHD	ischaemic heart disease
IHOPE	Indigenous Health Outcomes Patient Evaluation
INOIS	Integrated Numerical Offender Identification System
MCCD	Medical Certificate of Causes of Death
MCEECDYA	Ministerial Council for Education, Early Childhood Development and Youth Affairs
MCHRDB	Maternal and Child Health Research Database
MDC	Midwives Data Collection
MHIS	Mental Health Information System
MNS/MWDS	Midwives Notification System
NAS	neonatal abstinence syndrome
NDI	National Death Index
NIDD	Western Australian Notifiable Infectious Diseases Database
NOCS	Queensland Health Notifiable Conditions database
NSW	New South Wales
NTCR	Northern Territory Cancer Register
NTER	Northern Territory Emergency Response
NTGPS	Northern Territory Government Pathology Service
NTNDS	Northern Territory Notifiable Diseases Database
OIMS	Offender Integrated Management Services
PAARS	Perth Aboriginal Atherosclerosis Risk Study
PAF	population attributable fraction
PDC	Perinatal Data Collection
PHDAS	Pharmaceutical Drugs of Addiction System

QHAPDC	Queensland Hospital Administration Patient Data Collection
RBDM	Registry of Births, Deaths and Marriages
SEARCH	Study of Environment on Aboriginal Resilience and Child Health
SES	socioeconomic status
SEIFA	Socio-Economic Indexes for Areas
STI	sexually transmitted infection
TIA	transient ischaemic attack
TICHR	Telethon Institute for Child Health Research
UMRN	Unit Medical Record Number
UQ	University of Queensland
UWA	University of Western Australia
VAED	Victorian Admitted Episodes Dataset
VCCR	Victorian Cervical Cytology Register
VIVAS	Vaccination Information/Vaccination Administration System
WA	Western Australia
WAACHS	Western Australian Aboriginal Child Health Survey
WADLS	West Australian Data Linkage System

# Summary

This report contains an alphabetical listing and description of past (published since 1991), current and planned data linkage studies relating to Aboriginal and Torres Strait Islander people. The publication provides a brief listing of:

- the name of the project
- the names of the investigators
- the date of the study
- the jurisdiction where the study is based
- the datasets used in the study
- the core issue, or theme, of the study
- the method of analysis
- the method or algorithms used or intended to be used to derive Indigenous status information, if required.

This list should be read in conjunction with the *National best practice guidelines for data linkage activities relating to Aboriginal and Torres Strait Islander People* and its online attachment, *Report on the use of linked data relating to Aboriginal and Torres Strait Islander people*.

The list was compiled from consultations with jurisdictional departments and researchers who use linked data relating to Aboriginal and Torres Strait Islander Australians and from reports and academic journal articles that describe the analysis of linked data relating to Aboriginal and Torres Strait Islander Australians.

# Introduction

This report consists of a thematic list of projects that used, or are using, data linkage in regard to Aboriginal and Torres Strait Islander people. The report is intended to be a resource for analysts and data linkers, who are considering project design or just researching data linkage that has been conducted according to various medical themes or conditions affecting Aboriginal and Torres Strait Islander Australians.

The AIHW refers to the Indigenous people of Australia as Aboriginal and Torres Strait Islander people. However, Aboriginal and Torres Strait Islander people are referred to in various ways in the data linkage literature listed in this report. Throughout this report, the practice of each study or report in using terms such as 'Indigenous', 'Aboriginal' or 'Aboriginal and Torres Strait Islander' has been retained when describing each study, as imposing AIHW practice may risk misrepresenting the reviewed studies.

## Breast cancer

Project	Safety and Quality of Surgical Care Project — Breast Cancer Management and Survival
Investigators	Sonja Hall, D'Arcy Holman.
Jurisdiction/s	Western Australia (WA).
Year/s	1982–2000.
Publications/outputs	Hall & Holman 2003, two other journal articles, one presentation, one poster, eight media runs.
Datasets	Hospital morbidity, cancer registrations and death records from WA Record Linkage Project, now known as Western Australian Data Linkage System (WADLS). 11,024 non-Indigenous/not stated and 151 Indigenous participants.
Project description	WA Record Linkage Project was used to extract records of all WA resident women that mention breast cancer for 1 January 1982–31 December 2000. Rates of breast reconstructive surgery were calculated and compared between several variables, including Indigenous status (non-Indigenous/not stated versus Indigenous). Conclusion: Indigenous women were less likely to get reconstructive surgery than non-Indigenous women (half the rate). See <i>Report on the use of linked data relating to Aboriginal and Torres Strait Islander people</i> , page 31.
Linkage details	Linkages current as of 1 October 2001. No details of linkage, other than total numbers used.

Project	Participation in cervical and breast cancer screening among Victorian women of Indigenous, and culturally and linguistically diverse (CALD) backgrounds
Investigators	Victoria Cytology Service (Julia Brotherton, Dorota Gertig, Genevieve Chappell); Screening and Cancer Prevention, Department of Health Victoria (Louise Galloway); possibly BreastScreen Victoria.
Jurisdiction/s	Victoria.
Year/s	From 2000 onwards.
Publications/outputs	None to date.
Datasets	Victorian Cervical Cytology Register, Victorian Admitted Episodes Dataset, Victorian Emergency Minimum Dataset, BreastScreen Victoria Register.
Project description	The main objective of the project is to use data linkage to provide baseline information about cervical screening uptake among Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities in Victoria. The Victorian Cervical Cytology Register (VCCR) does not collect information on Indigenous or ethnic status. It is therefore difficult to determine comparative screening rates in these communities. Data linkage will be used to obtain information on Indigenous and ethnic status from the other datasets. The project will compare cervical and breast screening participation and behaviour among Victorian women of CALD background, Indigenous women and other Victorian women. It will also compare patterns and demographic predictors of screening attendance for either, or both, cervical and breast screening, among women of eligible age for both programs. Ethics approval has been obtained. The linkage will be conducted by Victorian Data Linkages.
Linkage details	Not yet available.

# Cancer (general)

Project	Northern Territory Cancer Register Data Quality 1981–2001
Investigators	J Condon, Y Zhao, B Armstrong, A Barnes.
Jurisdiction/s	Northern Territory.
Year/s	1981–2001 (accessed August 2003).
Publications/outputs	Condon et al. 2004b.
Datasets	Northern Territory Cancer Register (NCR), Caresys Client Master Index (CMI) derived from the Hospital Separations Dataset, Hospital Separations Dataset, Northern Territory Registry of Births, Deaths and Marriages (NT RBDM) death registrations (January 1991–December 2002).
Project description	<p>NCR data was audited systematically, with data linkage used in a number of components. Indigenous under-identification and comparison of data quality of other variables between Indigenous and non-Indigenous patients were among the audited attributes. These particular attributes were:</p> <ul style="list-style-type: none"> <li>• As part of the re–screening of data sources for the NCR: <ul style="list-style-type: none"> <li>– hospital separations with a cancer diagnosis were linked to the NCR by Hospital Registration Number (HRN) via the CMI.</li> <li>– registered deaths due to cancer were linked to the NCR.</li> </ul> </li> <li>• To allow comparison of registration rates, NCR records with missing or unknown Indigenous status were resolved with their Indigenous status on the CMI (presumably matched using the HRN). Those that could still not be resolved were included with non-Indigenous records for subsequent calculations.</li> <li>• Misclassification of NCR Indigenous status was quantified by randomly sampling 500 NCR records diagnosed between 1991 and 1999 and matching them to the CMI. The subset of records that matched was used to calculate the ratio of patients expected to self-identify as Indigenous or non-Indigenous, based on a previous audit of the CMI (Condon et al. 1998) versus their Indigenous status on the NCR.</li> </ul> <p>The proportion of cases missed by the NCR was found to be similar for Indigenous and non-Indigenous patients (2.4% and 2.8% respectively). Data accuracy was found to be lower for Indigenous patients. Furthermore, a small proportion of Indigenous patients were misclassified as non-Indigenous, resulting in a 15% under-estimation of Indigenous cancer incidence rates. With the exception of estimated year of birth, particularly amongst older patients, a high proportion of Indigenous registrations had no birth date data. However, there was no evidence that this lack of birth dates biased the age–standardised incidence rates.</p>
Linkage details	<p>A relatively large amount of detail was reported. The linkage mostly used the HRN as the sole linkage variable, so the linkage may have been easy to describe. After electronic matching of the hospital dataset, unmatched separations were manually matched by name and date of birth. Deaths data (which did not have the HRN) were linked by name, sex and date of birth, after which unlinked records were manually checked against the NCR. The remainder of these were then followed–up with doctors and hospitals directly.</p> <p>Accuracy of HRNs in the NCR was previously assessed by linking the NCR and the CMI using different sets of personal data as linking variables rather than using the HRN. The process and results of this linkage are detailed in the report’s Appendix (Condon et al. 2004b).</p> <p>Indigenous status on the NCR is primarily obtained from the CMI, supplemented by death certificates, hospital medical records, and contact with treating doctors.</p>

<b>Project</b>	<b>Aboriginal Patterns of Cancer Care (APOCC) Project</b>
Investigators	Dianne O'Connell, Phyllis Butow, Bruce Armstrong, Carla Treloar, Anthony Dillon, Christy Newman, Rajah Supramaniam (Cancer Epidemiology Research Unit, Cancer Council NSW).
Jurisdiction/s	New South Wales.
Year/s	July 1993–July 2003 (APDC), NSW Central Cancer Registry (1994–2002).
Publications/outputs	None to date.
Datasets	Admitted Patients Data Collection, NSW Central Cancer Registry.
Project description	The APOCC project explores possible reasons for increased death rates from cancer for NSW Aboriginal people by looking at late diagnosis, barriers to diagnosis and care as well as current care for Aboriginal cancer patients compared to non-Aboriginal patients. The first phase analyses linked cancer and hospital records for all patients in NSW and compares Aboriginal and non-Aboriginal patient outcomes. The 'ever-Indigenous' algorithm was used since this algorithm is presumed to still undercount Aboriginal cancer numbers despite being highly sensitive. Several factors are being analysed including surgery for cancer, location of residence, and comorbidities. Surgery rates and waiting times were found to be similar between Aboriginal and non-Aboriginal patients with breast cancer, but survival rates after 6 years were significantly lower for Aboriginal women. Further phases of this project, not involving data linkage, should provide more information about the radiotherapy and chemotherapy for Aboriginal people with cancer.
Linkage details	Not yet available.

## Cardiovascular

<b>Project</b>	<b>Circulatory disease — Aboriginality</b>
Investigators	Carol Cameron (DoHWA)
Jurisdiction/s	Western Australia.
Year/s	Project proposal date 1996.
Publications/outputs	None.
Datasets	Unknown. Most probably WADLS core linked datasets.
Project description	None available.
Linkage details	None available.

<b>Project</b>	<b>Stroke Risk Factors, Cardiac Treatment and Outcomes</b>
Investigators	Peter Somerford, Stella Serafino.
Jurisdiction/s	Western Australia (also compared with South Australian and Northern Territory data).
Year/s	Project proposal date 2000.
Publications/outputs	Draper et al. 2005, Lee et al. 2003, 2004b.
Datasets	WA inpatient hospital morbidity records, WA death records. For Draper G. et al. 2005: National and state health registers data, surveys and ad hoc studies.
Project description	<p>Draper et al. 2005: See <i>Report on the use of linked data</i>, page 22. This report updates health status indicators and extends trend data for the Western Australian population from an earlier edition published in 2000. Changes in health status were described over time and, where possible, national data were included for the purpose of providing a benchmark against which to assess WA findings. Aboriginal mortality trends were derived for WA and then compared to the Northern Territory and South Australian Aboriginal populations. The study found that over the past decade, mortality rates among the WA Aboriginal population have decreased, while mortality rates among NT and SA Aboriginal populations, have remained stable.</p> <p>Lee et al. 2004b: See <i>Report on the use of linked data</i>, pages 29 and 31. This study investigated the risk factors for ischaemic stroke recurrence among patients admitted to hospital after their first ischaemic stroke, through a retrospective study involving linked hospitalisation and death records in WA. The study found that Aboriginality and transfer to another hospital upon admission, for first-ever ischaemic stroke, were important risk factors for ischaemic stroke recurrence.</p> <p>Lee et al. 2003: See <i>Report on the use of linked data</i>, page 31. This project used data linkage to determine factors influencing survival rates among patients admitted to WA hospitals for the first time for stroke or transient ischaemic attack (TIA). Linked hospitalisation and death records of patients (7,784) admitted to hospital for first-ever stroke or TIA between July 1995 and December 1998 were retrieved to determine survival rates. The use of linked hospitalisation and death data allowed the authors to increase the scope and size of the study compared with previous studies of survival after stroke and TIA in WA. The study found Aboriginality to be one of the predictors of survival after stroke.</p>
Linkage details	Few details reported.

