Improved Reporting of Aboriginal and Torres Strait Islander Peoples on Population Datasets in New South Wales using Record Linkage

– a Feasibility Study



NSW Ministry of Health

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Contents

Ack	Acknowledgements2					
Acro	onyms and Abbreviations	3				
Sum	nmary	4				
1	Introduction	6				
2	Methods	7				
2.1	Ethical approval	7				
2.2	Data sources					
2.3	Record linkage and dataset preparation	8				
2.4	Consistency of reporting of Aboriginal and					
	Torres Strait Islander peoples on linked					
	records	9				
2.5	Development of methods for improving					
	reporting of Aboriginal and Torres Strait					
	Islander peoples using linked records	10				
2.6	Enhancement of ABS death data					
2.7	Enhancement of Registry of Births Deaths					
2.7	and Marriages birth registration data					
	– babies	14				
2.8	Enhancement of Registry of Births Deaths					
2.0	and Marriages birth registration data					
	– mothers	1/1				
2.9	Enhancement of Perinatal Data Collection	14				
2.5	- babies	1/				
2.10	Enhancement of Perinatal Data Collection	14				
2.10	- mothers	15				
2.11	Enhancement of Emergency Department	15				
2.11	Data Collection	16				
2 1 2	Enhancement of Admitted Patient Data					
2.12 2.13	Enhancement of the NSW Central Cancer	17				
2.15		10				
71/	Registry					
2.14	Data analysis	19				
3	ABS death registrations	20				
3.1	Persons					
3.2	Selected indicators					

4	Registry of Births, Deaths and Marriages birth registration data	97
41	Babies	
4.1	Mothers	
4.2		.20
5	Perinatal Data Collection	29
5.1	Babies	.29
5.2	Mothers	.30
5.3	Reporting by hospital	.31
5.4	Selected indicators	.34
6	Emergency Department Data	
	Collection	37
6.1	Persons	.37
6.2	Reporting by hospital	.37
7	Hospitalisations	
7.1	Persons	
7.2	Reporting by hospital	
7.3	Selected indicators	.47
•		40
8	Cancer Registrations	
8.1	Persons	
8.2	Selected indicators	.49
9	Discussion	50
Ref	erences	54

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Acronyms and Abbreviations

ABS	Australian Bureau of Statistics	RBDM	NSW Registry of Births, Deaths and Marriages
AH&MRC	Aboriginal Health and Medical Research Council	SLA	Statistical Local Area
APD	NSW public and private admitted patient data	SMR	Standardised mortality ratio
ARIA	Accessibility/Remoteness Index of Australia		
CHeReL	Centre for Health Record Linkage		
CI	Confidence interval		
CCR	NSW Central Cancer Registry		
DSR	Directly standardised rate		
EDDC	NSW Emergency Department Data Collection		
HIE	NSW Health Information Exchange		
ICD	International Classification of Diseases		
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification		
LHD	Local Health District		
MLK	Master Linkage Key		
NSW	New South Wales		
PAS	Patient administration system		
PDC	NSW Perinatal Data Collection		
PPN	Project Person Number		

Summary

The Australian Government's National Partnership Agreement on Closing the Gap on Indigenous Health Outcomes aims to reduce the disadvantage experienced by Aboriginal and Torres Strait Islander peoples with respect to life expectancy, child mortality, access to early childhood education, educational achievement and employment outcomes. Correct reporting of Aboriginal and Torres Strait Islander peoples on health and health-related data collections is essential to measure the effectiveness of policies and programmes aimed at reducing this disadvantage.

Aboriginal and Torres Strait Islander peoples are known to be under-reported on population-based health and healthrelated data collections in New South Wales. This project developed a method to improve reporting of Aboriginal and Torres Strait Islander peoples on administrative data collections using record linkage, a process that we have termed "enhanced" reporting.

The following datasets were linked: Australian Bureau of Statistics death registration data, Registry of Births, Deaths and Marriages birth registration data, the NSW Perinatal Data Collection, the NSW Emergency Department Data Collection, the NSW Admitted Patient Data, and the NSW Central Cancer Registry. Personal identifiers, such as name and address, were removed from the linked dataset used for analysis.

Enhanced reporting relies on having independent sources of information on whether a person is Aboriginal or Torres Strait Islander. Each independent report was counted as a "unit of information" that contributed to the weight of evidence as to whether a person was reported as Aboriginal or Torres Strait Islander. The following approach was used:

- where a person is reported as Aboriginal or Torres Strait Islander on the dataset of interest this is accepted as reported;
- 2. otherwise:
 - i) if the person has 3 or more units of information, at least 2 indicating that the person is Aboriginal

or Torres Strait Islander are required to report the person as Aboriginal or Torres Strait Islander; or

 ii) if the person has 1 or 2 units of information, 1 is sufficient to report the person as Aboriginal or Torres Strait Islander.

This approach, which we refer to as "the algorithm", is modified slightly in the case of datasets where there may be more than one unit of information for a person, such as multiple records of hospitalisations for one person in Admitted Patient Data. Where there are multiple units of information in the same data collection for the same person, the above approach is modified so that part 1 of the algorithm reads: "where a person is always reported as Aboriginal or Torres Strait Islander on the dataset of interest this is accepted as reported".

Using the algorithm, the level of enhancement ranged from 4% for RBDM birth registration data, for babies born to Aboriginal or Torres Strait Islander mothers, to 73% for the Emergency Department Data Collection. Enhancement resulted in a substantially greater increase in reporting of: older Aboriginal and Torres Strait Islander peoples compared to younger people; people living in urban versus rural areas; and people with chronic conditions compared to acute conditions.

Using the algorithm as the standard the level of reporting of Aboriginal and Torres Strait Islander peoples was found to be 86% in Admitted Patient Data for public hospitals, 71% in the Emergency Department Data Collection, and 93% in the Perinatal Data Collection for babies born to Aboriginal or Torres Strait Islander mothers. The level of reporting was found to vary markedly between hospitals and Local Health Districts.

Enhancement of reporting of Aboriginal and Torres Strait Islander peoples using record linkage does not define that a person is Aboriginal or Torres Strait Islander. Enhancement is a statistical construct that results in improved information about Aboriginal and Torres Strait Islander peoples and may be used for planning and evaluation of health services. The algorithm was developed for use at a NSW state level and may need to be modified for use in other settings. Factors that should be taken into account in determining which datasets should be linked for enhancement purposes and whether the algorithm should be modified for a particular purpose include: previous validation studies on the source datasets, the degree to which the dataset is representative of the Aboriginal and Torres Strait Islander population, and the extent to which information in each dataset is collected independently.

While record linkage may be used to improve reporting of Aboriginal and Torres Strait Islander peoples on historical data, it should not replace ongoing investment to improve the quality of recording of information on Aboriginal and Torres Strait Islander persons at the point of care throughout the NSW health system.

CHAPTER 1

Introduction

The Australian Government's National Partnership Agreement on Closing the Gap on Indigenous Health Outcomes¹ aims to reduce the disadvantage experienced by Aboriginal and Torres Strait Islander peoples with respect to life expectancy, child mortality, access to early childhood education, educational achievement and employment outcomes.