<b>Project</b>	<b>Incidence and survival analysis for acute myocardial infarctions (AMI) in the Northern Territory</b>
Investigators	Jiqiong You, John Condon, Yuejen Zhao, Steve Guthridge.
Jurisdiction/s	Northern Territory.
Year/s	1992–2004.
Publications/outputs	You et al. 2009.
Datasets	NT hospital separations dataset (1 July 1990–31 December 2004, minus patients with first AMI admission prior to 1 January 1992), ABS-coded deaths data held by NT Health (deaths between 1 January 1992 and 31 December 2004), National Death Index (NDI).
Project description	Incidence and survival rates for AMI were estimated and compared for NT Indigenous and non-Indigenous populations, through a retrospective cohort study for all new AMI cases recorded in hospital admissions data and/or registered deaths due to ischaemic heart disease (IHD) between 1992 and 2004. For further details, see <i>Report on the use of linked data</i> , pages 28–9.
Linkage details	<p>See <i>Report on the use of linked data</i>, page 29.</p> <p>NT NDI data for the study period does not contain an Indigenous status variable, and as a result, the NDI was not available as a data source. Indigenous and non-Indigenous people were compared using their Indigenous status as indicated on their hospital records or, if not admitted to hospital for AMI, their death record in ABS-coded deaths data was used. Indigenous status was recorded inconsistently for less than 5% of study participants between their deaths record and hospital records. In these instances, Indigenous status in the admissions record was consistent with other hospital records, so the hospital record was used. Validation studies of NT hospital records had also shown their Indigenous status variable to be of high quality (94% and 97% in 1998 and 2008 respectively), meaning that researchers were more inclined to regard these data as reliable (You 2011).</p>

<b>Project</b>	<b>Heart Disease Among Urban Australian Aboriginal People and the Use of Interventions to Treat Heart Disease</b>
Investigators	Peter Thompson, Judith Finn, and others.
Jurisdiction/s	Western Australia.
Year/s	Project proposal date 2007.
Publications/outputs	Bradshaw et al. 2009, 2010a, 2010b.
Datasets	WADLS core linked data – administrative data including: WA Hospital Morbidity Database (HMD); deaths from WA RBDM; Perth Aboriginal Atherosclerosis Risk Study (PAARS). For Bradshaw et al. 2010a and Bradshaw et al. 2010b, the WA Data Linkage Branch (DoHWA) used age, sex, and census collection district from the electoral roll to recruit non-Indigenous people and linked them to the HMD to find those with ischemic heart disease (IHD). Records for this control group identified from the HMD as being for Indigenous people were then excluded. WA death registrations were also linked for Bradshaw et al. 2010b. HMD and deaths were used as the source of Indigenous status data to exclude Aboriginal and Torres Strait Islander people from the 'non-Indigenous' comparison group.
Project description	<p>Bradshaw et al. 2009: See <i>Report on the use of linked data</i>, pages 12, 15–6, 19 and 21. Sensitivity of Indigenous identification was assessed in the HMD by linking them to PAARS, a longitudinal study of self-identified Aboriginal people.</p> <p>Bradshaw et al. 2010b: See <i>Report on the use of linked data</i>, pages 21 and 22. Use of coronary revascularisation was compared between Aboriginal and Torres Strait Islander people with IHD in the PAARS with a matched non-Indigenous group. No differences between groups except that Indigenous patients were more likely to have a coronary artery bypass graft than a percutaneous coronary intervention. Reasons for the latter are discussed in regards to the higher incidence of diabetes in the Indigenous group.</p> <p>Bradshaw et al. 2010a: See <i>Report on the use of linked data</i>, pages 12, 21 and 22. PAARS participants and a matched non-Indigenous comparison group who had not had a coronary heart disease (CHD) event were followed up from 1998–2006 for CHD events. Socioeconomic disadvantage was controlled for using Socio-Economic Indexes for Areas (SEIFA) and postcode. Diabetes was the major risk factor in greater rate; 52% of participants with a CHD event had diabetes, with women having a greater risk factor in comparison to men. PAARS participants also had events at a much younger age. Relatively high employment rates for PAARS participants compared to the general Indigenous population, and controlling for socioeconomic status, suggests that the overall gap between Indigenous and non-Indigenous people would be even worse. CHD rates were not significantly different between men and women for Aboriginal and Torres Strait Islander people, which was not the case for non-Indigenous people.</p> <p>Also see <i>Report on the use of linked data</i>, pages 11–12, 15, 18, 20–21 and 22.</p>
Linkage details	<p>Bradshaw et al. 2009: Extensive reporting on linkage. Probabilistic matching was used. Linking variables and coding are reported. Proportions of correct identifications per patient were ranked by 10 percentile partitions. Sensitivity: Numbers of admissions correctly identified / total admissions. Trend in sensitivity over time was also calculated.</p> <p>Bradshaw et al. 2010b: Probabilistic matching was used, with linking variables listed. No quality measures are mentioned except to repeat the standard WADLS false positive and negative levels reported in Holman et al. 1999.</p> <p>Bradshaw et al. 2010a: PAARS and the comparison group were linked to hospital morbidity database and deaths registrations to add clinical information. Follow-up was conducted using data linkage. Some details of data confidentiality are described.</p>

<b>Project</b>	<b>Case fatality following Acute Myocardial Infarction in Aboriginal and Non-Aboriginal Western Australians</b>
Investigators	Judith Katzenellenbogen, Frank Sanfilippo, Michael Hobbs, Tom Briffa, Steve Ridout, Matthew Knuiman, Lyn Dimer, Kate Taylor, Peter Thompson, Sandra Thompson.
Jurisdiction/s	Western Australia.
Year/s	2000–2004.
Publications/output s	Katzenellenbogen et al. 2010.
Datasets	WADLS core linked data (Hospital Morbidity Data Collection, mortality data 1985–2004, and WA deaths data 2000–2004).
Project description	See <i>Report on the use of linked data</i> , pages 21 and 23–4.
Linkage details	See <i>Report on the use of linked data</i> , pages 23–4.

<b>Project</b>	<b>Under-ascertainment of Aboriginality in records of cardiovascular disease in hospital morbidity and mortality data in Western Australia: a data linkage study (related to previous project)</b>
Investigators	Tom Briffa, Frank Sanfilippo, Michael Hobbs, Steve Ridout, Judith Katzenellenbogen, Peter Thompson, Sandra Thompson.
Jurisdiction/s	Western Australia.
Year/s	2000–2005.
Publications/outputs	Briffa et al. 2010.
Datasets	WADLS core linked data (Hospital Morbidity Data Collection (HMDC) 1980–2005, and WA deaths data 2000–2005).
Project description	See <i>Report on the use of linked data</i> , pages 11–12 and 21.
Linkage details	See <i>Report on the use of linked data</i> , pages 11–12.
<b>Project</b>	<b>Burden of Stroke in Indigenous Western Australians: a study using data linkage</b>
Investigators	J Katzenellenbogen, T Vos, P Somerford, S Begg, J Semmens, J Codde.
Jurisdiction/s	Western Australia.
Year/s	July 1997–June 2002.
Publications/outputs	Katzenellenbogen et al. 2011.
Datasets	WA Hospital Morbidity Data Collection (aged 15 and over), WA mortality records, Perth Community Stroke Study.
Project description	The incidence and burden of stroke on Aboriginal and Torres Strait Islander people and on non-Indigenous people in WA was compared. Incidence and excess mortality rates were estimated from linked hospital and mortality data. Fatal and non-fatal burden was calculated as Disability Adjusted Life Years. Indigenous patients had a higher excess mortality rate and lower estimates of duration (time between stroke and death in the study period). See <i>Report on the use of linked data</i> , page 24.
Linkage details	Data linked through WADLS. Survival status was gauged from incident cases who survived to 28 days which were identified by merging these hospital records with mortality records. Linkage variables were not reported. 84% of Indigenous cases were consistently Indigenous across their linked hospital and mortality records, which was compatible with previous evaluations of Indigenous identification in hospital data (Young 2001). Cases were coded as Indigenous if any hospital admission between 1988 and 2002 identified them as Indigenous or death records identified them as Indigenous. For further details, see <i>Report on the use of linked data</i> , page 24.
<b>Project</b>	<b>Indigenous health: Towards development of evidence based policies using data linkage techniques</b>
Investigators	M Coory, IA Scott, P Baade, WF Walsh.
Jurisdiction/s	Queensland.
Year/s	1998, 1998–2002.
Publications/outputs	Coory et al. 2002, Coory & Walsh 2005.
Datasets	Queensland Hospital Admitted Patients' Data Collection (QHAPDC); Queensland death registrations.
Project description	Coory et al. 2002: 3531 patients admitted for acute myocardial infarction (AMI) in 1998 were selected and followed up for 1 year using linkage, to analyse rate of invasive coronary procedures (ICP) by socioeconomic status (SES). They examined time to ICP by SES and public–private status using a proportional hazards model. No Indigenous comparison was done.  Coory & Walsh 2005: Described as first study in Australia to look at racial differences in coronary procedure rates (compared to at least 25 from the United States at the time). See <i>Report on the use of linked data</i> , page 28.
Linkage details	Coory et al. 2002: Probabilistic internal linkage based on Medicare number, date of birth, sex, country of birth, and address of usual residence. No other information about linkage.  Coory & Walsh 2005: See <i>Report on the use of linked data</i> , page 28. Torres Strait Islander numbers were <0.6%, so they were included in Indigenous numbers. Characteristics of Indigenous and non-Indigenous patients in the cohort were compared before the main analysis. No other information about linkage (e.g. how Indigenous status was resolved for conflicting records) was described.

# Child Health

<b>Project</b>	<b>Western Australian Maternal and Child Health Research Database (MCHRDB)</b>
Investigators	Fiona Stanley, Anne Read, Jennifer Kurinczuk, Maxine Croft, Carol Bower.
Jurisdiction/s	Western Australia.
Year/s	1980– (ongoing)
Publications/outputs	Stanley et al. 1994, Stanley et al. 1997.
Datasets	Midwives' Birth Notifications; WA RBDM – Birth registrations and Death Certificates (post-ABS validation); Inpatient hospital morbidity data for children aged up to 15; WA Birth Defects Registry and WA Cerebral Palsy Register.
Project description	MCHRDB constructed progressively over 3 decades, with additional datasets being linked to it as they became available. See <i>Report on the use of linked data</i> , page 26–7.
Linkage details	First, Midwives' Birth Notifications were linked to birth registrations (WA RBDM) with identifiers given to each mother/infant pair. Death information was then added. Secondly, inpatient hospital morbidity data for children aged up to 15 were linked. Thirdly, annual linkage of Birth Defects Registry and Cerebral Palsy Register — but only to attach the MCHRDB Identifier to each record in these registries (no additional data put into MCHRDB). Finally, siblings were to be internally linked. Aboriginality was detected through Indigenous status of mother only. The first and third linkages were deterministic, the second linkage was probabilistic with its own weights generated, followed by some manual clerical review.
<b>Project</b>	<b>Genitourinary tract infections in pregnancy and low birth weight</b>
Investigators	Rosalie Schultz, Anne W Read, Judith AY Straton, Fiona J Stanley, Patricia Morich.
Jurisdiction/s	Western Australia.
Year/s	Unknown.
Publications/outputs	Schultz et al. 1991.
Datasets	MCHRDB.
Project description	Case-control study. MCHRDB used to find children, with Indigenous mothers, of particular birth weight, and then linked with hospital and Aboriginal Medical Service records of genitourinary tract infections in the mothers. Infections by some pathogens were found to be significant predictors of low birth weight (and by extension preterm birth). Infections were the strongest predictor of low birth weight when threatened miscarriage and prolonged premature membranes rupture cases were removed. See <i>Report on the use of linked data</i> , page 26.
Linkage details	Numbers of linked and unlinked records were reported. Other details about the linkage were not published.
<b>Project</b>	<b>Stillbirths, neonatal and post-neonatal mortality by race, birthweight and gestational age</b>
Investigators	EV Kliewer, FJ Stanley.
Jurisdiction/s	Western Australia.
Year/s	1980–86.
Publications/outputs	Kliewer & Stanley 1993.
Datasets	MCHRDB, WA births, neonatal and postnatal deaths.
Project description	WA MCHRDB live and still births for 1980–86 linked to births, neonatal and postnatal deaths from WA Health. Mortality risks were found to be higher for Aboriginals than whites, except when accounting for lower birthweight and shorter gestation times. Gap increased with age of death. Possible reasons for pattern explored. See <i>Report on the use of linked data</i> , page 26.
Linkage details	Children with Aboriginal fathers and white mothers were grouped with white children. Source of Indigenous status and how missing Indigenous status was treated during the analysis is not stated. Extracted analysis variables are given, but no details of linkage (this study predates WADLS, so the datasets may not necessarily have already been linked).

<b>Project</b>	<b>Hospital admissions before the age of 2 years in Western Australia</b>
Investigators	Anne W Read, John Gibbins, Fiona J Stanley, Patricia Morich.
Jurisdiction/s	Western Australia.
Year/s	1986.
Publications/outputs	Read et al. 1994.
Datasets	MCHRDB (as Midwives Notifications plus birth registrations), WA Hospital Morbidity Data Collection.
Project description	MCHRDB (as Midwives Notifications plus birth registrations) linked with WA Hospital Morbidity Data Collection. Hospital discharge records were linked to individual birth records. Described linked data for the first 2 years of life for all WA-born children in 1986. Supplemented some morbidities by 'going back to individual hospitals'. Admission rates for Aboriginal children were much higher and admission times were longer. Aboriginal and non-Aboriginal children were compared for all conditions. This paper is the 'first step in series of studies on WA children's hospital admissions'. See <i>Report on the use of linked data</i> , page 27.
Linkage details	Linkage rate was 96% for non-Aboriginal children versus 88% for Aboriginal children. Children of unknown race were excluded from analysis. Data source for Indigenous status not specified.

<b>Project</b>	<b>Hospital admissions for lower respiratory tract illness before the age of 2 in Western Australia</b>
Investigators	Anne W Read, John Gibbins, Fiona J Stanley.
Jurisdiction/s	Western Australia.
Year/s	1986.
Publications/outputs	Read et al. 1996.
Datasets	MCHRDB (as Midwives Notifications plus birth registrations), WA Hospital Morbidity Data Collection.
Project description	Similar data as for Read et al. 1994 (see above), but focussed on lower respiratory tract infections. Refers to Read et al. 1994 with respect to the data. The study compared Aboriginal with non-Aboriginal children for most variables and different respiratory infections. The study found that incidence for Aboriginal children was higher for most variables and for admissions, but a smaller proportion of admissions were for perinatal conditions (though higher per 1000 live births). Further, non-Aboriginal admissions were decreasing over time while Aboriginal admissions were increasing. See <i>Report on the use of linked data</i> , page 27.
Linkage details	See above for Read et al. 1994.