New South Wales (NSW) has the largest population and the largest Aboriginal and Torres Strait Islander population of all Australian States and Territories; comprising 7.2 million people (32% of the Australian population), and about 155,700 people (30% of the Australian Aboriginal and Torres Strait Islander population) respectively.²

Aboriginal and Torres Strait Islander peoples are known to be under-reported on population-based health and healthrelated data collections. Using a record linkage method (linking Census to death registrations data), the Australian Bureau of Statistics (ABS) estimated that the level of completeness in reporting of deaths among Aboriginal and Torres Strait Islander peoples in NSW was 76% in 2006-07.³ A national survey estimated the level of correct reporting of Aboriginal and Torres Strait Islander peoples on NSW public hospital admitted patient data to be 88% in 2007,⁴ while a NSW data quality survey estimated the level of correct reporting to be 91% in 2010.⁵ An analysis of linked records estimated the level of correct reporting and Torres Strait Islander peoples on the NSW Perinatal Data Collection to be 68%.⁶

The aims of this project were to:

- develop methods for improving reporting of Aboriginal and Torres Strait Islander peoples on population datasets using record linkage;
- 2. 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.

The following data collections were examined in the project:

- 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

Development of the methods is described in Chapter 2 and estimates of improvements in reporting and the impact on selected indicators are described for each data collection in Chapters 3–7. The results and implications for further use of record linkage as a tool for improving reporting of Aboriginal and Torres Strait Islander peoples are discussed in Chapter 8.

Methods

2.1 Ethical approval

Ethical approval for the project was obtained from the NSW Population and Health Services Research Ethics Committee and the Aboriginal Health and Medical Research Council Ethics Committee.

2.2 Data sources

The project used six data collections:

1. NSW Registry of Births, Deaths and Marriages birth registration data

The Registry of Births, Deaths and Marriages (RBDM) birth registration data covers all births occurring in NSW. It includes all live births, and stillbirths of at least 20 weeks gestation or, if the gestational age is not known, at least 400 grams birth weight. The RBDM birth registration data includes information on Aboriginal and Torres Strait Islander mothers and fathers only; that is, information on Aboriginal and Torres Strait Islander babies is not collected separately. The dataset is based on calendar year of registration of the birth.

2. NSW Perinatal Data Collection

The NSW Perinatal Data Collection (PDC) is a populationbased data collection covering all births in NSW public and private hospitals, as well as home births. It does not include births to NSW residents who gave birth interstate. Up to 2005, it included all live births and stillbirths of at least 20 weeks gestation or at least 400 grams birth weight. From 2006 onwards it includes all live births, and stillbirths of at least 20 weeks gestation or at least 400 grams birth weight. The PDC reports Aboriginal and Torres Strait Islander mothers only, that is, information on Aboriginal and Torres Strait Islander babies is not collected separately. The dataset is based on calendar year of birth.

3. ABS death registration data

The ABS compiles and processes death registration data collected by Australian state and territory RBDMs. The ABS death registration data (ABS death data) used for this project included deaths occurring in NSW and includes both coronial and non-coronial deaths. The dataset does not include deaths of NSW residents who died interstate. The dataset is based on calendar year of registration of the death.

4. NSW Admitted Patient Data

NSW Admitted Patient Data (APD) comprises a census of all admitted patient services provided by NSW public hospitals, public psychiatric hospitals, public multi-purpose services, private hospitals, and private day procedure centres. It covers demographic and episode related data for every hospital separation in NSW. Separation can result from discharge, transfer, death, or change in care type. For public hospitals, the APD enumerates episodes of care. An episode of care ends by either the patient ending a period of stay in hospital (i.e. by discharge, transfer or death) or by the patient undergoing a change in care type within the same period of stay in hospital. In contrast, private hospital data is based on period of stay. Both public hospital episode of care and private hospital period of stay records were included for this project. All types of hospitalisations, including hospitalisations for patients who were admitted and discharged from emergency departments and patients who received Hospital in the Home care, were included. While Albury/Wodonga Health Authority is not part of NSW Health, records of hospitalisations occurring in Albury Base Hospital were included in this project because the hospital is geographically located in NSW and plays an important role in providing health services to the local NSW residents.

5. NSW Emergency Department Data Collection

The NSW Emergency Department Data Collection (EDDC) covers demographic and emergency treatment related data for every person that presents to participating public emergency departments in NSW, which includes all metropolitan public hospital emergency departments and emergency departments in rural base hospitals. The dataset used for this project is based on calendar year of emergency department attendance.

6. NSW Central Cancer Registry

The NSW Central Cancer Registry (CCR) maintains a Register of all malignant cases of cancer diagnosed in NSW since the beginning of 1972. Notifications of cancer are made under the NSW Public Health Act 1991. The dataset is based on calendar year of diagnosis.

2.3 Record linkage and dataset preparation

Record linkage was carried out by the Centre for Health Record Linkage (CHeReL).⁷ The CHeReL uses best practice in privacy preserving record linkage whereby record linkage, which requires access to personal identifiers, is separated from the analysis of linked health records, which does not require access to personal identifiers.⁸

The data for this project was drawn from the CHeReL Master Linkage Key (MLK).⁹ Probabilistic linkage was carried out using the open source software ChoiceMaker.¹⁰ ChoiceMaker uses "blocking" and "scoring" to identify definite and possible matches. During blocking ChoiceMaker searches the target datasets for records that are possible matches to each other. There are two types of blocking. The exact blocking algorithm requires records to have the same set of valid fields and the same values for these fields. The automated blocking algorithm builds a set of conditions that are used to find as many as possible records that potentially match each other. Scoring employs a combination of a probabilistic decision, which is computed using a machine learning technique, and absolute rules, which include upper and lower probability cut-offs, to determine the final decision as to whether each match denotes or possibly denotes the same person. The ABS death data was deterministically linked to RBDM death registration records using the death registration number. Quality assurance procedures at the CHeReL ensure that there were no more than 5/1,000 false positive links and no more than 5/1,000 missed links in the CHeReL MLK.¹¹ For the linked dataset used for this project, the CHeReL reported the quality as less than 4/1,000 false positive links and less than 5/1,000 missed links.

Linkage keys were provided by the CHeReL to each data custodian. Linkage keys comprised the record number from the source dataset and a project person number (PPN). Data custodians provided datasets for analysis to the Centre for Epidemiology and Evidence in the NSW Ministry of Health and the Monitoring, Evaluation and Research Branch of the Cancer Institute NSW. Analysis datasets comprised the variables that were approved by the ethics committee for the project plus the PPN. The final analysis dataset was created by joining datasets together using the PPN.

For the PDC, if the mother was reported as Aboriginal or Torres Strait Islander, then a variable was created indicating that the baby is reported as Aboriginal or Torres Strait Islander. For RBDM birth registrations, if the mother was reported as Aboriginal or Torres Strait Islander, then a variable was created indicating that the baby was born to an Aboriginal or Torres Strait Islander mother; if the mother and/or father were reported as Aboriginal or Torres Strait Islander, then a variable was created indicating that the baby was born of an Aboriginal or Torres Strait Islander parent. For the APD, episode of care records were compiled into one record per hospital stay.

The Accessibility/Remoteness Index of Australia (ARIA+)¹² was used as a measure of geographic remoteness. An ARIA+ category was assigned to all records in the APD, PDC, EDDC and ABS death data using the Statistical Local Area (SLA), and to all RBDM birth registration records using postcode. An ARIA+ code could not be assigned to 2.3% of records.