<b>Project</b>	<b>Cumulative mortality in children aged 1–6 born in Western Australia from 1980–89</b>
Investigators	Louisa M Alessandri, Helen M Chambers, Carol Garfield, Sharon Vukovich, Anne W Read.
Jurisdiction/s	Western Australia.
Year/s	1980–89.
Publications/outputs	Alessandri et al. 1999.
Datasets	MCHRDB, ABS/WA deaths data (National Mortality Database), post-mortem record from forensic pathology section of WA State Health Lab Services, Princess Margaret Hospital for Children, Perth Coroner's office (who also source the County Coroner's office).
Project description	See <i>Report on the use of linked data</i> , page 32. The study also compared by gender, birth weight, gestational and maternal age, parity and marital status. The type of accident that mostly caused mortality differed between Indigenous and non-Indigenous children.
Linkage details	Numbers of records which could not be linked between deaths dataset and MCHRDB are given, and some different sources of cause of death, but no other variable.

<b>Project</b>	<b>Patterns, trends, and increasing disparities in mortality for Aboriginal and non-Aboriginal infants born in Western Australia, 1980–2001</b>
Investigators	C Jane Freemantle, Anne W Read, Nicholas H de Klerk, Daniel McAullay, Ian P Anderson, Fiona J Stanley.
Jurisdiction/s	Western Australia.
Year/s	1980–2001.
Publications/outputs	Freemantle et al. 2006.
Datasets	MCHRDB, WA Hospital Morbidity Data Collection, ABS/WA deaths data, autopsy reports.
Project description	Determined all-cause mortality for WA-born Aboriginal and non-Aboriginal infants born 1980–2001. Extracted live births linked to deaths. Causes of death were taken from Registrar-General and autopsy reports, and individually scrutinised. Indigenous status data supplemented from morbidity data. Compared across Indigenous status, causes of death, and age of mother. Neonatal and post-neonatal deaths were separated and compared. Indigenous and remote areas had worse mortality, with the gap between Indigenous and non-Indigenous mortality widening due to greater improvements in non-Indigenous mortality numbers. Rates declined for almost all classes. See <i>Report on the use of linked data</i> , page 27.
Linkage details	Detailed description of Indigenous status in MCHRDB. Infants whose mothers were recorded as Aboriginal or Torres Strait Islander in MCHRDB were used, which is ultimately from Midwives Notification System (citing the 14th annual report on DoHWA perinatal statistics). Indigenous status of mother was sought from morbidity data if missing in MCHRDB. If the father is Indigenous and the mother is non-Indigenous, the child was treated as non-Indigenous because it was not statistically possible to distinguish these children from non-Indigenous children. If the ethnicity of the mother or child was still unknown, they were excluded from analysis (the numbers of these are stated). Other quantities or measures of linkage were not reported.

<b>Project</b>	<b>Western Australian Aboriginal Intergenerational Fetal Growth Study</b>
Investigators	Sandra Eades, Fiona Stanley, Bridgette McNamara, Glenn Pearson, Amanda Langridge, Carrington Shepherd, Nick de Klerk and others (Baker IDI, Telethon Institute of Child Health Research).
Jurisdiction/s	Western Australia.
Year/s	1980–2009.
Publications/outputs	Preliminary results presented at the 2011 Coalition for Research to Improve Aboriginal Health (CRIA) Conference.
Datasets	Datasets formerly used for the Maternal and Child Health Research Database (MCHRDB) including data on all pregnancies, births and perinatal factors, hospitalisations, deaths, mental health and birth defects in babies of Aboriginal mothers only.
Project description	Fetal growth is being examined over three generations by linking data across the above datasets for women who had given birth after 1980, their daughters who had given birth, and their offspring. For further details, see <i>Report on the use of linked data</i> , pages 41–2.
Linkage details	Not available at this time.

<b>Project</b>	<b>Western Australian Aboriginal Child Health Survey (WAACHS) linkage</b>
Investigators	David Lawrence, Steve Zubrick (TICHR).
Jurisdiction/s	Western Australia.
Year/s	2002.
Publications/outputs	Silburn et al. 2007, Oddy et al. 2008, Zubrick et al. 2011, one report. (WA Aboriginal Child Health Survey (Silburn et al. 2006; Silburn et al. 1996; Zubrick et al. 2004; Zubrick et al. 2006).
Datasets	<p>Silburn et al. 2007: WAACHS consists of a random representative sample of 5,289 Aboriginal children aged 0–17, including 1,480 adolescents aged 12–17, who were surveyed through household based interviews with carers and adolescents, questionnaire data from schools and consensual record linkage to health service and education system data.</p> <p>Oddy et al. 2008: Data from the Western Australian Aboriginal Child Health Survey, which included families in Western Australia with children less than 18 years old of Aboriginal or Torres Strait descent; WA Hospital Morbidity System; Maternal and Child Health Research Data Base (birth registrations combined with midwives notification data).</p> <p>Zubrick et al. 2011: Data from the WAACHS, WA death registrations held by WA RBDM.</p>
Project description	<p>See <i>Report on the use of linked data</i>, page 41.</p> <p>Silburn et al. 2007: Using data from the Western Australian Aboriginal Child Health Survey, the study looks at the prevalence and relative impact of developmental and environmental factors associated with the health and mental outcomes of Aboriginal adolescents (data linkage was a small aspect of the study). The study found that the major portion of the overall burden of disorder is now evident in the more urbanised living settings of Aboriginal families. Some health risk behaviours such as poor dietary intake, smoking, unprotected sex and insufficient physical exercise are more common in Aboriginal adolescents. However, others such as alcohol and marijuana use and suicidal behaviour occur at similar levels to those seen in non-Aboriginal youth.</p> <p>Oddy et al. 2008: Project examined the feeding associations with parent-reported infections and hospitalisations in Western Australian Aboriginal infants and children. Data from the Western Australian Aboriginal Child Health Survey were linked with the Hospital Morbidity System to identify hospitalisations for infections for the same children. Breastfeeding for less than 3 months and birth weight less than 2,500 g were risk factors for parent-reported chest infections and hospitalisations for upper and wheezing lower respiratory infections.</p> <p>Zubrick et al. 2011: The social and emotional impact of maternal loss, either through mother's death or being raised by a different primary carer, on Aboriginal children and young people was assessed. The WAACHS collects a great range of variables about its participants including education participation and is collected from the children's primary carers and their school teachers as well as themselves. Maternal death was detected by linking to perinatal data (WA Midwives' Notifications). After adjusting for age and gender, it was found that, relative to children who were living with their birth mother, children whose birth mother had died were at higher risk for sniffing glue or other substances, using other drugs, and talking about or attempting suicide.</p>
Linkage details	None reported for Silburn et al. 2007 and Oddy et al. 2008. For Zubrick et al. 2011, probabilistic linkage was used, but linkage variables and process was not reported. The number of records that were not included in the linkage because consent was not given for data linkage during the WAACHS data collection was reported. Also reported were the number of records that were linked as well as some characteristics of the linked and unlinked records.

<b>Project</b>	<b>WA Aboriginal Child Health Survey – 2001 Births</b>
Investigators	Steve Zubrick, Peter Cosgrove.
Jurisdiction/s	Western Australia.
Year/s	2003.
Publications/outputs	Listed as none yet by WADLS.
Datasets	Presumably WAACHS and birth registrations.
Project description	None available.
Linkage details	None available.

<b>Project</b>	<b>Growing up in the Territory</b>
Investigators	Shu Qin Li, Susan Jacklyn, Bronwyn Carson, Steve Guthridge, Mary-Anne Measey.
Jurisdiction/s	Northern Territory.
Year/s	2004.
Publications/outputs	Carson et al. 2006; Li et al. 2006.
Datasets	NT health and education datasets, parent and schools surveys.
Project description	<p>The health, development, learning and wellbeing of children are regularly monitored by the NT Government through this project. Random phone surveys are conducted targeting parents with children with various health and welfare characteristics. During these surveys, consent is obtained to survey the children's teachers and to link the survey data to NT Government-held data. Very few Aboriginal people in remote locations have landline phones, so the surveys are known to under-sample Aboriginal children and to be biased towards Aboriginal children in relatively affluent families and non-remote residences. Non-Indigenous and Indigenous children were examined separately. Data linkage was used to incorporate information beyond the surveys into the analysis from NT Government data. Descriptive data were examined for social-emotional wellbeing, learning outcomes, and influences on these variables. The sample size of Aboriginal children was small, so the analysis for Aboriginal children was not as extensive as for non-Indigenous children. The Aboriginal group was at slightly higher risk of emotional and behavioural difficulties, and more Aboriginal children fell within the 'below age level' for academic performance.</p> <p>For further details, see <i>Report on the use of linked data</i>, pages 35–6.</p>
Linkage details	None published.

<b>Project</b>	<b>Hospital admissions as indicator of child abuse</b>
Investigators	Melissa O'Donnell, Natasha Nassar, Helen Leonard, Peter Jacoby, Richard Matthews, Yvonne Peterson, Fiona Stanley.
Jurisdiction/s	Western Australia.
Year/s	1980–2005.
Publications/outputs	O'Donnell et al. 2010a; O'Donnell et al. 2010b.
Datasets	<p>O'Donnell et al. 2010a: WADLS core linked data from the Midwives Notifications System, Birth Registrations, Hospital Morbidity Database and the Mental Health Database. Disabled children were ascertained using the Cerebral Palsy Register, Births Defects Register and Intellectual Disability Exploring Answers (IDEA) dataset.</p> <p>O'Donnell et al. 2010b: WADLS core linked data from hospital morbidity, death registrations, midwives notifications and birth registrations datasets.</p>
Project description	<p>O'Donnell et al. 2010a: Child and parental factors associated with increased vulnerability to substantiated child maltreatment were investigated. For further details, see <i>Report on the use of linked data</i>, pages 27–8.</p> <p>O'Donnell et al. 2010b: Maltreatment and assault-related hospital admissions and deaths among children were investigated, using a retrospective cohort study of all children who were aged between 0–17 in WA from 1980–2005 in addition to all children born in WA during this period. For further details, see <i>Report on the use of linked data</i>, pages 33–4.</p>
Linkage details	<p>O'Donnell et al. 2010a: Probabilistic linkage by WADLS, using multiple passes and with doubtful links clerically reviewed. Indigenous status was determined firstly from information about the child and mother from Birth Registrations and Midwives Notifications; unknown Indigenous status was then resolved using child protection data (which, of the datasets used, had the lowest proportion of records with missing Indigenous status) (O'Donnell 2011).</p> <p>O'Donnell et al. 2010b: Indigenous status determined from Birth Registrations and Midwives Notifications datasets.</p>

<b>Project</b>	<b>Evaluation of the Northern Territory Emergency Response (NTER) Child Health Check Initiative (CHCI)</b>
Investigators	Allen and Clarke Policy and Regulatory Specialists.
Jurisdiction/s	Northern Territory.
Year/s	2007–2008.
Publications/outputs	Allen & Clarke 2011.
Datasets	AIHW Child Health Check (CHC) dataset (July 2007–June 2009), NT Department of Health Client Master Index (CMI), NT Hospital Morbidity dataset (admissions 1 July 1991–30 June 2007), NT Midwives dataset (2000–2008 (low coverage of HRNs in this dataset prior to 2001), Aboriginal children only), Growth Assessment and Action (GAA) dataset (1992–2003; 2008).
Project description	The NTER Child Health Check Initiative was evaluated for whether child health checks reached the target population and the findings of these health checks. See <i>Report on the use of linked data</i> , pages 39–40.
Linkage details	<p>Patient HRNs, date of birth, sex and community identifiers from patients, their parents or guardians and local clinics, were used as linkage variables to match CHCI records to records in the CMI. Matched records were then linked to the Morbidity and Midwives datasets using the HRN. Data linkage was carried out at the NT Department of Health, which holds the CMI, and Morbidity, Midwives, and GAA datasets. The linkage process is relatively well-reported, including a linkage diagram for the CHCI-CMI linkage.</p> <p>Indigenous status as recorded in the CMI was used. NTER Child Health Checks were carried out in Aboriginal communities and town camps, so Indigenous status was not collected as an additional variable for the CHCI database. Of the 100,097 CMI records extracted for NT residents for this evaluation, 4,575 had unknown Indigenous status (of whom nine received a CHC).</p>

<b>Project</b>	<b>Patterns, trends, and increasing disparities in mortality for Aboriginal and non-Aboriginal infants born in Victoria</b>
Investigators	Jane Freemantle.
Jurisdiction/s	Victoria.
Year/s	To be determined.
Publications/outputs	None at this time.
Datasets	Hospital and deaths data.
Project description	Aims to examine all-cause mortality in infants in the same vein as Freemantle et al. (2004). See <i>Report on the use of linked data</i> , page 29.
Linkage details	Not yet determined.

## Chronic disease

Project	Chronic disease outcomes and enhanced primary care
Investigators	D'Arcy Holman, Kate Brameld.
Jurisdiction/s	Western Australia.
Year/s	2005.
Publications/outputs	Brameld & Holman 2006.
Datasets	WADLS (hospital morbidity and deaths, 1994–99).
Project description	WADLS data for specific chronic diseases were extracted, and the effects of particular demographic factors, including Indigenous status, on hospital admission rates were also investigated. Aboriginal and Torres Strait Islander people had significantly higher admission rates for all chronic conditions studied except middle ear infection (lower) and severe mental disorders (no significant difference). Authors attributed the latter to locational disadvantage with respect to access to hospital, and accessing alternate services.
Linkage details	No additional linkage performed. Pre-linked data from WADLS was used. How Indigenous status was derived was not stated (e.g. if it was derived from more than one hospital admission or just the first admission).