Records of births and deaths were checked for duplicates. For any person with more than one ABS death record the following information was checked for agreement: the date of death, cause of death, sex, age at death, SLA of residence, and whether the death was reported as an Aboriginal and Torres Strait Islander person. If all records agreed for all this information, the record was reduced to a single death record; otherwise all records for the person were excluded. For RBDM birth registration and PDC data, duplicate birth records were excluded. The final linked dataset available for analysis contained 29 713 803 records (Table 2.1). Dataset preparation and analyses were carried out using SAS 9.2.¹³

Table 2.1 Linked dataset by data source

Data source	Years	Records No.	Persons No.
	reals	Records No.	reisons no.
ABS	1/01/2001–31/12/2007	338 717	338 717
APD ^a	1/07/2000–31/12/2008	18 489 899	5 580 151
EDDC	1/01/2005–31/12/2008	7 472 458	3 224 003
RBDM birth registrations (mothers)	1/01/2000–31/12/2008	773 081	522 877
RBDM birth registrations (infants)	1/01/2000–31/12/2008	773 081	773 081
PDC (mothers)	1/01/2000-31/12/2008	807 200	528 628
PDC (infants)	1/01/2000–31/12/2008	807 200	807 200
CCR	1/07/2000–31/12/2007	252 167	240 305
Total ^b		29 713 803	6 666 091

a The number of records is the number of hospital stays.

b The total number of persons is less than the sum of persons from each data source as one person may be represented in more than one data source.

2.4 Consistency of reporting of Aboriginal and Torres Strait Islander peoples on linked records

Of the 6 666 091 persons represented on the linked dataset, 159 456 (2.4%) persons had at least one linked record that reported the person as Aboriginal or Torres Strait Islander. Of these 159 456 persons, 26 499 (16.6%) had only one record, and the remaining 132 957 (83.4%) had two or more linked records that reported the person as Aboriginal or Torres Strait Islander. Of those with two or more linked records 46 192 (34.7%) persons were always reported as Aboriginal or Torres Strait Islander on all their linked records and 86 765 (65.3%) were inconsistently reported (Table 2.2).

Number of linked records Always reported as Aboriginal and Torres Strait Islander				Strait Islander		
	N	D	Ye	es	T	otal
	No.		No.		No.	
1 record only	_	_	26 499	100.0	26 499	100.0
2 or more records	86 765	65.3	46 192	34.7	132 957	100.0
Total	86 765	54.4	72 691	45.6	159 456	100.0

Table 2.2 Consistency of reporting of Aboriginal and Torres Strait Islander peoples on linked records

2.5 Development of methods for improving reporting of Aboriginal and Torres Strait Islander peoples using linked records

In examining the reporting of Aboriginal and Torres Strait Islander peoples on the linked dataset we considered the degree to which information on each data collection is collected independently. Furthermore, where people may be recorded more than once on the same data collection, such as the APD, we considered the degree to which information is collected independently for each event or service encounter. To the extent that information is collected independently, each event or service encounter contributes a "unit of information" to the evidence that a person is Aboriginal or Torres Strait Islander. On review, we found that:

- the CCR obtains information on whether a person is Aboriginal or Torres Strait Islander from sources of cancer notification including: public hospital notifications via the Health Information Exchange (HIE); private hospitals via the NSW CCR cancer notification portal, patient administration system (PAS) or paper form; and aged care facilities via paper form. In addition, some enhancement is achieved through linking CCR with ABS death data.
- Information in RBDM birth registrations is obtained from birth registration forms completed by the family.
- Information on whether a person is Aboriginal or Torres Strait Islander in ABS death data for deaths occurring in NSW is obtained from funeral directors.
- Procedures for collection of demographic information in NSW public hospitals, for both admitted patients and emergency department attendances, operate so that information on whether a person is Aboriginal or Torres Strait Islander is, in the majority of cases, collected and recorded on the PAS independently for each hospital stay and each emergency department attendance.
- For the PDC, information is collected through a variety of mechanisms. For the PDC, the most widely used maternity information system in NSW public hospitals is ObstetriX. On ObstetriX demographic information (except information concerning whether a person is Aboriginal or Torres Strait Islander) is obtained from the PAS; information on whether a person is Aboriginal or Torres Strait Islander is collected independently by midwives.

There was no information on procedures used by NSW private hospitals to collect information on whether a person is Aboriginal or Torres Strait Islander.

For this project, we defined a "unit of information" as information on an Aboriginal or Torres Strait Islander person obtained from one of: a RBDM birth registration record, a PDC record, an EDDC record, an ABS death record, or a record from the APD representing a hospital stay. Linked CCR records were not used to contribute to reporting of Aboriginal and Torres Strait Islander peoples on other data collections as this would duplicate information already available from another linked data source. Likewise, data collections that are sources of cancer notifications were not used for enhancement of the CCR as this would duplicate information already available on the CCR.

As the number of Torres Strait Islander people in NSW is relatively small, and some people are reported as both Aboriginal and Torres Strait Islander, we combined Aboriginal and Torres Strait Islander peoples into one group for the purpose of analysis.

The lower bound of number of persons reported as Aboriginal or Torres Strait Islander on each data collection is the number reported on the unlinked data collection. This is the minimum population of Aboriginal or Torres Strait Islander people reported for the data collection and we refer to this as "As reported".

An upper bound or maximum population of Aboriginal or Torres Strait Islander people was created by reporting an individual as Aboriginal or Torres Strait Islander if they are reported as Aboriginal or Torres Strait Islander on any linked unit of information. As linked records may contain some incorrect links and data entry errors, it is possible that this approach will result in some non-Aboriginal or Torres Strait Islander people being incorrectly reported as Aboriginal or Torres Strait Islander. In this project the dataset was constructed so that each unit of information is represented by one record, and we refer to this approach as "At least one linked record".

In order to compensate for incorrect links or data entry errors, we developed an approach using a weight of evidence from linked records. Previous work using linked death and hospital records found that an algorithm relying on the number of linked records and number of hospitals reporting a person as Aboriginal or Torres Strait Islander resulted in a higher number of reported deaths than an algorithm relying on a proportion of linked records and/or hospitals.¹⁴ A weight of evidence was developed as follows:

- if the person has 3 or more units of information, at least 2 indicating that the person is Aboriginal or Torres Strait Islander are required to report the person as Aboriginal or Torres Strait Islander;
- otherwise, if the person has 1 or 2 units of information, 1 is sufficient to report the person as Aboriginal or Torres Strait Islander.

This approach was modified slightly in the case of datasets where there may be more than one unit of information for a person, such as multiple records of hospitalisations for one person in the APD. Where there are multiple units of information in the same data collection for the same person, the above approach is modified as follows:

- where a person is always reported as Aboriginal or Torres Strait Islander on the dataset of interest this is accepted as reported;
- 2. otherwise:
 - i) if the person has 3 or more units of information, at least 2 indicating that the person is Aboriginal or Torres Strait Islander are required to report the person as Aboriginal or Torres Strait Islander; or
 - ii) if the person has 1 or 2 units of information, 1 is sufficient to report the person as Aboriginal or Torres Strait Islander.

Algorithms for applying this weight of evidence were developed for each dataset. We refer to these algorithms as "enhancing" the reporting of Aboriginal and Torres Strait Islander peoples. We considered the options of either:

- using the weight of evidence from linked records alone (weight of evidence A), or
- accepting records reported as relating to Aboriginal and Torres Strait Islander peoples in the dataset of interest on an "As reported" basis and using the weight of evidence from the remaining linked records to enhance reporting (weight of evidence B).

To inform this decision we analysed the ABS death data and the associated linked records using both methods. We found the weight of evidence from linked records alone (weight of evidence A), produced far less enhancement in the reporting of deaths compared to weight of evidence B (Table 2.3). Furthermore, the weight of evidence from linked records alone resulted in fewer deaths reported among people aged 70–74 years compared to the original ABS death data.

As the purpose of this project is to develop methods for correcting the under-reporting of Aboriginal and Torres Strait Islander peoples on administrative datasets, we decided to incorporate weight of evidence B into the enhancement algorithms used for this project. That is, we accept records reported as relating to Aboriginal and Torres Strait Islander peoples in the dataset of interest on an "As reported" basis and use the weight of evidence from the remaining linked records to enhance reporting.

2.6 Enhancement of ABS death data

For the ABS death data, a unit of information was defined as one of: a RBDM birth registration record for the mother or baby, a PDC record for the mother or baby, an EDDC record, an ABS death record or a record from the APD representing a hospital stay. A person is reported as being Aboriginal or Torres Strait Islander according to the following algorithm:

- where a person is reported as Aboriginal or Torres Strait Islander on the ABS death data this is accepted as reported;
- 2. otherwise:
 - i) if the person has 3 or more units of information, at least 2 indicating that the person is Aboriginal or Torres Strait Islander are required to report the person as Aboriginal or Torres Strait Islander; or
 - ii) if the person has 1 or 2 units of information, 1 is sufficient to report the person as Aboriginal or Torres Strait Islander.

The analysis dataset for 2007 comprised 46 139 ABS death records linked to 648 845 records from population datasets: APD n = 511 949, EDDC n = 135 657, RBDM birth registration records (mothers) n = 194, RBDM birth registration records (infants) n = 334, PDC records (mothers) n = 211, and PDC records (infants) n = 403. There was at least one linked record for 44 328 (96.1%) deaths.

The analysis dataset for 2005–2007 comprised 135 953 ABS death records linked to 1 620 940 records from population datasets: APD n = 1 332 283, EDDC n = 285276, RBDM birth registration records (mothers) n = 433,

Age (years)			Reporting method		
	As reported		Enhanced	reporting	
		Weight of	evidence A ^a	Weight of	evidence B ^b
	No.	No.	% ^c	No.	% ^c
0	38	42	10.5	45	18.4
1-4	6	6	0.0	7	16.7
5–9	1	1	0.0	1	0.0
10–14	2	2	0.0	4	100.0
15–19	3	4	33.3	4	33.3
20–24	6	9	50.0	9	50.0
25–29	7	11	57.1	11	57.1
30–34	16	20	25.0	21	31.3
35–39	20	21	5.0	25	25.0
40-44	36	42	16.7	46	27.8
45–49	50	59	18.0	62	24.0
50–54	47	53	12.8	60	27.7
55–59	45	45	0.0	57	26.7
60–64	65	69	6.2	80	23.1
65–69	59	66	11.9	78	32.2
70–74	55	52	-5.5	73	32.7
75–79	38	42	10.5	58	52.6
80–84	29	29	0.0	47	62.1
85 +	57	57	0.0	92	61.4
Total ^d	580	630	8.6	780	34.5

Table 2.3 Deaths among Aboriginal and Torres Strait Islander persons by age and method of reporting, NSW 2007

Source: ABS death registrations in NSW for 2007 linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a For 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

b If reported as Aboriginal and Torres Strait Islander the person is accepted "As reported ". In addition, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

c Difference between the number of enhanced deaths and the "As reported" deaths as a percentage of the "As reported" number of deaths.

d Total includes records with missing information on age.

RBDM birth registration records (infants) n = 1084, PDC records (mothers) n = 473, and PDC records (infants) n = 1278. There was at least one linked record for 129 318 (95.1%) deaths.

Table 2.4 shows the contribution of each dataset to enhanced reporting of Aboriginal and Torres Strait Islander deaths. The APD resulted in the largest contribution of deaths when included alone, increasing the count of deaths by 171 from the ABS deaths baseline using the algorithm and by 255 for "At least one linked record". Similarly omitting the APD from the total linked dataset resulted in the largest loss in the reported number of deaths. The EDDC had the greatest impact on the reported number of deaths after the APD, while the RBDM birth registration data and PDC contributed only very small numbers to the enhancement of death reporting. A similar pattern was found for enhancement of deaths occurring in 2005–2007 (Table 2.5).

2.7 Enhancement of Registry of Births Deaths and Marriages birth registration data – babies

For babies whose births were reported to the RBDM, the definition of a unit of information was defined as one of: a RBDM birth registration record, a PDC record, or a birth record from the APD representing a hospital stay. The EDDC was not used for enhancement of reporting of Aboriginal babies as births in emergency departments are very rare. Mortality records were also not used as this would result in relatively greater enhancement of Aboriginal and Torres Strait Islander babies who died.

Information on Aboriginal or Torres Strait Islander mothers and fathers is recorded on RBDM birth registration records. For this analysis we defined an Aboriginal or Torres Strait Islander baby as a baby born to an Aboriginal or Torres Strait Islander mother or father. A baby is therefore

Table 2.4 ABS deaths, NSW 2007– enhanced counts of deaths by data source contribution and method of enhanced reporting

Data source	Data source lin	Data source linked to ABS deaths		from total linked dataset
	Algorithm ^a	At least 1 linked record	Algorithm ^a	At least 1 linked record
	No.	No.	No.	No.
ABS deaths (baseline) $n = 580$	_	-	-	_
APD	751	835	685	737
EDDC	678	722	752	842
PDC (mothers)	589	589	777	906
PDC (babies)	583	584	780	907
RBDM birth registrations (mothers)	583	583	780	908
RBDM birth registrations (babies)	587	587	779	905
All	780	908	_	_

Source: ABS death data linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Records of deaths reported among Aboriginal or Torres Strait Islander people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

Table 2.5 ABS deaths, NSW 2005 to 2007– enhanced counts of deaths by data source contribution and method of enhanced reporting

Data source	Data source lin	ked to ABS deaths	Data source omitted f	from total linked dataset
	Algorithm ^a	At least 1 linked record	Algorithm ^a	At least 1 linked record
	No.	No.	No.	No.
ABS deaths (baseline) $n = 1584$	-	-	-	-
APD	2033	2296	1833	1952
EDDC	1814	1900	2036	2327
PDC (mothers)	1606	1606	2087	2450
PDC (babies)	1590	1591	2091	2453
RBDM birth registrations (babies)	1622	1622	2084	2432
RBDM birth registrations (mothers)	1591	1591	2091	2453
All	2091	2454	_	_

Source: ABS death data linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Records of deaths reported among Aboriginal or Torres Strait Islander people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

reported as being Aboriginal or Torres Strait Islander according to the following algorithm:

- where either parent is reported as Aboriginal or Torres Strait Islander on the RBDM birth registration data this is accepted as reported;
- 2. otherwise:
 - a) if the baby has 3 or more units of information, at least 2 indicating that the baby is Aboriginal or Torres Strait Islander are required to report the baby as Aboriginal or Torres Strait Islander; or
 - b) if the baby has 1 or 2 units of information, 1 is sufficient to report the baby as Aboriginal or Torres Strait Islander.

The analysis dataset for 2008 comprised 98 264 RBDM birth records linked to 190 549 records from population datasets: APD (n = 95 529), and PDC records (n = 95 020). There was at least one linked record for 97 409 (99.1%) births.

Table 2.6 shows the contribution of each data source to the linked dataset. The APD results in the largest contribution of births when included alone, increasing the number of reported births by 376. The enhancement resulting from using both linked APD and PDC records is lower than using the APD alone because the former requires only one of two linked records while the latter requires two of three linked records to report the baby as Aboriginal or Torres Strait Islander.