Project	Diabetes and Related Disorders in Urban Aboriginal and Torres Strait Islander people in the Darwin region/Darwin Region Urban Indigenous Diabetes Study (DRUID)
Investigators	Joan Cunningham, Terry Dunbar, Kerin O'Dea, Louise Maple–Brown, Yin Paradies, Jacqui Boyle, Kalinda Griffiths, Tarun Weeramanthri, Jonathan Shaw, Paul Zimmet and a further 15 DRUID staff members.
Jurisdiction/s	Northern Territory.
Year/s	2003–2009.
Publications/outputs	Cunningham et al. 2006.
Datasets	DRUID survey, NT hospital separations data, National Death Index (NDI).
Project description	To account for the lack of health data available about urban Aboriginal and Torres Strait Islander residents compared to those in remote communities, the DRUID study has surveyed more than 1000 Aboriginal and Torres Strait Islander residents of Darwin for diabetes and a range of health and social characteristics. Ethics approval was recently obtained to follow up participants in the DRUID study by linking their data to NT hospitals data and the NDI. DRUID participants were asked for consent for data to be followed-up about them during the survey; more than 90% consented. A follow-up with all participants is also planned; linkage to the NDI will ensure that attempting to contact participants who have passed away can be avoided. See <i>Report on the use of linked data</i> , pages 45–6.
Linkage details	Not yet available.

## Crime

Project	Road Injury Database
Investigators	Diana Rosman.
Jurisdiction/s	Western Australia.
Year/s	1996.
Publications/outputs	Rosman et al. 2001. Also, 5 other journal articles, 34 reports, 5 posters, but only peripheral relevance to Aboriginal and Torres Strait Islander people.
Datasets	Integrated Numerical Offender Identification System (INOIS) offender database, Crime Research Centre, University of Western Australia (Indigenous status police-assessed); WA Road Injury Database (does not have Indigenous status).
Project description	See <i>Report on the use of linked data</i> , pages 34–5.
Linkage details	Probabilistic linkage used. No quality of linkage given, but linking variables were given (licence number, date, time and location of offence). Total numbers of links were given. No apparent attempt made to detect and discard false links, or find false non-links. Did not use standard or other self-reported source for Indigenous status.

<b>Project</b>	<b>Road crashes in the Northern Territory</b>
Investigators	Karen Dempsey (PhD student), Soufiane Boufous (supervisor).
Jurisdiction/s	Northern Territory.
Year/s	Not determined at time of writing.
Publications/outputs	Research may be published in 2012.
Datasets	NT health records, NT police crash casualty records.
Project description	The extent to which hospital records and police records in the NT can be used to represent road crashes is being investigated. See <i>Report on the use of linked data</i> , page 37.
Linkage details	Options for linkage variables are restricted due to the absence of date of birth data in police records. Name, age at time of crash, sex, date of event and Indigenous status are being used as linkage variables. Probabilistic linkage is being used along with clerical review of true matches.

## Diabetes

<b>Project</b>	<b>Association of diabetes with survival among cohorts of Indigenous and non-Indigenous Australians with cancer</b>
Investigators	JH Martin, MD Coory, PC Valery, AC Green.
Jurisdiction/s	Queensland.
Year/s	2006.
Publications/outputs	Martin et al. 2009, Valery et al. 2006.
Datasets	Queensland Cancer Registry first diagnoses 1997–2002, National Death Index, Queensland public hospital administrative data. Also linked to discharge abstracts to find stage of diagnosis and co-morbidities.
Project description	See <i>Report on the use of linked data</i> , page 26. Martin et al. 2009: Assessed survival, stratified by diabetes, among Indigenous and non-Indigenous Australian cancer patients. Valery et al. 2006: Same data analysis as Martin et al. 2009, except Valery et al. 2006 compared Indigenous and non-Indigenous Australians rather than treating diabetes as a cross-variable.
Linkage details	No published details.

## Gastrointestinal

<b>Project</b>	<b>Recurrent Gastroenteritis among Infants in WA (not listed in WADLS project list)</b>
Investigators	Andy Lee, James Flexman, Wang Kui, Kelvin Yau.
Jurisdiction/s	Western Australia.
Year/s	1995–2002.
Publications/outputs	Lee et al. 2004a.
Datasets	WA Hospital Morbidity Data System; WA deaths. May be an extraction of WADLS linked data originally from WA Hospital Morbidity Data System and 'ABS mortality database'.
Project description	See <i>Report on the use of linked data</i> , page 31.
Linkage details	Linked data contained discharge data, sex, Indigenous status, place of residence, admission type, and co-morbidities. Unique Patient number was used to link the hospital records in the data about the same patients to each other (essentially an internal linkage). No other information about the linkage was reported. Indigenous status was presumably taken from hospital data, though this is not explicit. It was not stated as to what was done if there was inconsistent Indigenous status between hospital records or with deaths data.

# Hospital care

<b>Project</b>	<b>Northern Territory Hospital Morbidity Dataset – Validation of demographic data 1997</b>
Investigators	John Condon, Desley Williams, Michael Pearce, Elizabeth Moss.
Jurisdiction/s	Northern Territory.
Year/s	1997.
Publications/outputs	Condon et al. 1998.
Datasets	Hospital morbidity dataset (i.e. separations).
Project description	A data quality audit of this dataset was conducted, partly to inform the design and establishment of the NT Caresys Client Master Index (CMI). A sample of patients admitted to NT public hospitals were interviewed about several characteristics, including Indigenous status. These interview records were then linked with their hospital morbidity dataset record. Interviewees were selected from daily admissions lists and interviewed from September–November 1997. A correction factor of 1.05 was calculated to factor in under-count in this dataset. Of 400 interviewees, only one had unstated Indigenous status in their morbidity dataset, while two had unstated Indigenous status from their interview; all three were identified as non-Indigenous in the opposite dataset. Interactions were not published for most audited variables. See <i>Report on the use of linked data</i> , page 49.
Linkage details	Interview and morbidity records were linked using Hospital Registration Number (HRN) and hospital, with interview date falling between the admission and discharge dates as a blocking variable.
<b>Project</b>	<b>Hospitalisations in Western Australian Aboriginal and Non-Aboriginal Children</b>
Investigators	H Moore, KS Carville, D Lehmann, G Hall, P Richmond, N de Klerk, D Burgner, P Jacoby.
Jurisdiction/s	Western Australia.
Year/s	1990–2000.
Publications/outputs	Moore et al. 2007, Carville et al. 2007.
Datasets	Singleton live births in WA between January 1, 1990 and December 31, 2000 (identified off WADLS core linked data); WA RBDM and WA Admitted Patients Data; WA Midwives' Notification System (source of Indigenous status, treated as being of superior quality to that in others).
Project description	Moore et al. 2007: See <i>Report on the use of linked data</i> , pages 24–5. Carville et al. 2007: See <i>Report on the use of linked data</i> , pages 24–5.
Linkage details	No additional linkage details reported. Children were considered Aboriginal if at least one record in the extracted data recorded them as Aboriginal.
<b>Project</b>	<b>Linkage of hospitalisation and death records for Indigenous patients to identify trends in hospitalisations and deaths from chronic disease over the past decade</b>
Investigators	Trisha Johnston, M Coory, W Hoy.
Jurisdiction/s	Queensland.
Year/s	c.2008.
Publications/outputs	Coory & Johnston 2006.
Datasets	Hospital data 1997–98 to 2004–05.
Project description	Project describes trends in the annual prevalence of hospitalisation in remote Indigenous communities in Queensland, 1997/98 to 2004/05. See <i>Report on the use of linked data</i> , pages 40–1.
Linkage details	Authors used probabilistic matching of computerised discharge abstracts to identify all the admissions to any hospital in Queensland of individual Aboriginal and Torres Strait Islander people whose usual residence was one of the remote Indigenous communities. The probabilistic matching was based on name, sex, address and date of birth. By defining Indigenous status based on place of residence, the authors avoided the problem of differential propensity to identify as Indigenous over time.

<b>Project</b>	<b>Indigenous health: Towards development of evidence based policies using data linkage techniques</b>
Investigators	Srinivas Kondalsamy–Chennakesavan, Wendy Hoy (School of Medicine, University of Queensland).
Jurisdiction/s	Queensland.
Year/s	2009– (ongoing).
Publications/outputs	None yet available.
Datasets	Queensland Hospital Admitted Patients' Data Collection (QHAPDC), internally linked (episodes of care to individuals instead), Queensland RBDM (deaths), Qld Perinatal Data Collection, Qld Cancer Registry.
Project description	A proposed PhD project that seeks to link hospital separations over 10–12 years to explore hospitalisations of Aboriginal and Torres Strait Islander people for chronic diseases, and examine case fatality rates through linkage to death registration data. The project was awaiting approval by the Queensland Health Ethics Committee and University of Queensland (UQ) Medical Research Ethics Committee at the time of writing (a similar project was approved in 2006). The aim of linkage is to imitate the WADLS process. See <i>Report on the use of linked data</i> , pages 16–7.
Linkage details	Probabilistic linkage, using the Febri software. No other details available at time of writing.

<b>Project</b>	<b>Hospitals Admission data</b>
Investigators	Victoria Health.
Jurisdiction/s	Victoria.
Year/s	Ongoing.
Publications/outputs	None yet available.
Datasets	Victorian Admitted Episodes Dataset, Hospital admissions data.
Project description	The Victorian Admitted Episodes Dataset (VAED) is occasionally used to match inpatient separations to track transfers of Aboriginal patients between hospitals. See <i>Report on the use of linked data</i> , page 30.
Linkage details	Linked by age, sex, residence, admission date and separation/admission code. There is no unique identifier across the Victorian hospital system that would allow an alternate way to track patients between hospitals (Sullivan 2010).

<b>Project</b>	<b>Indigenous Health Outcomes Patient Evaluation (IHOPE)</b>
Investigators	Louisa Jorm (University of Western Sydney, The Sax Institute), Alastair Leyland (Medical Research Council/Chief Scientist Office Social and Public Health Sciences Unit), Timothy Churches (The Sax Institute), Mary Haines (The Sax Institute), Sandra Eades (Baker IDI Heart and Diabetes Institute), Sanja Lujic (University of Western Sydney), Deborah Randall (University of Western Sydney).
Jurisdiction/s	New South Wales.
Year/s	July 2000–December 2008.
Publications/outputs	Presented by Deborah Randall at 2011 Coalition for Research to Improve Aboriginal Health (CRIA) conference. Other publications to follow.
Datasets	NSW Admitted Patients Data Collection (APDC), NSW death data.
Project description	<p>The project uses data linked by the Centre for Health Record Linkage (CHeReL) to investigate factors influencing health outcomes after a hospital admission for Indigenous compared to non-Indigenous people in NSW, e.g. short and long term mortality after admission for Acute Myocardial Infarction (AMI). In this instance, Indigenous status was taken from the most recent record in the APDC for each patient ('most recent' algorithm). The quality of the Indigenous status field in the APDC was regarded as being higher than in the field in the deaths data. Individuals with missing Indigenous status were treated as non-Indigenous.</p> <p>Performance was compared for other identification algorithms, including: 'Indigenous' on all hospital admissions ('always-Indigenous'), which identified the fewest people as Indigenous; and 'Indigenous' on at least one admission ('ever-Indigenous'), which identified the most people as Indigenous. A standardised admission ratio (adjusting for age, sex and year) for Indigenous relative to non-Indigenous patients increased as the algorithms became less strict and identified more people as Indigenous. However, the relative disparity between Indigenous and non-Indigenous patients in 30-day standardised mortality decreased as more people were identified as Indigenous. Further investigation revealed that the 'always-Indigenous' algorithm included a higher proportion of people with only one admission than other algorithms, as the likelihood of not being identified as Indigenous on at least one record increased with an increasing number of records. Patients with only one admission were more likely to have died shortly after admission than those with more than one admission, and this may have biased the mortality ratios. For this reason, the 'most recent' algorithm was preferred for the AMI analysis, as it was not related to the number of admissions for each person. Furthermore, identification was known to have improved over time in the APDC.</p> <p>The IHOPE investigators are currently validating the different algorithms by linking the APDC to the 45 and Up Study and using the self-reported Indigenous status from the baseline questionnaire as a comparison (the 45 and Up Study is an ongoing cohort study of the health of roughly 10% of the NSW population aged 45 and over).</p> <p>Other conditions will be analysed using IHOPE, including road traffic injuries, ear disease, and infections in children. Sensitivity analyses with different algorithms will also be conducted for these to see if choice of algorithm affects conclusions.</p>
Linkage details	No additional details available at time of writing.

## Immunisation

<b>Project</b>	<b>Predictors of incomplete immunisation in Victorian children</b>
Investigators	K Haynes, C Stone (Victorian Department of Human Services).
Jurisdiction/s	Victoria.
Year/s	2004.
Publications/outputs	Haynes & Stone 2004.
Datasets	Records of all births in Victoria in 1998 were linked with records from the Australian Childhood Immunisation Register (ACIR).
Project description	This study aimed to determine the predictors of incomplete immunisation in Victorian children. See <i>Report on the use of linked data</i> , page 38.
Linkage details	Used probabilistic linkage. Few other published details.