Table 2.6 RBDM birth registration data, NSW 2008:

Aboriginal and Torres Strait Islander babies

by data source contribution and method of enhanced reporting

1	5	
Data source	Algorithm ^a	At least 1 linked record
	No.	No.
RBDM birth registrations (baseline) $n = 5465$	-	-
APD only	5800	5800
PDC (babies)	5841	5841
All	5688	5986

Source: RBDM birth registration data linked with records of the NSW Admitted Patient Data and NSW Perinatal Data Collection.

a Records of births reported among babies born to Aboriginal or Torres Strait Islander mothers or fathers accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report a baby as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

2.8 Enhancement of Registry of Births Deaths and Marriages birth registration data – mothers

For mothers whose births were reported to the RBDM, the definition of a unit of information was defined as one of: an ABS death record, an EDDC record, a PDC record, or a record from the APD representing a hospital stay.

A mother may give birth more than once and may therefore have multiple birth records on the RBDM birth registration data. In order to take into account possible inconsistent reporting of Aboriginal and Torres Strait Islander mothers within the PDC, a mother is reported as being Aboriginal or Torres Strait Islander according to the following algorithm:

- where a mother is always reported as Aboriginal or Torres Strait Islander on the RBDM birth registration data this is accepted as reported;
- 2. otherwise:
 - i) if the mother has 3 or more units of information, at least 2 indicating that the mother is Aboriginal or Torres Strait Islander are required to report the mother as Aboriginal or Torres Strait Islander; or
 - ii) if the mother has 1 or 2 units of information, 1 is sufficient to report the mother as Aboriginal or Torres Strait Islander.

The analysis dataset comprised 158 103 RBDM birth registrations (2000–2008) for the 95 872 mothers that had registered births in 2008. These data linked to 589 573 records from population datasets: ABS death records n = 5, EDDC n = 111 039, PDC records (mothers) n = 158 260, and APD n = 320 269. There was at least one linked record for 92 639 (96.6%) of mothers.

Table 2.7 shows the contribution of each data source to the final analysis dataset. The APD results in the largest contribution when included alone, increasing the number of reported mothers giving birth by 556 using the algorithm and 1157 using "At least one linked record".

2.9 Enhancement of Perinatal Data Collection – babies

In 2008, the PDC collected information on the Aboriginality of the mother only. However, the RBDM birth registration data includes information on Aboriginal or Torres Strait Islander mothers and fathers. Enhancement was therefore carried out in two ways: first, for babies born to Aboriginal or Torres Strait Islander mothers; and second for babies born to Aboriginal or Torres Strait Islander mothers or fathers.

For babies reported to the PDC, the definition of a unit of information was defined as one of: a RBDM birth registration record, a PDC record, or a birth record from the APD representing a hospital stay. The EDDC was not used for enhancement of reporting of Aboriginal babies as births in emergency departments are very rare. Mortality records were also not used as this would result in relatively greater enhancement of Aboriginal and Torres Strait Islander babies who died.

A baby is therefore reported as being Aboriginal or Torres Strait Islander according to the following algorithm:

- where a baby is reported as Aboriginal or Torres Strait Islander on the PDC data this is accepted as reported;
- 2. otherwise:
 - a) if the baby has 3 or more units of information, at least 2 indicating that the baby is Aboriginal or Torres Strait Islander are required to report the baby as Aboriginal or Torres Strait Islander; or
 - b) if the baby has 1 or 2 units of information, 1 is sufficient to report the baby as Aboriginal or Torres Strait Islander.

The analysis dataset for 2008 comprised 96 223 birth records linked to 174 860 records from population datasets: APD n = 93 007, and RBDM birth registration records (infants) n = 81 853. There was at least one linked record for 94 512 (98.2%) births.

Table 2.8 shows the contribution of each data source to the enhanced reporting of babies born to Aboriginal or Torres Strait Islander mothers. The overall contributions of

Table 2.7 RBDM birth registration data, NSW 2008 – Aboriginal and Torres Strait Islander mothers by data source contribution and method of enhanced reporting

Data source	Data source linked to RBDM birth registration data		Data source omitted from total linked dataset	
	Algorithm ^a At least 1 linked record		Algorithm ^a	At least 1 linked record
	No.	No.	No.	No.
RBDM birth registrations (baseline) $n = 3084^{b}$	3598	3760	-	-
ABS deaths	3598	3760	3777	4603
EDDC	3595	3974	3715	4500
PDC (mothers)	3616	4237	3701	4346
APD	3640	4241	3626	4376
All	3777	4603	_	_

Source: RBDM birth registration data linked with records of ABS death data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and NSW Admitted Patient Data. a Where a mother is always reported as Aboriginal or Torres Strait Islander in the RBDM birth registration data this is accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report the mother as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

b Baseline differs from figures shown for "Algorithm" and "At least one linked record" due to enhancement from RBDM records representing multiple births for some mothers.

the three data sources increased the count of births by 224 using the algorithm and by 1368 using "At least one linked record" compared to the baseline reporting in the PDC. The RBDM birth registration data was the largest contributor to the enhancement when included alone.

Table 2.9 shows the contribution of each data source to the enhanced reporting of babies born to Aboriginal or Torres Strait Islander mothers or fathers. The overall contributions of the three data sources increased the count of births by 458 using the algorithm and by 2438 using "At least one linked record" compared to the baseline reporting in the PDC. The RBDM birth registration data was the largest contributor to the enhancement when included alone.

Table 2.8 Perinatal Data Collection, NSW 2008 – babies born to Aboriginal or Torres Strait Islander mothers by data source contribution and method of enhanced reporting

Data source	Algorithm ^a	At least 1 linked record
	No.	No.
PDC babies (baseline) <i>n</i> = 3013	_	-
RBDM birth registration data	3987	3987
APD	3489	3489
All	3237	4381

Source: NSW Perinatal Data Collection linked with records of the NSW Admitted Patient Data and Registry of Births, Deaths and Marriages birth registration data.

a Records of babies born to Aboriginal or Torres Strait mothers accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report a baby as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient. Table 2.9 Perinatal Data Collection, NSW 2008 – babies born to Aboriginal or Torres Strait Islander mothers or fathers by data source contribution and method of enhanced reporting

Data source	Algorithm ^a	At least 1 linked record
	No.	No.
PDC babies (baseline) $n = 3013$	-	-
RBDM birth registration data	5246	5246
APD	3489	3489
All	3471	5451

Source: NSW Perinatal Data Collection linked with records of the NSW Admitted Patient Data and Registry of Births, Deaths and Marriages birth registration data.

a Records of babies born to Aboriginal or Torres Strait mothers or fathers accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report the baby as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

2.10 Enhancement of Perinatal Data Collection – mothers

For mothers reported to the PDC, a unit of information was defined as one of: a RBDM birth registration record, an EDDC record, a PDC record, an ABS death record, or a birth record from the APD representing a hospital stay.

A mother may give birth more than once and may therefore have multiple birth records on the PDC. In order to take into account possible inconsistent reporting of Aboriginal and Torres Strait Islander mothers within the PDC, a mother is reported as being Aboriginal or Torres Strait Islander according to the following algorithm:

 where a mother is always reported as Aboriginal or Torres Strait Islander on PDC this is accepted as reported;

- 2. otherwise:
 - i) if the mother has 3 or more units of information, at least 2 indicating that the mother is Aboriginal or Torres Strait Islander are required to report the mother as Aboriginal or Torres Strait Islander; or
 - ii) if the mother has 1 or 2 units of information, 1 is sufficient to report the mother as Aboriginal or Torres Strait Islander.

The analysis dataset comprised 162 482 PDC birth records (2000–2008) for the 94 703 mothers that gave birth in 2008. These data linked to 583 738 records from population datasets: APD n = 325 562, EDDC n = 114 292, ABS death records n = 0, and RBDM birth registration records (mothers) n = 143 884. There was at least one linked record for 94 396 (99.6%) of mothers.

Table 2.10 shows the contribution of each data source to the enhanced reporting of Aboriginal or Torres Strait Islander mothers. The overall contributions of the five data sources increased the count of Aboriginal or Torres Strait Islander mothers by 414 using the algorithm and by 1633 using "At least one linked record" compared to the baseline reporting in the PDC. The RBDM birth registration data was the largest contributor to the enhancement.

2.11 Enhancement of Emergency Department Data Collection

For the EDDC, a unit of information is defined as one of: an EDDC record, a RBDM birth registration record for the mother or baby, a PDC record for the mother or baby, an ABS death record or a record from the APD representing a hospital stay.

A person may attend an emergency department more than once and may therefore have multiple records on the EDDC. In order to take into account possible inconsistent reporting of Aboriginal and Torres Strait Islander persons within the EDDC, a person is reported as being Aboriginal or Torres Strait Islander according to the following algorithm:

- where a person is always reported as Aboriginal or Torres Strait Islander on the EDDC this is accepted as reported;
- 2. otherwise:
 - i) if the person has 3 or more units of information, at least 2 indicating that the person is Aboriginal or Torres Strait Islander are required to report the person as Aboriginal or Torres Strait Islander; or

is sufficient to report the person as Aboriginal or Torres Strait Islander.

The analysis dataset comprised 4 076 688 EDDC (2005–2008) records for 1 259 730 persons attending an emergency department in 2007-08. These data linked to 9 746 618 records from other datasets: APD n = 5 074 936, PDC (mothers) n = 125 265, PDC (infants) n = 174 338, RBDM birth registrations (mothers) n = 113 245, RBDM birth registrations (infants) n = 169 349, and ABS death records n = 12 797. Of the 1 259 730 persons that attended an emergency department in 2007-08, 1 059 488 (84.1%) had more than one linked record.

Table 2.11 shows the contribution of each data source to the linked dataset used for analysis of the EDDC. The overall contributions of the seven data sources increased the count of Aboriginal or Torres Strait Islander people by 17 640 using the algorithm and by 26 287 using "At least one linked record" compared to the baseline reporting in the EDDC. The APD was the largest contributor to the enhancement.

2.12 Enhancement of Admitted Patient Data

For the APD, a unit of information is defined as one of: a RBDM birth registration record for the mother or baby, a PDC record for the mother or baby, an EDDC record, an ABS death record or a record from the APD representing a hospital stay.

A person may be hospitalised more than once and may therefore have multiple hospitalisations on the APD. In order to take into account possible inconsistent reporting of Aboriginal and Torres Strait Islander persons within the APD, a person is reported as being Aboriginal or Torres Strait Islander according to the following algorithm:

- where a person is always reported as Aboriginal or Torres Strait Islander on the APD this is accepted as reported;
- 2. otherwise:
 - i) if the person has 3 or more units of information, at least 2 indicating that the person is Aboriginal or Torres Strait Islander are required to report the person as Aboriginal or Torres Strait Islander; or
 - ii) if the person has 1 or 2 units of information, 1 is sufficient to report the person as Aboriginal or Torres Strait Islander.
- ii) if the person has 1 or 2 units of information, 1

Table 2.10 Perinatal Data Collection, NSW 2008 -	– Aboriginal or Torres Strait Islander mothers by data source contribution and
method of enhanced reporting	

Data source	Data sour	ce linked to PDC	Data source omitted from total linked dataset		
	Algorithm ^a	At least 1 linked record	Algorithm ^a	At least 1 linked record	
	No.	No.	No.	No.	
PDC mothers (baseline) $n = 2472^{b}$	3055	3284	_	-	
ABS death registrations	3055	3284	3469	4718	
APD	3220	3656	3569	4469	
EDDC	3071	3470	3409	4612	
RBDM birth registrations	3685	4322	3281	3784	
All	3469	4718	_	_	

Source: NSW Perinatal Data Collection linked with records of the ABS death data, NSW Admitted Patient Data, NSW Emergency Department Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Where a mother is always reported as Aboriginal or Torres Strait Islander on the Perinatal Data Collection this is accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report a mother as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

b Baseline differs from figures shown for "Algorithm" and "At least one linked record" due to enhancement from PDC records representing multiple births for some mothers.

Table 2.11 Emergency Department Data Collection, NSW 2007-08 – Aboriginal or Torres Strait Islander peoples attending emergency departments by data source contribution and method of enhanced reporting

5 5 1	,		1	5	
Data source	Data sourc	e linked to EDDC	Data source omitted from total linked datas		
	Algorithm ^a	At least 1 linked record	Algorithm ^a	At least 1 linked record	
	No.	No.	No.	No.	
EDDC (baseline) $n = 24 \ 135^{b}$	35 010	38 409	-	-	
ABS death data	35 037	38 485	41 349	50 363	
APD	40 385	46 090	36 414	44 820	
PDC (babies)	35 649	39 904	41 055	50 107	
PDC (mothers)	35 636	39 546	41 221	50 150	
RBDM birth registration (babies)	36 618	42 325	40 680	47 838	
RBDM birth registration (mothers)	35 830	39 842	41 095	49 791	
All	41 775	50 422	_	_	

Source: NSW Emergency Department Data Collection linked with records of the ABS death data, NSW Admitted Patient Data, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Where a person is always reported as Aboriginal or Torres Strait Islander in the Emergency Department Data Collection this is accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

b Baseline differs from EDDC records representing multiple emergency department attendances for some individuals.

The analysis dataset comprised 2 395 528 APD records (July 2000–December 2008) for the 1 297 222 persons that were separated from hospital (discharged, transferred or died) in 2007-08. These data linked to 3 265 084 records from population datasets: EDDC n = 2494 818, PDC (mothers) n = 238 666, PDC (infants) n = 148 917, RBDM birth registrations (mothers) n = 222 775, RBDM birth registrations (infants) n = 144 063, and ABS death records n = 15 845. Of the 1 297 222 persons that had a hospital separation in 2007-08, 957 652 (73.8%) had more than one linked record.

Table 2.12 shows the contribution of each dataset to enhanced reporting of Aboriginal and Torres Strait Islander peoples. The overall contribution of the seven data sources increased the count of hospital separations among Aboriginal or Torres Strait Islander peoples by 12 163 using the algorithm and by 20 629 using "At least 1 linked record" compared to the baseline reporting in the APD. RBDM birth registrations were the largest single contributor to the enhancement.

Table 2.12 Admitted Patient Data, NSW 2007-08 – hospital separations among Aboriginal and Torres Strait Islander peoples	
by data source contribution and method of enhanced reporting	

Data source	Data sour	ce linked to APD	Data source omitted from total linked dataset		
	Algorithm ^a	At least 1 linked record	Algorithm ^a	At least 1 linked record	
	No.	No.	No.	No.	
APD (baseline) $n = 17\ 103^{\text{b}}$	26 552	29 835	_	-	
ABS deaths	26 561	29 904	29 058	37 666	
EDDC	28 094	32 443	26 963	35 411	
PDC (Babies)	26 708	30 438	30 099	37 455	
PDC (Mothers)	26 825	30 471	29 056	37 330	
RBDM birth registration (Babies)	28 606	33 062	28 707	34 977	
RBDM birth registration (Mothers)	27 244	31 415	28 700	36 411	
All	29 266	37 732	_	_	

Source: NSW Admitted Patient Data linked with records of ABS death data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Where a person is always reported as Aboriginal or Torres Strait Islander in the Admitted Patient Data this is accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

b Baseline differs from figures shown for "Algorithm" and "At least one linked record" due to enhancement from APD records representing multiple hospital separations for some individuals.