# Indigenous Identification

<b>Project</b>	<b>Assessing the Quality of Identification of Aboriginal and Torres Strait Islander People in Western Australia Hospital Data</b>
Investigators	MJ Young.
Jurisdiction/s	Western Australia.
Year/s	2000.
Publications/outputs	Young 2001.
Datasets	Survey data from four different Health Regions; WA Hospital Morbidity Dataset (HMDS).
Project description	The accuracy of Indigenous status data in hospital data was assessed using a survey of WA hospital patients. See <i>Report on the use of linked data</i> , page 19.
Linkage details	Linking variables were reported: Unit Medical Record Number (UMRN); hospital number; interview date between admission and discharge dates, of which 96.4% were linked. The other 3.6% were linked to previous episodes of care using UMRN and hospital number. Full statistics were published for the linkage rate for Indigenous status options, as well as for some other variables. The proportion of 'Correctly recorded' records was calculated for each interview option.

  

<b>Project</b>	<b>ACT Hospitals Data Linkage project</b>
Investigators	AIHW Hospitals Unit.
Jurisdiction/s	Australian Capital Territory.
Year/s	2006.
Publications/outputs	Described in Indigenous identification in hospital separations data – quality report, February 2010 (AIHW 2010).
Datasets	ACT Hospitals data; Winnunga Nimmityjah Aboriginal medical service data.
Project description	See <i>Report on the use of linked data</i> , page 20.
Linkage details	No additional details reported.

  

<b>Project</b>	<b>Indigenous identification in administrative data collections and the implications for reporting Indigenous health status</b>
Investigators	Bryan Kennedy, Stuart Howell, Clinton Breckell (Health Statistics Centre, Queensland Health).
Jurisdiction/s	Queensland.
Year/s	1995–2007.
Publications/outputs	Kennedy et al. 2009b.
Datasets	Individuals who had identified as Indigenous on at least one formal admission for an acute episode of care at a Queensland public hospital between July 1, 1995 and June 30, 2007; Queensland Hospital Admitted Patient Data Collection (QHAPDC); Queensland Health Public Hospital Client Directory Project.
Project description	This study examined the consistency of recording Indigenous status in the Queensland Hospital Admitted Patient Data Collection (QHAPDC) and evaluated the impact of using an 'Ever' Indigenous identified approach compared with the current practice of using Indigenous status as recorded in the most recent record. See <i>Report on the use of linked data</i> , pages 13–16.
Linkage details	See <i>Report on the use of linked data</i> , pages 13–16.

<b>Project</b>	<b>Indigenous Mortality Data Enhancement Project</b>
Investigators	Australian Institute of Health and Welfare.
Jurisdiction/s	Australia (all states and territories).
Year/s	2001–2006, 2006–2011.
Publications/outputs	An enhanced mortality database for estimating Indigenous life expectancy: A feasibility study (AIHW 2012).
Datasets	ABS and AIHW National Mortality Database, National Death Index, Residential Aged Care dataset, Hospital Morbidity dataset, neo–natal death data from the National Peri–natal Data Collection and the Victoria Aboriginal Hospital Liaison Officers Data Collection.
Project description	An AIHW feasibility study that sought to investigate whether it is possible to enhance Indigenous death data through the joint use of several alternative data sources that contain information on Indigenous deaths and Indigenous status. See <i>Report on the use of linked data</i> , pages 4–6.
Linkage details	Linkage details are extensively described. Probabilistic linkage was used, with the weight calculation procedure described. Each dataset was linked progressively, with several passes used for each linkage, and the linkage and blocking variables for each pass listed in the Appendix. An ‘ever-Indigenous’ algorithm was used. Numbers and proportions of linked and unlinked records are detailed.

<b>Project</b>	<b>Census Data Enhancement Study Indigenous Mortality Quality Study</b>
Investigators	Australian Bureau of Statistics.
Jurisdiction/s	Australia (all states and territories).
Year/s	2006–07.
Publications/outputs	Census Data Enhancement – Indigenous Mortality Quality Study 2006–07 (cat. no. 4723.0) (ABS 2008b). See also: Assessment of Methods for Developing Life Tables for Aboriginal and Torres Strait Islander Australians 2006 (cat. no. 3302.0.55.002) (ABS 2008a); Linking Census Records to Death Registrations (cat. no. 1351.0.55.030) (ABS 2010b); Methodology of Evaluating the Quality of Probabilistic Linking (cat. no. 1351.0.55.018) (ABS 2007); Exploring Methods for Creating a Longitudinal Census Dataset (cat. no. 1352.0.55.076) (ABS 2005); Enhancing the Population Census: Developing a Longitudinal View 2006 (cat. no. 2060.0) (ABS 2006); Census Data Enhancement Project: An Update, Australia (cat. no. 2062.0) (ABS 2010a).
Datasets	2006 Census data; death registration records, 9 August 2006–30 June 2007 (except for Victoria, where data for only 9 Aug 2006–mid-March 2007 were available).
Project description	See <i>Report on the use of linked data</i> , pages 6–9.
Linkage details	Linkage and measures of linkage quality are extensively detailed. Probabilistic linkage was done using a version of Febrl 0.3 that had been modified. The number and proportion of missing responses for each linking variable disaggregated by Indigenous status was calculated (excluding invalid and incomplete responses). Levels were consistently higher for Aboriginal and Torres Strait Islander people than for non-Indigenous people, across most linking variables, in both datasets. Mesh block was worst. First name, surname, and date of birth (DOB) in the deaths dataset have no or almost no missing responses. Four passes were used with the linking and blocking variables listed. Input probabilities for the weights were taken from the smaller Census Dress Rehearsal Project. Linkage quality was assessed by examining population characteristics of linked and unlinked death records; finding out the reasons for unlinked death records; estimating the number of false links; estimating match–link rate and link accuracy; and observing effect of false links on analysis.

Project	Enhanced reporting of Aboriginality in Administrative Health Datasets using record linkage – a Feasibility Study
Investigators	Lee Taylor, Deborah Baker, Helen Moore, Jennifer Hunt, Richard Madden, Sarah Neville. Also S Lujic and K Lim.
Jurisdiction/s	New South Wales.
Year/s	2002–06 Neville et al. 2011.
Publications/outputs	<p>Provision of information to ABS concerning Indigenous identification on ABS mortality data that has been linked to the NSW Admitted Patients Data Collection. Ad hoc provision of information to government on Indigenous identification in mortality data and renal failure.</p> <p>Conference Presentations: Lujic &amp; Taylor 2007, Taylor et al. 2008b, Taylor et al. 2008a, Moore &amp; Taylor 2008, Hay et al. 2009, Lujic &amp; Jorm .</p> <p>Also Neville et al. 2011.</p>
Datasets	ABS death registrations (2001–06), NSW Admitted Patients Data Collection (also known as the NSW Inpatient Statistics Collection) (2002–06), NSW RBDM death registrations.
Project description	<p>See <i>Report on the use of linked data</i>, page 17.</p> <p>Linkage of the NSW Inpatient Statistics Collection with data on deaths held by the Registry of Births, Deaths and Marriages and the ABS was done to provide a means of examining outcomes of hospital care in NSW (as preliminary work for the Indigenous identification project described in Neville et al. (2011)).</p> <p>The potential of record linkage between ABS mortality data and the APDC to improve reporting of deaths among Aboriginal and Torres Strait Islander people was investigated. Six alternate algorithms to resolve Indigenous status from the linked data sources were tested and compared for their capacity to enumerate Indigenous deaths. Possible bias by age, sex and geographic remoteness were investigated. Algorithm 2 ('ever-Indigenous') resulted in the largest enhancement (29.7% for 2006 data above the baseline Algorithm 1). Algorithms 5 and 6 were regarded by the authors as the most methodologically sound. Enhancement was most likely in females, older people, and residents in major cities.</p>
Linkage details	<p>A relatively large amount of detail was reported. The APDC was first internally linked by CHeReL (by probabilistic linkage) using full name, address, sex, date of birth, country of birth, hospital code, medical record number, dates of admission and discharge, hospital transferred to, hospital transferred from, and date of death for hospital deaths. RBDM death records were then probabilistically linked to these, using full name, address, sex, date of birth, and date of death. ABS mortality data was then deterministically linked to RBDM death registration records using the death registration number. Aboriginal people, Torres Strait Islanders, and people who were both Aboriginal and Torres Strait Islander were condensed as Aboriginal or Torres Strait Islander peoples. Some information was available about linkage quality, notably false positive and false negative rates and consistency between APDC records.</p> <p>These Indigenous status algorithms were tested and compared:</p> <p>Algorithm 1 (baseline): Indigenous status solely from the ABS mortality data.</p> <p>Algorithm 2: 'ever-Indigenous' i.e. Aboriginal or Torres Strait Islander if indicated as such on any mortality or APDC record.</p> <p>Algorithm 3: 'majority' i.e. Aboriginal or Torres Strait Islander if indicated as such on mortality record or at least 50% of their APDC records.</p> <p>Algorithm 4: modified 'most recent' i.e. Aboriginal or Torres Strait Islander if indicated as such on mortality record or at least 50% of their most recent APDC records from each facility visited.</p> <p>Algorithm 5: Aboriginal or Torres Strait Islander if indicated as such on mortality record or 50% or more APDC records in 50% or more facilities visited (modified 'majority').</p> <p>Algorithm 6: Aboriginal or Torres Strait Islander if indicated as such on either i) mortality record; or ii) 2 or more APDC records in 2 or more facilities – unless only 1 or 2 records in 1 or 2 facilities were available, in which case 1 record in 1 facility was considered sufficient.</p> <p>Each algorithm was applied in two ways:</p> <p>Each year of mortality data was enhanced using the current and previous year of APDC data only.</p> <p>2006 mortality data was enhanced using 2, 3, 4, 5 and 6 years of APDC data.</p> <p>False positive reports were ascertained by determining the number of mortality records reported as Aboriginal or Torres Strait Islander which were never reported as Aboriginal or Torres Strait Islander in linked APDC records. Neville et al. (2011) contains a relatively thorough discussion of the limits of what this study appraises, pointing out that beyond this false positive analysis, the accuracy of mortality records reported as Aboriginal or Torres Strait Islander was not tested through the linkage.</p> <p>Percentage enhancement for algorithms 2 and 6 was calculated as the difference between number of enhanced deaths and the baseline as a fraction of the baseline number of deaths.</p>

<b>Project</b>	<b>Enhanced reporting of Aboriginality in Administrative Health Datasets using record linkage – extension to multiple datasets</b>
Investigators	Lee Taylor, Jason Bentley, Helen Moore (Centre for Epidemiology and Research, NSW Department of Health), Deborah Baker (Cancer Institute NSW), Peter Brandt (Demand and Performance Management, NSW Health), Jenny Hunt (Aboriginal Health and Medical Research Council), Richard Madden (Faculty of Health Sciences, University of Sydney), Sybille McKeown (Australian Bureau of Statistics).
Jurisdiction/s	New South Wales.
Year/s	1 July 2000–31 December 2007.
Publications/outputs	Population and Public Health Division 2012.
Datasets	Registry of Births, Deaths and Marriages birth registration data; NSW Perinatal Data Collection; ABS death registration data; NSW Admitted Patient Data; NSW Emergency Department Data Collection; NSW Central Cancer Registry.
Project description	<p>See <i>Report on the use of linked data</i>, page 17.</p> <p>Following on from the feasibility study (Enhanced reporting of Aboriginality in Administrative Health Datasets using record linkage) by some of the same investigators (see above (Neville et al. 2011)), inclusion of other datasets was felt to be warranted to eliminate the bias of using the APDC only. These researchers therefore subsequently linked the ABS mortality data with the APDC, NSW RBDM birth and death records, emergency department admissions, and perinatal data. Cancer registry data was initially included, but ultimately not used since its Indigenous status field was derived from APDC data. Three Indigenous status algorithms were compared (see below). The capacity of this linkage to enhance all the datasets, rather than just the ABS mortality data, was assessed. Results of this linkage were in the process of being published at the time of writing.</p> <p>This project aims to measure under-reporting of Aboriginal people in NSW death registration records, and to see if record linkage could be used to help correct this. The project also aims to develop methods for improving reporting of Aboriginal and Torres Strait Islander peoples on population datasets using record linkage, describe the improvements in reporting achieved by record linkage and explore the impact of any changes in reporting due to record linkage on a selection of indicators of health status and health service utilisation.</p>
Linkage details	<p>An algorithm has been developed for reporting a person as Aboriginal or Torres Strait Islander on each dataset using linked records. The algorithm takes into account the following: the extent to which information on whether a person is Aboriginal or Torres Strait Islander is collected independently at each event represented by a linked record; the rate of false positive links; the likelihood of data entry errors; and the weight of evidence that a person is Aboriginal or Torres Strait Islander. The project will assess the effect of enhanced reporting of Aboriginal or Torres Strait Islander people using the algorithm on various health indicators (Taylor &amp; McKeown 2011).</p> <p>The subsequent six–dataset linkage used a linkage process similar to Neville et al. (2011). Three algorithms used previously and described above were compared. These were the baseline (Algorithm 1); ‘ever-Indigenous’ across any record in any of the linked datasets (aka Algorithm 2); and an algorithm similar to Algorithm 6, which emphasised the independence of multiple sources of collection of Indigenous status data.</p>

<b>Project</b>	<b>Linkage of records from Notifiable Diseases Database with other routinely collected population health databases to improve completeness of Aboriginal status recording</b>
Investigators	Mr Mark Bartlett, Ms Hanisah Corner, Dr Jeremy McAnulty, Mr James Ward.
Jurisdiction/s	New South Wales.
Year/s	Unknown.
Publications/outputs	None at time of writing.
Datasets	Notifiable Diseases Database, other NSW administrative datasets.
Project description	See <i>Report on the use of linked data</i> , pages 17–8.
Linkage details	None available at time of writing.