2.13 Enhancement of the Central Cancer Registry

The CCR is a person based Registry. If a person is reported on any notification as Aboriginal or Torres Strait Islander, then the person is recorded as Aboriginal or Torres Strait Islander in the CCR. In the development of methods for the enhancement, we considered the degree to which information on each data collection is collected independently from other data collections. In the case of the CCR, information on whether a person is Aboriginal or Torres Strait Islander is obtained from sources of cancer notifications including: public hospital notifications via the HIE, private hospitals via the NSW CCR cancer notification portal, PAS or paper form; and linkage of ABS death data by the Registry. These sources were not used for enhancement as this would duplicate information already available on the CCR. For the CCR, a unit of information was therefore defined as one of: an APD record that does not have a cancer related diagnosis, an EDDC record, a PDC record for the mother or baby or a RBDM birth registration record for the mother or baby.

For the enhancement, a person is reported as being Aboriginal or Torres Strait Islander according to the following algorithm:

 where a person is always reported as Aboriginal or Torres Strait Islander on the CCR this is accepted as reported.

2. otherwise:

- i) if the person has 3 or more units of information, at least 2 indicating that the person is Aboriginal or Torres Strait Islander are required to report the person as Aboriginal or Torres Strait Islander; or
- ii) if the person has 1 or 2 units of information, 1 is sufficient to report the person as Aboriginal or Torres Strait Islander.

The analysis dataset comprised 36 039 cases for the 35 472 persons diagnosed with cancer in 2007. These records linked to 100 576 records from the following datasets: APD n = 28 351, EDDC records n = 70 364, PDC (mothers) n = 858, PDC (infants) n = 88, RBDM birth registrations (mothers) n = 826, and RBDM birth registrations (infants) n = 89.

Table 2.12 shows the contribution of each data source to the enhanced reporting of Aboriginal and Torres Strait Islander cancer cases. The overall contributions of the 6 data sources increased cancer cases by 76 using the algorithm and 150 for at least 1 linked record. The APD (non-cancer related records) was the largest contributor to the enhancement when included alone, increasing cancer cases by 49 using the algorithm and 90 for at least 1 linked record. Similarly omitting the APD from the total linked dataset resulted in the largest loss in the reported number of cancer cases.

Data source	Data sour	ce linked to CCR	Data source omitted from total linked dataset		
	Algorithm ^a	At least 1 linked record	Algorithm ^a	At least 1 linked record	
	No.	No.	No.	No.	
CCR baseline (<i>n</i> = 305)	305	305	-	-	
APD (non-cancer records) ^b	354	395	349	387	
EDDC	348	381	358	402	
PDC (babies)	306	306	380	455	
PDC (mothers)	310	311	380	454	
RBDM birth registration (babies)	307	307	380	454	
RBDM birth registration (mothers)	310	311	381	453	
All	381	455	_	_	

Table 2.12 Central Cancer Registry, NSW 2007 – cancer cases among Aboriginal and Torres Strait Islander peoples by data source contributions and method of enhanced reporting

Source: NSW Central Cancer Registry data linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Records of cancer cases reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

b Excluded records with the following ICD-10-AM diagnosis codes: C00–C96, B21, D03, D05, D45, D46, D47.1, D47.3, L41.2.

2.14 Data analysis

For each dataset, the number of people reported as Aboriginal or Torres Strait Islander was ascertained using the three approaches: "As reported", "At least one linked record" and the relevant algorithm; and unenhanced and enhanced counts of persons by age, sex, and geographic remoteness (ARIA+) were examined. In addition, the following indicators were calculated:

- For the ABS death data, median age at death, agespecific crude death rates and indirectly standardised mortality ratios (SMRs) for cardiovascular diseases (ICD-10¹⁵: I00–I99), cancer (ICD-10: C00–C96), external causes of death (ICD-10: V00–Y98) and potentially avoidable deaths¹⁶ were examined.
- For the APD, directly standardised hospitalisation rates for all causes, cardiovascular diseases (ICD-10-AM¹⁷: I00–I99) diabetes (ICD-10-AM: E10–E14, O24), and injury and poisoning (ICD-10-AM: S00–T99) were calculated.
- For the PDC, rates of premature birth (less than 37 weeks gestation), low birth weight (less than 2,500 grams) infants and commencement of antenatal care prior to 20 weeks were estimated.
- Levels of reporting for individual hospitals were estimated for the APD, EDDC and PDC.
- For the CCR, directly standardised incidence rates for all cancers (ICD-10-AM: C00–C96, D45, D46, D47.1, D47.3, L41.2 and excluding non-melanoma skin cancer (C44)), lung cancer (ICD-10-AM: C33–C34), breast

cancer (ICD-10-AM: C50) and colon cancer (ICD-10-AM: C18) were calculated.

The denominator population for crude death rates and rates of hospital discharges was obtained from Series B of the ABS estimated NSW Aboriginal and Torres Strait Islander population for 2007.²

SMRs were calculated as follows: standard death rates by five year age group were obtained using ABS Australian death data for 2006 and the ABS estimated resident Australian population for the Census year 2006¹⁸; these rates were applied to the ABS estimated Aboriginal and Torres Strait Islander population NSW 2007² by sex and five year age group and summed to obtain expected number of Aboriginal and Torres Strait Islander deaths; and the ratios of observed number of deaths for the three groups "As reported", the algorithm and "At least one linked record" were compared to the expected number of deaths to give SMRs for the three groups.

Directly age standardised cancer incidence rates were calculated using Series B of the ABS estimated NSW Aboriginal and Torres Strait Islander population for 2007² and the ABS estimated Australian population at 30 June 2001 as the standard population.¹⁹

Ninety-five per cent confidence intervals around the SMRs and standardised cancer incidence rates were calculated using the gamma distribution.²⁰

CHAPTER 3

ABS Death Registrations

3.1 Persons

The development of the datasets for analysis of the enhancement of reporting of Aboriginal and Torres Strait Islander peoples on the ABS death data is described in detail in the Section 2.6 of the Methods.

In summary, the analysis dataset for 2007 comprised 46 139 ABS death records linked to 648 845 records from population datasets: APD n = 511 949, EDDC n = 135 657, RBDM birth registration records (mothers) n = 194, RBDM birth registration records (infants) n = 334, PDC records (mothers) n = 211, and PDC records (infants) n = 403. There was at least one linked record for 44 328 (96.1%) deaths.

There were 580 ABS records of deaths among Aboriginal and Torres Strait Islander peoples that were registered in NSW in 2007 (Table 3.1). This represents the minimum number of reported deaths and provides a baseline for comparison. After record linkage, enhancement resulted in 780 reported deaths using the algorithm and 908 reported deaths using "At least one linked record" where the person was reported as Aboriginal or Torres Strait Islander.

Apart from those less than one year of age, there was little increase in the numbers of reported deaths among Aboriginal and Torres Strait Islander children and young people, while reported deaths increased by over 30% in those aged 65 years and over, and over 50% in those aged 75 years and over. Each enhancement method produced similar rates of increased reporting for both males and females. For geographic remoteness, the increase in number of reported deaths was greatest in the major cities, with enhancement rates decreasing with increasing remoteness.