<b>Project</b>	<b>Census Data Enhancement Project: Indigenous Mortality Project (ABS 2010a)</b>
Investigators	Australian Bureau of Statistics.
Jurisdiction/s	Australia.
Year/s	August 2011–August 2012.
Publications/outputs	ABS 2010a.
Datasets	2011 Census; death registrations from August 2011–August 2012.
Project description	This project repeats the ABS Indigenous Mortality Quality Study that was conducted using the 2006 Census for the Census Data Enhancement project (ABS 2008b) (see above). See <i>Report on the use of linked data</i> , page 8.
Linkage details	Names and addresses from the Census are retained during the Census processing period, which will be linked to death registrations during the processing period (i.e. 9 August 2011–August 2012). The linked dataset will be used to derive adjustment factors for Indigenous under-identification, which will in turn be used to calculate life expectancy estimates. The consistency of Indigenous status between the Census and death registrations will be assessed, and measures of under-coverage of Indigenous deaths will be estimated by state and territory and by remoteness. Names and addresses from the Census and this linked dataset are destroyed after the processing period.

<b>Project</b>	<b>Using record linkage to survey data to adjust for under-identification of Aboriginal births on the WA birth register</b>
Investigators	David Lawrence, Francis Mitrou, Glenn Draper, Daniel Christensen, Kirsten Hancock, Kate Hafekost, Steve Zubrick.
Jurisdiction/s	Western Australia.
Year/s	Survey data collected May 2000–July 2002. Births data 1980–2006.
Publications/outputs	Results from this project were presented at the 2010 Australian Statistics Conference, the 2010 Australian Early Development Index (AEDI) Policy Forum, and the 2011 Ministerial Council for Education, Early Childhood Development and Youth Affairs (MCEECDYA) National Data Linkage Forum, but details are yet to be published at time of writing.
Datasets	WA birth registrations, Western Australian Aboriginal Child Health Survey (WAACHS), WA Midwives Notification System.
Project description	See <i>Report on the use of linked data</i> , pages 19–20.
Linkage details	No additional details available at time of writing.

<b>Project</b>	<b>Getting Our Story Right — a cross agency data linkage and analysis project to better understand and improve information about Aboriginal and Torres Strait Islander peoples using administrative data collections</b>
Investigators	Australian Bureau of Statistics, Department of Health Western Australia, Telethon Institute for Child Health Research.
Jurisdiction/s	Western Australia.
Year/s	Seeks data from the beginning of collection of each dataset to most recent available data from each dataset.
Publications/outputs	None at time of writing.
Datasets	WA Literacy and Numeracy Assessment 1999–2005, WA Register General of Births, Deaths, and Marriages Death Registrations 1969–2011, WA Register General of Births, Deaths, and Marriages Birth Registrations 1974–2011, WA Aboriginal Child Health Survey 2002, WA Health and Wellbeing Surveillance System 2002–2010, WA Hospital Morbidity Data System 1970–2010, WA Mental Health Data System 1966–2010, WA Midwives Notification System 1980–2011, WA Cancer Registry 1982–2011, WA Emergency Database 2002–2011, WA Notifiable and Infectious Disease Database 1990–2009.
Project description	The project aims to explore and develop different methods for deriving Indigenous status from multiple data sources. By utilising the resources of the WA Data Linkage System, the project is examining the impact of these methods on a sample of health and educational outcomes among the Aboriginal and Torres Strait Islander population. See <i>Report on the use of linked data</i> , page 10.
Linkage details	None available at time of writing.

<b>Project</b>	<b>Developing an optimal method for identifying Aboriginal and Torres Strait Islander people across datasets</b>
Investigators	Carrington Shepherd and others (Telethon Institute of Child Health Research).
Jurisdiction/s	Western Australia.
Year/s	Not determined at time of writing.
Publications/outputs	None at time of writing.
Datasets	Birth registrations, Death Registrations, midwives' notifications, and hospital admissions.
Project description	See <i>Report on the use of linked data</i> , page 13.
Linkage details	Not yet determined at time of writing.

## Infectious disease

<b>Project</b>	<b>Improving identification of race in statutory notifiable infectious disease data using data linkage</b>
Investigators	Donna B Mak, Rochelle E Watkins.
Jurisdiction/s	Western Australia.
Year/s	2005.
Publications/outputs	Mak & Watkins 2008.
Datasets	WA Notifiable Infectious Diseases Database (NIDD) (extracted all notified cases of STIs and BBVs (excluding HIV cases) in WA with a case report data between 1 January 2004 and 31 December 2004); WADLS core linked data — Mortality, Morbidity, MNS, MHIS.
Project description	See <i>Report on the use of linked data</i> , pages 10–11.
Linkage details	Linkage method was described well. Probabilistic linkage with NIDD records with unknown Indigenous status only. Linked with surname, first name, DOB, sex, residential address, initial, and unit medical record number. Name compression algorithms were used to improve linkage of name variables. Linkage used multiple passes with blocking. Weights assigned, classed into definite links and non-links and possible links. All possible links were clerically reviewed, while definite links were kept and definite non-links discarded.

<b>Project</b>	<b>Rotavirus Epidemiology in Queensland during the pre-vaccine era</b>
Investigators	SJ Campbell, MD Nissen, S B Lambert.
Jurisdiction/s	Queensland.
Year/s	2001–06.
Publications/outputs	Campbell et al. 2009.
Datasets	Queensland Health Patient Admitted Dataset: All private and public hospital separations in children less than 5 years in Queensland, with a rotavirus-specific principal or other diagnosis code (ICD-10-AM code A08.0) from 1 July 2001–June 2006; Queensland Health Auslab database: only every 10th separation was linked.
Project description	To better understand rotavirus epidemiology in Queensland prior to vaccine introduction, they: <ul style="list-style-type: none"> <li>analysed hospital records of all children less than 5 years admitted to Queensland hospitals between July 2001 and June 2006 with any rotavirus-specific code or with an acute gastroenteritis (AGE) code in the principal field</li> <li>linked a sample of public hospital admission records to laboratory test requests (Qld Health Auslab) to determine the extent of diagnostic testing for causes of AGE, and</li> <li>analysed rotavirus notifications for the same age group between December 2005 and December 2006 disaggregated by Indigenous status.</li> </ul> See <i>Report on the use of linked data</i> , pages 37–8, for further details.
Linkage details	Indigenous status was used from the record of the most recent contact with the hospital system (but there were few multiple admissions in the subset). Names were not accessed. The unique identifier was used to link with the sample of Auslab pathology results, then age group, gender, month of notification and facility, and the match was only accepted if it was by all of these variables. Auslab records were linked by events not individuals. The Queensland Health Notifiable Conditions database (NOCS) was not linked because it contained no linkable variables (they didn't have names for Admitted Patients, and NOCS didn't contain the hospital identifier). There was no stated Indigenous status in 42% of NOCS records and no corresponding record in Auslab for 3% of the

sampled admitted patient records.

<b>Project</b>	<b>Pneumococcal vaccinations</b>
Investigators	Kerry–Ann O’Grady, Katherine Lee, John Carlin, Paul Torzillo, Anne Chang, Kim Mulholland, Stephen Lambert, Ross Andrews, TM Nolan, A Ruben.
Jurisdiction/s	Northern Territory.
Year/s	1998–2005 (O’Grady et al. 2010b); 2000–2004 (O’Grady et al. 2010a).
Publications/outputs	O’Grady et al. 2010b, O’Grady et al. 2010a.
Datasets	NT Immunisation Register, NT Hospital Discharge Dataset.
Project description	<p>See <i>Report on the use of linked data</i>, page 42.</p> <p>O’Grady et al. 2010b: Part of a larger nested pneumonia study. The effectiveness of a 7-valent pneumococcal conjugate vaccine program in preventing radiologically diagnosed pneumonia was evaluated. Chest X-rays taken for any and all Indigenous children born 1 April 1998–28 February 2005, who were admitted to hospital up to 31 March 2005, were examined for signs of a pneumonia event, and compared to doses of vaccine received. Children were examined together or subdivided by age group. There was limited evidence for reduced incidence of pneumonia diagnosed this way among vaccinated children, though completion of the vaccination regime was found to be poor.</p> <p>O’Grady et al. 2010a: A subset of the same records used for O’Grady et al. 2010b and examined more thoroughly, including the 23-valent pneumococcal vaccine and hospitalised episodes of other conditions, notably gastroenteritis, which was used to control for the potential confounding factor of greater access to hospitals by fully vaccinated children. Incidence rates for Acute Lower Respiratory Infections (ALRI) and for specific manifestations of pneumonia. There was found to be increased risk of ALRI and pneumonia and not of radiologically confirmed pneumonia nor of the control condition gastroenteritis. Association was especially strong for the 23-valent booster, whose use the authors thought should be re–evaluated. The authors explore some possible reasons for the increased risk, notably that other strains of pneumonia may have displaced and thrived while strains targeted by the vaccine were suppressed.</p>
Linkage details	See <i>Report on the use of linked data</i> , page 42.

<b>Project</b>	<b>Burden, Aetiology and Antecedents of Acute Lower Respiratory Infections in a Birth Cohort of Western Australian children</b>
Investigators	Hannah Moore, Nicholas de Klerk, Peter Richmond, Deborah Lehmann, Peter Jacoby.
Jurisdiction/s	Western Australia.
Year/s	1996–2005.
Publications/outputs	Moore et al. 2010, Moore et al. 2011.
Datasets	WADLS core linked data (Midwives’ Notifications System, birth registrations, death registrations, and Hospital Morbidity Database System).
Project description	<p>Moore et al. 2010: See <i>Report on the use of linked data</i>, page 25. The degree to which different risk factors contribute to the burden of ALRI in Aboriginal and non-Aboriginal children in WA was determined by calculating population attributable fractions (PAFs) for various risk factors for which data could be found in the datasets above. Proportion of children admitted for various ALRIs with each of the risk factors was assessed to determine risk direction first. Multiple logistic regression was used to generate separate models for Aboriginal and non-Aboriginal children for an outcome of at least one admission for ALRI before the age of 2. Adjusted and combined PAFs were calculated where the latter estimated the proportional amount by which disease risk would be reduced if all the risk factors were eliminated. Categories with the lowest risk were used as the reference level for other risk factors. Odds ratios and PAFs for each risk factor were reported separately for Aboriginal and non-Aboriginal children. There was no difference between these two cohorts for the risk pattern for individual infection types, so logistic regression models were generated for any ALRI within each cohort. Maternal age was important for Aboriginal children. Elective caesareans had a much greater PAF for non-Aboriginal children, while PAFs for Aboriginal children were greater for the most disadvantaged and most remote categories.</p> <p>Moore et al. 2011: See <i>Report on the use of linked data</i>, pages 25–6. Population trends in hospitalisation rates for pneumonia in Indigenous and non-Indigenous children aged 5 or less were examined in a period before and after the introduction in 2001 of 7-valent pneumococcal conjugate vaccine.</p>
Linkage details	No details about linkage. Aboriginal children were identified from their birth register and hospital morbidity data, and from their mothers’ identification in midwives (perinatal) data.

<b>Project</b>	<b>Rotavirus Vaccine and Prevention of Gastroenteritis Hospitalizations in Aboriginal and Torres Strait Islander children in Queensland and the Northern Territory</b>
Investigators	Stephen Lambert and others (Queensland Children's Medical Research Institute and Menzies School of Health Research).
Jurisdiction/s	Queensland and Northern Territory.
Year/s	2000–2011.
Publications/outputs	None at time of writing.
Datasets	Queensland Health Patient Admitted Dataset, Queensland Health Notifiable Conditions database (NOCS), and Vaccination Information/Vaccination Administration System (VIVAS), Northern Territory Notifiable Diseases Database (NTNDS), information on emergency department presentations (acute gastroenteritis), hospitalisations (Caresys), laboratory testing data (NTGPS database), Northern Territory Immunisation Register.
Project description	See <i>Report on the use of linked data</i> , page 38.
Linkage details	The linkage will be conducted according to the same methodology used by Field et al. (2010). 'Ever-Indigenous' algorithm will be used to identify Indigenous children across the linked datasets.

## Intellectual disability

<b>Project</b>	<b>Disability Counts Project</b>
Investigators	Carol Bower, Helen Leonard.
Jurisdiction/s	Western Australia.
Year/s	1999.
Publications/outputs	Leonard et al. 2003, Leonard et al. 2005, Leonard et al. 2008.
Datasets	WA births, children born 1983–1992, alive in 2000, extracted from WA Maternal and Child Health Research Database (MCHRDB) (dataset of births, linked to deaths); WA Disabilities Services Commission (DSC); WA Department of Education, Catholic Education, Association of Independent Schools. Later, the Intellectual Disability Exploring Answers (IDEA) database was used for Leonard et al. 2008.
Project description	Leonard et al. 2003: See <i>Report on the use of linked data</i> , page 33. Prevalence of children with an intellectual disability in WA was determined. MCHRDB (births), DSC, and educational services data were linked to identify children with intellectual disability (ID) born 1983–1992 in WA who were alive at the end of 1999. Leonard et al. 2005: See <i>Report on the use of linked data</i> , page 33. Leonard et al. 2008: IDEA (Pettersen et al. 2005) linked to Midwives Notification System (within MCHRDB). See <i>Report on the use of linked data</i> , page 33.
Linkage details	Reported in Leonard et al. 2003. Probabilistic linkage was conducted using Automatch. Linking variables are reported, as are the number of records linked and not linked from each dataset used. Prevalence between ID children linked from different sources is compared. Some manual checking was done, though educational sources could not be manually checked. Only Indigenous status of mother was available. Describes the problem with the use of different measures of severe, mild–moderate and unspecified level of ID in DSC and educational sources.

<b>Project</b>	<b>An assessment of intellectual disability among Aboriginal Australians (not listed on WADLS project list)</b>
Investigators	EJ Glasson, SG Sullivan, R Hussain, AH Bittles.
Jurisdiction/s	Western Australia.
Year/s	2000.
Publications/outputs	Glasson et al. 2005.
Datasets	WA Disabilities Services Commission; WA Hospital Morbidity Data System; WA Deaths Registry; National Death Index (NDI).
Project description	DSC data at 31 December 2000 for all DSC-listed people diagnosed with an intellectual disability were linked with the other three datasets to find deaths and Indigenous status. See <i>Report on the use of linked data</i> , page 27.
Linkage details	No other details of linkage were given, including algorithm or the proportion of records that were linked. Multiple ethics committees are listed including AIHW.

## Kidney diseases

<b>Project</b>	<b>End Stage Renal Failure</b>
Investigators	Kate Brameld.
Jurisdiction/s	Western Australia.
Year/s	1996.
Publications/outputs	Brameld et al. 1999.
Datasets	WADLS extract at 3 September 1996.
Project description	WADLS-linked data were linked to compare rates of renal failure between Indigenous and non-Indigenous Australians. See <i>Report on the use of linked data</i> , page 22.
Linkage details	Origin of Indigenous status is not stated.

<b>Project</b>	<b>Discordance in cause of death information between deaths data and the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA)</b>
Investigators	Shu Qin Li, Alan Cass, Joan Cunningham.
Jurisdiction/s	Australia (excluding Queensland, Victoria and Tasmania).
Year/s	1997–1999 (registered by 31 December 1999).
Publications/outputs	Li et al. 2003.
Datasets	Australian and New Zealand Dialysis and Transplant Registry, Deaths data (died 1997–99, held by RBDMs and coded with causes of death by ABS using causes of death recorded on MCCDs).
Project description	See <i>Report on the use of linked data</i> , pages 30–1.
Linkage details	See <i>Report on the use of linked data</i> , pages 30–1.

# Lung Cancer

Project	Lung cancer management and survival
Investigators	Sonja Hall.
Jurisdiction/s	Western Australia.
Year/s	Project listed 2002.
Publications/outputs	Hall et al. 2004.
Datasets	WADLS (hospital morbidity, cancer registration, death records) – WA residents with first lung cancer diagnosis date 1 January 1982–31 December 2001.
Project description	The study compared rates of surgery in lung cancer patients between various components of the Index of Relative Socio-economic Disadvantage. Non-Indigenous people or people with unknown Indigenous status were found to be more likely to have surgery than Aboriginal and Torres Strait Islander people even after adjusting for other factors such as poverty and location.
Linkage details	A WADLS pre-linked data extract was used, with no additional linkage. Source of Indigenous status not stated, but presumably is Indigenous status in hospital morbidity record of first diagnosis date. Aboriginal and Torres Strait Islander people were compared with combined non-Indigenous people and people of unknown Indigenous status.

# Mental health

Project	Comorbidity in people with mental illness
Investigators	David Lawrence, D'Arcy Holman.
Jurisdiction/s	Western Australia.
Year/s	1966–95.
Publications/outputs	Lawrence et al. 2000
Datasets	WADLS core linked data, Mental Health Information System (MHIS).
Project description	See <i>Report on the use of linked data</i> , page 32. Mortality of psychiatric patients during a period of health delivery reform was determined. Complete chains of records for all patients who had contact with WA mental health services 1966–95 were extracted from WADLS, along with a file of all deaths from 1980–95. The first file was then restricted to those with whose first contact with mental services was in 1980–95. Principal psychiatric diagnosis was assigned to each using the MHIS. Age-standardised mortality rates were calculated. Relative survival analysis and regression analysis against two models were done, including by Indigenous status.
Linkage details	Little additional detail.

Project	Continuation of work on mental health outcomes for people involved in violence
Investigators	Lynn Meuleners and others (Curtin University).
Jurisdiction/s	Western Australia.
Year/s	Previous research used data for 1990–2004; current research uses more recent data.
Publications/outputs	None at time of writing.
Datasets	WA Hospital Morbidity Data System (admitted patients) (HMDS); WA Mortality Database; MHIS.
Project description	Continues work on interpersonal violence published in Meuleners et al. 2008 and Meuleners et al. 2009 (see <i>Report on the use of linked data</i> , page 32).
Linkage details	See below ('Social aspects', page 32) and <i>Report on the use of linked data</i> , page 32.

# Mortality

Project	Aboriginal deaths 2000
Investigators	Jim Codde, Sue Pearce (DoHWA Health Statistics).
Jurisdiction/s	Western Australia.
Year/s	2001.
Publications/outputs	No report available.
Datasets	Unknown.
Project description	Estimates of Aboriginal population, including births and deaths.
Linkage details	Not available.

Project	Kimberley Aboriginal survey analysis
Investigators	Ernest Hunter, D'Arcy Holman (UWA Population Health).
Jurisdiction/s	Western Australia.
Year/s	2002.
Publications/outputs	Calver et al. 2005, Burke et al. 2007, one report (not determined).
Datasets	Calver et al. 2005: Community Health and Leprosy Survey Register – 1/12th stratified sample Aborigines aged 15–80 at 1 January 1988; Control: Remaining Aborigines on Register, same age and date; questionnaires on alcohol and blood pressure; hospital, cancer, and deaths. Burke et al. 2007: Kimberley Aboriginal survey, 1988–89, 514 from Community Health Client Register; hospital, cancer (DoHWA) and death registrations (WA RBDM) from 1 January 1988–31 December 2002.
Project description	Calver et al. 2005: See <i>Report on the use of linked data</i> , page 40. Burke et al. 2007: See <i>Report on the use of linked data</i> , page 40.
Linkage details	No aspects of the quality of the linkage is recorded in either paper, including whether any records failed to link, false links, algorithms, or whether linkage was deterministic or probabilistic.

Project	Aboriginal population estimates — deaths 2001
Investigators	Sue Pearce (DoHWA).
Jurisdiction/s	Western Australia.
Year/s	2002.
Publications/outputs	See <i>Aboriginal deaths 2000</i> (above, this page).
Datasets	Unknown.
Project description	See <i>Aboriginal deaths 2000</i> (above, this page).
Linkage details	Unknown.

<b>Project</b>	<b>Improving indigenous status reporting</b>
Investigators	Sonny Pilkington, Peter Somerford.
Jurisdiction/s	Western Australia.
Year/s	1997–2002. Work commenced 2005.
Publications/outputs	Draper et al. 2009.
Datasets	WA Deaths (WA RBDM) 1997–2002; WADLS linked data: Hospital Morbidity Dataset System (HMDS) 1970–2002, Mental Health Information System (MHIS) 1966–2002, Midwives Notification System (MNS/MWDS) 1970–2002.
Project description	See <i>Report on the use of linked data</i> , pages 9–10.
Linkage details	Two alternate algorithms for Indigenous status were compared: 'majority' (i.e. if the number of times a record was coded as Indigenous was greater than the total number of times it was coded as non-Indigenous or unknown, then the record was declared Indigenous; otherwise it was deemed non-Indigenous), and 'ever'. Few other details about the linkage were reported. Only deaths with missing Indigenous status were linked — linkage was not used to assess Indigenous identification quality in death records other than not-stated entries. Indigenous status from each dataset were treated as separate variables to facilitate algorithm application.

<b>Project</b>	<b>Victorian deaths</b>
Investigators	Victoria Health.
Jurisdiction/s	Victoria.
Year/s	Ongoing.
Publications/outputs	No direct outputs.
Datasets	Victorian Aboriginal Hospital Liaison Officers Data Collection, Hospital admissions data.
Project description	Victorian deaths in hospitals are linked with all registered deaths, including Indigenous deaths. See <i>Report on the use of linked data</i> , page 38.
Linkage details	Not available.

## Overall health

<b>Project</b>	<b>Western Australian Aboriginal Coordinated Care Trial</b>
Investigators	Bob Looten, Gerry Anderson, Karen Aucote.
Jurisdiction/s	Western Australia.
Year/s	1998.
Publications/outputs	Western Australian Aboriginal Coordinated Care Trial: Baseline Report. Arto Consulting (WA) Pty Ltd. March 1999 (Arto 1999).
Datasets	Unknown.
Project description	Report no longer available.
Linkage details	Unknown.

<b>Project</b>	<b>Exploring the contributions of individual, area and service-level factors to Indigenous health outcomes</b>
Investigators	Louisa Jorm, collaborators from UK Medical Research Council, NSW Department of Health, Sax Institute, Baker Heart Research Institute, University of Western Sydney.
Jurisdiction/s	New South Wales.
Year/s	c.2006–2009.
Publications/outputs	Unknown.
Datasets	Unknown.
Project description	Not available.
Linkage details	Unknown.

## Palliative Care

<b>Project</b>	<b>Palliative Care Constituency.</b>
Investigators	Beverley McNamara, Janine Calver.
Jurisdiction/s	Western Australia.
Year/s	2003.
Publications/outputs	Rosenwax & McNamara 2006.
Datasets	Australian Bureau of Statistics Mortality Register, Hospital Morbidity Data System, Silver Chain Nursing Association.
Project description	The project compared specialist palliative care given to people dying with cancer to people dying with some other conditions. Records for people who died between 1 July 2000 and 31 December 2002, and whose cause of death was either cancer or one of these conditions, were examined. See <i>Report on the use of linked data</i> , page 32.
Linkage details	Origin of the different variables in the linked dataset is listed. Indigenous status described: 'ever' (Aboriginality = Yes if listed as Aboriginal in either mortality register or hospital morbidity data system, otherwise 'No'. However, there are 'missing' in Table 2 whose origin is unclear).

## Perinatal

<b>Project</b>	<b>Midwives–Indigenous status assigned from birth registrations</b>
Investigators	Max Le.
Jurisdiction/s	Western Australia.
Year/s	Project proposal 2009. Scope years unknown.
Publications/outputs	Unknown.
Datasets	Unknown.
Project description	Not available.
Linkage details	Unknown.

<b>Project</b>	<b>Comprehensive linkage of maternal and infant health data for monitoring health outcomes and planning of maternity services in NSW</b>
Investigators	L Tan, L Taylor, K Lim, J Simpson, C Roberts, L Burns, J Morris, and others at NSW Health.
Jurisdiction/s	New South Wales.
Year/s	Since 2000.
Publications/outputs	Conference presentation (Tan et al. 2008); annual Australia's Mothers and Babies reports (e.g. AIHW: Laws et al. 2007); annual NSW Mothers and Babies reports (e.g. Taylor & Bejuk 2009).
Datasets	Midwives Data Collection (MDC), Admitted Patient Data Collection (APDC), RBDM births.
Project description	Data has been linked routinely on an ongoing basis since 2000 for reporting purposes. For example, two linkages conducted for NSW Health support the reporting of Aboriginality for the annual NSW Mothers and Babies report (e.g. Taylor & Bejuk 2009). Data from the NSW Admitted Patient Data Collection (APDC) for public and private hospitals in NSW were linked by the CHeReL to MDC data to produce information on postnatal length of stay in NSW hospitals, and mother's health insurance status. Records of births reported to the MDC were also linked to birth registration records of the NSW Registry of Births, Deaths and Marriages for births. To date, capture–recapture methods have been used on a linked sample used to adjust estimates of counts to reflect ascertainment level or undercounting. Data linkage is likely to continue to be used for future reporting. Also see <i>Report on the use of linked data</i> , pages 22 and 30.
Linkage details	Some details are reported. Probabilistic linkage was applied using Automatch. Prior to the births–MDC linkage, residential address and mothers' name are standardised using a standardisation software (Autostan) (2007), implying that these are the variables that are used for linkage. The percentages of MDC records that linked and birth registrations that linked for this linkage are reported.

<b>Project</b>	<b>Measuring Indigenous perinatal outcomes — should we use the Indigenous status of the mother, father or baby?</b>
Investigators	Bryan Kennedy, Sue Cornes, Sandra Martyn, Rachel–Anne Wills, Clint Breckell (Health Statistics Centre, Queensland Health).
Jurisdiction/s	Queensland.
Year/s	2006.
Publications/outputs	Kennedy et al. 2009a.
Datasets	Queensland Registrar General's Birth registrations 2003–2006; Queensland Perinatal Data Collection (PDC) 2003–2006; Queensland Hospital Admitted Patient Data Collection (QHAPDC) 2003–2006.
Project description	The project explored whether the patterns of perinatal outcomes, historically drawn from the Perinatal (midwives) Data Collection and based on the Indigenous status of the mother, would be changed if babies born with an Indigenous father and a non-Indigenous mother were included. See <i>Report on the use of linked data</i> , pages 13–4.
Linkage details	QHAPDC and PDC data were linked. They stated that it was not possible to link birth registrations (the HSC did not have birth registrations incorporated into their linkage system at the time of this study). The proportion of unmatched records was published (0.11%). Indigenous status from PDC was used for the mother, as the variable in QHAPDC was often not stated. Indigenous status for the baby was taken from QHAPDC. Linked data therefore had perinatal outcomes associated with baby's Indigenous status. The risks of sourcing the Indigenous status variable for mother and baby from different places were discussed. No other linkage details were published.

<b>Project</b>	<b>Preterm births</b>
Investigators	Amanda Langridge, Natasha Nassar, Jianghong Li, Fiona Stanley.
Jurisdiction/s	Western Australia.
Year/s	1984–2006.
Publications/outputs	Langridge et al. 2010.
Datasets	Midwives' Notification System (perinatal data), birth registrations.
Project description	Social and racial inequalities in preterm birth among Aboriginal and non-Aboriginal infants were investigated, with inequality measures adjusted to detect contributing factors. See <i>Report on the use of linked data</i> , page 34.
Linkage details	Data were linked by Data Linkage WA, located at the Department of Health WA. Some variables used in the linkage are listed, namely full name, address, date of birth and gender.

<b>Project</b>	<b>Validation of Indigenous births in Victorian hospital data</b>
Investigators	Mary Sullivan, Victorian Aboriginal Hospital Liaison Officers (AHLOs).
Jurisdiction/s	Victoria.
Year/s	Since 1998.
Publications/outputs	No direct outputs.
Datasets	Victorian Admitted Episodes Dataset (VAED), Victorian Aboriginal Hospital Liaison Officers Data Collection, Hospital admissions data, perinatal data.
Project description	See <i>Report on the use of linked data</i> , pages 20–1. Births are recorded by the hospital admission system, the perinatal system (midwives), and the Aboriginal Hospital Liaison Officers. AHLOs are not employed at all hospitals. AHLO reports are matched as far as possible with the VAED records, particularly to search for babies with Aboriginal fathers only. (Sullivan 2010).
Linkage details	No additional details available.

## Population size

<b>Project</b>	<b>Demographic characteristics and trends of the Northern Territory Indigenous population, 1996–2001</b>
Investigators	John Condon, Tony Barnes, Joan Cunningham, Len Smith.
Jurisdiction/s	Northern Territory.
Year/s	1996–2001.
Publications/outputs	Condon et al. 2004a.
Datasets	ABS deaths data, NT Registry of Births, Deaths and Marriages death registrations.
Project description	No time-series of population estimates, births or deaths data for Aboriginal and Torres Strait Islander Australians in the NT had been available. Death registration records for Aboriginal and Torres Strait Islander people are more accurate in the NT compared to elsewhere, so these were used along with the most recent (for 2001) ABS estimates of the size and age distribution of the NT Indigenous population to produce estimates of the population size and number of deaths in the NT Indigenous population from 2001 back to 1966 using a back-casting method. It was found that the population size had more than doubled in that time, and the age distribution became 'older'. Mortality declined across all age groups, but not as much as for the non-Indigenous population. The general fertility rate declined by 50%.
Linkage details	Data linkage was used initially to link NT death registration records with de-identified death records from the ABS for 1967–2001, using the death registration number to match them. Indigenous status was taken from the death registration form for records of deaths in the NT from 1988 onwards (when Indigenous status was added to death registrations in the NT), and for records from 1966–1988, by inference based on several characteristics such as name, place of birth and burial, and tribal marriage status (the inference process was validated in a separate study against post-1988 death registrations and was found to be consistent with the Indigenous status on death registrations for 94% of deaths) (Condon et al. 2004a).

<b>Project</b>	<b>Annual production of small area Aboriginal population counts</b>
Investigators	Mark Peel.
Jurisdiction/s	Western Australia.
Year/s	2005.
Publications/outputs	Unknown.
Datasets	Unknown.
Project description	Not available.
Linkage details	Not available.

<b>Project</b>	<b>Annual Estimation of Small Area Aboriginal Population Counts</b>
Investigators	Peter Somerford.
Jurisdiction/s	Western Australia.
Year/s	2006– (ongoing).
Publications/outputs	Unknown.
Datasets	Unknown.
Project description	Not available.
Linkage details	Not available.

## Prisoner and ex-prisoner death rates

<b>Project</b>	<b>Linkage of the NSW department of Corrective Services' Offender Integrated Management System with the AIHW's National Death index to study prisoner death rates</b>
Investigators	A Karimina, TG Butler, S P Corben, MH Levy, L Grant, JM Kaldor, MG Law.
Jurisdiction/s	New South Wales.
Year/s	1988–2002.
Publications/outputs	Karimina et al. 2007a; Karimina et al. 2007b; (Original linkage described in Karimina et al. 2005).
Datasets	National Death Index (NDI); NSW Corrective Services' Offender Integrated Management Services (OIMS).
Project description	Aim of project was measurement of prisoner death rates by linkage of the two datasets. The population selected from the OIMS dataset were full-time prisoners in custody between 1 January 1988 and 31 December 2002 (85,203 unique records (prisoners): 145,979 total records (incarcerations)). OIMS was then linked to the NDI. See <i>Report on the use of linked data</i> , page 35.
Linkage details	Linkage well-described, with sensitivity and specificity measures. Match performed using common identifiers: full name (or alias from OIMS data) DOB, and date of last contact with the prison system. Matches were manually reviewed by a blinded reviewer. Only highest level matches were accepted. Linkage was assessed to be 88.4% sensitive and 99.7% specific.

## Social aspects

<b>Project</b>	<b>Interpersonal violence (not listed on WADLS project lists)</b>
Investigators	Lynn Meuleners, Delia Hendrie, Andy Lee.
Jurisdiction/s	Western Australia.
Year/s	1990–2004.
Publications/outputs	Meuleners et al. 2008, Meuleners et al. 2009.
Datasets	WA Hospital Morbidity Data System (admitted patients) (HMDS); WA Mortality Database; MHIS.
Project description	<p>Meuleners et al. 2008: Quantifies hospitalisations due to interpersonal violence in WA. Hospital records for 1990–2004 for ‘injury inflicted by another’ linked to deaths and MHIS. Several risk factors compared using proportional hazards regression model, including Indigenous status. See <i>Report on the use of linked data</i>, page 32.</p> <p>Meuleners et al. 2009: WADLS linked the HMDS for 1990–2004 for records of victims injured by interpersonal violence to the MHIS for 1966 onwards by principal diagnosis. Linked data were analysed for different risk factors, including Indigenous status. Indigenous victims of interpersonal violence were more likely to be admitted for mental illness. (Indigenous proportions of both categories of victims of violence were about 10 times that of their proportion of the general population. See <i>Report on the use of linked data</i>, page 32.</p>
Linkage details	<p>Meuleners et al. 2008: Linking variables and quality of linkage were not reported. Indigenous status was taken from HMDS. Records with missing Indigenous status were not resolved: these records were quantified, but then excluded from analysis. See <i>Report on the use of linked data</i>, page 32.</p> <p>Meuleners et al. 2009: Principal linkage variables were named: Name, residential address, DOB, and sex. Probabilistic linkage used. Multiple admissions combined with initial patient record. Indigenous status treated as Indigenous or non-Indigenous. Source of Indigenous status was not reported, and it is not reported as to how unknowns were treated. See <i>Report on the use of linked data</i>, page 32.</p>
<b>Project</b>	<b>Adverse maternal and fetal outcomes for pregnant women involved in violence</b>
Investigators	Lynn Meuleners and others (Curtin University).
Jurisdiction/s	Western Australia.
Year/s	Not determined.
Publications/outputs	Project now completed. A publication about this project was being prepared at time of writing.
Datasets	Hospitals (different years from previous papers published by Dr Meuleners), Midwives Notification System.
Project description	Not yet available.
Linkage details	Not yet available.
<b>Project</b>	<b>Examination of Emergency Department admissions for violence</b>
Investigators	Lynn Meuleners and others (Curtin University).
Jurisdiction/s	Western Australia.
Year/s	Not determined.
Publications/outputs	None at time of writing.
Datasets	WA Emergency Department Data Collection.
Project description	Continues work on interpersonal violence published in Meuleners L. et al. 2008 and Meuleners et al. 2009. See above, page 32.
Linkage details	None available at time of writing.

## Substance use

Project	A linkage project on alcohol and illicit drug use during pregnancy that considered Indigenous status. Also looked at neonatal abstinence syndrome
Investigators	Lucy Burns, Richard Mattick, Margaret Cooke.
Jurisdiction/s	New South Wales.
Year/s	1998–2002.
Publications/outputs	Burns et al. 2006b, Burns et al. 2006c, Burns et al. 2006a, Burns & Mattick 2007.
Datasets	NSW Inpatient Statistics Collection was linked to birth information from the NSW Midwives Data Collection over a 5-year period (1998–2002). For Burns & Mattick 2007: NSW Inpatient Statistics Collection, NSW Midwives Data Collection (1992–2002), NSW Pharmaceutical Drugs of Addiction System (PHDAS) (record of approval to dispense methadone).
Project description	<p>See <i>Report on the use of linked data</i>, page 35.</p> <p>Burns et al. 2006b: The aim of this study was to examine the obstetric and neonatal outcomes for women with an alcohol-related hospital admission during pregnancy compared with the general obstetric population. Antenatal and delivery admissions to New South Wales (NSW) hospitals from the NSW Inpatient Statistics Collection were linked to birth information from the NSW Midwives Data Collection over the 5-year period from 1998–2002. Birth admissions were flagged as positive for maternal alcohol use where a birth admission or any pregnancy admission for that birth involved an alcohol-related International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM) code. Key demographic, obstetric, and neonatal variables were compared for births to mothers in the alcohol group with births where no alcohol-related ICD10-AM was recorded. Out of 416,834 birth records, 342 were positive for at least one alcohol-related ICD-10-AM diagnosis. Mothers in the alcohol group had a higher number of previous pregnancies, smoked more heavily, were more likely to not be privately insured, and were more likely to be Indigenous than those in the control group. They presented later in their pregnancy to antenatal services and were more likely to arrive at hospital unbooked for delivery. Caesarean sections were more common to women in the alcohol group and were performed more often for intrauterine growth retardation. Neonates born to women in the alcohol group were smaller for gestational age and were admitted to special care nursery more often.</p> <p>Burns et al. 2006c: Examined obstetric and perinatal outcomes for women with a drug-related hospital admission during pregnancy using the same sources as for Burns et al. 2006b. Over the same study period, 1,974 pregnancies had an opioid ICD-10-AM diagnosis recorded, 552 a stimulant-related ICD-10-AM and 2,172 a cannabis ICD-10-AM diagnosis. Women whose pregnancies and births were diagnosed with any of these drug conditions were younger, had a higher number of previous pregnancies, were Indigenous, smoked heavily and were more likely to not be privately insured. These women also presented later in their pregnancy to antenatal services and were more likely to arrive at hospital unbooked. Neonates born to women in each of the drug groups were more likely to be premature and were admitted to neonatal intensive care and special care nursery more often, with neonates born to women in the opioid group admitted most often.</p> <p>Burns &amp; Mattick 2007: Examined prevalence and several risk factors for neonatal abstinence syndrome (NAS). Mothers of babies with NAS more likely to be Indigenous.</p>
Linkage details	<p>Burns et al. 2006a; Burns et al. 2006b, 2006c: Probabilistic linkage using Automatch. Linkage was well documented. Linking variables are listed, and the NSW Health linked data release process was detailed. Methods similar for the two studies. Proportion of unlinked records was not stated.</p> <p>Burns &amp; Mattick 2007: Variable standardisation process before linkage well documented, some linking variables and blocking variables were listed. Eight passes were used during the linkage, but their details were not described. It is not explicitly stated as to whether Indigenous status was used as a linking variable as it was for Burns et al. 2006c and Burns et al. 2006b. Proportion of unlinked records is not stated. NSW Health linked data release process was detailed, as was some selecting of records before merging required by researchers of linked de-identified data.</p>

## Vasectomy reversals

Project	Vasectomy reversal (not listed in WADLS project lists)
Investigators	D'Arcy Holman, ZS Wisniewski, JB Semmens, John Bass.
Jurisdiction/s	Western Australia.
Year/s	1980–96.
Publications/outputs	Holman et al. 2000.
Datasets	Quality of Surgical Care Project from WADLS (Semmens et al. 1998), WA Births.
Project description	Data was extracted from Quality of Surgical Care Project from WADLS for men aged 20 or more with vasectomy or vasovasostomy 1980–96, with the extraction date–stamped at 15 January 1998. Data about men with vasovasostomy and identities of fathers on birth registrations in same period were then linked using Automatch. Results were compared to numbers of procedures in Medicare claims. Cox regression model used to assess independent effects of various risk factors including Aboriginality. Aboriginal men had a higher incidence of seeking reversals, but chance variation was not eliminated as an explanation for this. See <i>Report on the use of linked data</i> , page 31.
Linkage details	Linking variables for the ad-hoc linkage between vasovasostomies and paternity were listed, as were software, and name compression algorithms. Number of links was stated. Source of Indigenous status data was not explicitly stated.

## Youth

Project	Study of Environment on Aboriginal Resilience and Child Health (SEARCH)
Investigators	Anna Williamson, Emily Banks, Sally Redman, Jonathan Craig, Alan Cass, Debra Fernando, Sandra Eades, Sandra Bailey.
Jurisdiction/s	New South Wales.
Year/s	Cohort recruitment began from November 2008.
Publications/outputs	None at time of writing.
Datasets	SEARCH database, unnamed population health databases (may include GP services, medications, and hospital inpatient episodes).
Project description	The Study of Environment on Aboriginal Resilience and Child Health focuses on community health priority areas as identified by Aboriginal people (Williamson et al. 2010). A cohort was recruited through contact with 1 of 4 Aboriginal Community Controlled Health Organisations located in NSW, consisting of approximately 1,700 Aboriginal and Torres Strait Islander people aged 0–17. It has provisions for future follow up and data linkage. Participants supply data themselves and through parents/caregivers and permission was sort from all participants for future follow–up to occur every 5-years and for their data to be used for linkage to unspecified population health databases. Height, weight, waist circumference, blood pressure, audiometry, otoscopy, tympanometry results are documented. Participants aged 1–7 were assessed for speech and language abilities. Also see <i>Report on the use of linked data</i> , page 43.
Linkage details	None available at time of writing.

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