Four groups of causes of death were examined: cancer, cardiovascular diseases, external causes and potentially avoidable deaths. While deaths due to avoidable causes were the largest of the four groups examined, rates of enhancement among persons who died of cancer were

substantially higher than those of other causes of death. Deaths due to avoidable causes had the lowest levels of relative enhancement of the four groups.

Three years of death data from 2005 to 2007 were combined in order to explore the patterns of enhancement by age and sex more closely. The analysis dataset for 2005–2007 comprised 135 953 ABS death records linked to 1 620 940 records from population datasets: APD n = 1332283, EDDC n = 285 276, RBDM birth registration records (mothers) n = 433, RBDM birth registration records (infants) n = 1084, PDC records (mothers) n = 473, and PDC records (infants) n = 1278. There was at least one linked record for 129 318 (95.1%) deaths.

There were 1584 records of deaths among Aboriginal and Torres Strait Islander peoples that were registered in NSW in 2005–2007 (Table 3.2). The numbers of deaths among males were higher than females in the baseline ABS data and for both methods of enhanced reporting. For both males and females, the distribution of deaths did not change noticeably with enhancement method compared with the baseline. For males, peaks in the number of deaths occurred around 45-54 and 60-69 years. For females, the number of deaths peaked at around 40-54 years and then fluctuated from 60 years of age onwards. The number of adolescent deaths are similar between the sexes for all enhancement methods; there was a relatively greater number of deaths in the younger and middle ages (25-69 years) for males compared to females, while there were greater numbers of deaths in the oldest age group (85+ years) for females compared to males.

-	ting, NSW 2007						
Demographic cl	haracteristics			Reporting method			
		As reported		Enhanced			
				rithm ^a		inked record	
		No.	No.	% ^b	No	%b	
Sex	Male	311	420	35.0	486	56.3	
	Female	269	360	33.8	422	56.9	
Age (years)	0	38	45	18.4	50	31.6	
	1-4	6	7	16.7	8	33.3	
	5–9	1	1	0.0	1	0.0	
	10–14	2	4	100.0	5	150.0	
	15–19	3	4	33.3	4	33.3	
	20–24	6	9	50.0	9	50.0	
	25–29	7	11	57.1	11	57.1	
	30–34	16	21	31.3	22	37.5	
	35–39	20	25	25.0	30	50.0	
	40-44	36	46	27.8	49	36.1	
	45–49	50	62	24.0	66	32.0	
	50–54	47	60	27.7	64	36.2	
	55–59	45	57	26.7	64	42.2	
	60–64	65	80	23.1	89	36.9	
	65–69	59	78	32.2	90	52.5	
	70–74	55	73	32.7	83	50.9	
	75–79	38	58	52.6	77	102.6	
	80–84	29	47	62.1	65	124.1	
	85 +	57	92	61.4	121	112.3	
Geographic rem	oteness (ARIA+) ^C						
	Major cities	171	247	44.4	293	71.3	
	Inner regional	190	255	34.2	304	60.0	
	Outer regional	137	178	29.9	203	48.2	
	Remote	47	55	17.0	60	27.7	
	Very remote	23	26	13.0	28	21.7	
Cause of death							
	Cancer ^d	128	188	46.9	227	77.3	
	Cardiovascular diseases ^e	181	234	29.3	273	50.8	
	External causes ^f	56	73	30.4	85	51.8	
	Potentially avoidable deaths ^g	319	405	27.0	445	39.5	
Total ^h		580	780	34.5	908	56.6	

Table 3.1 Deaths among Aboriginal and Torres Strait Islander peoples by demographic characteristics and method of reporting, NSW 2007

Source: ABS death registrations in NSW for 2007 linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Records of deaths reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

b Difference between the number of enhanced deaths and the "As reported" deaths as a percentage of the "As reported" number of deaths.

c ARIA+: Accessibility/Remoteness Index of Australia.

d Cancer cause of death codes ICD-10: C00-C96.

e Cardiovascular diseases cause of death codes ICD-10: I00-I99.

f External causes of death codes ICD-10: V00-Y98.

g Page et al.16

h Total includes records with missing information on demographic characteristics.

Age (years)		Females			Males			All persons	
	As reported	Algorithm ^a	At least 1 linked record	As reported	Algorithm ^a	At least 1 linked record	As reported	Algorithm ^a	At least 1 linked record
	No.	No.	No.	No.	No.	No.	No.	No.	No.
0	37	49	60	48	57	70	85	106	130
1-4	6	7	9	8	9	12	14	16	21
5–9	2	4	4	4	5	6	6	9	10
10-14	2	3	4	3	5	5	5	8	9
15–19	3	5	5	13	18	21	16	23	26
20–24	5	7	7	21	27	30	26	34	37
25–29	14	19	19	14	21	22	28	40	41
30–34	21	25	26	29	37	39	50	62	65
35–39	26	31	38	51	58	62	77	89	100
40-44	42	54	60	59	73	78	101	127	138
45–49	40	57	59	71	92	98	111	149	157
50-54	44	54	60	83	102	113	127	156	173
55-59	41	53	57	67	91	102	108	144	159
60-64	71	92	106	109	137	146	180	229	252
65–69	61	80	92	86	109	127	147	189	219
70–74	82	101	115	73	99	125	155	200	240
75–79	58	75	91	55	82	105	113	157	196
80-84	47	66	93	44	66	91	91	132	184
85+	105	158	203	39	63	94	144	221	297
Total ^b	707	940	1108	877	1151	1346	1584	2091	2454

Table 3.2 Deaths among Aboriginal and Torres Strait Islander peoples by age, sex and method of reporting,	NSW 2005-2007
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Source: ABS death registrations in NSW for 2005 to 2007 linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Records of deaths reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

b Total includes deaths with missing age or sex information.

3.2 Selected indicators

The median age at death in 2007 was higher for males and females combined living in remote and very remote areas compared to more urban areas (Table 3.3). After enhancement, the median age at death increased among males and females combined for those living in major cities, with small variations in other remoteness groups. The effect of enhancement was to reduce the urban-remote differential in median age at death.

The median age at death for cardiovascular diseases rose by 3.2 years after enhancement with the algorithm, and 5.3 years after enhancement with "At least one linked record"; median ages at death for males and females followed a similar pattern. For cancer, avoidable mortality and external causes of death, the median age at death varied little between the two methods. Figure 3.1 shows the age-specific death rates for Aboriginal and Torres Strait Islander peoples for males and females by method of reporting for NSW in 2007. For the original ABS death data, as expected, the age specific death rates increase rapidly with increasing age over 60 years. Females have a lower age-specific death rate than males up to age 85 years, after which females have a substantially higher death rate than males. The disparity between male and female death rates in those aged less than 85 years increases with enhancement using both the algorithm and "At least one linked record".

Figures 3.2 to 3.5 show the age-specific death rates for various causes of death. There is a consistent pattern of higher death rates at younger ages for males compared to females. For deaths due to cancer, the death rates are higher for males than females at all ages, with the highest death rates among males aged 80–84 years (Figure 3.2). For cardiovascular diseases, death rates are higher for males

Table 3.3 Median age at death for Aboriginal and Torres Strait Islander peoples by sex, cause of death, geographic remoteness and method of reporting, NSW 2007

101	noteriess and met		, or an ig, i is i	. 2007						
Cause of					eporting n	nethod				
death- geographic		As repor	ted			Enhanced reporting				
remoteness						Algorithm ^a		At lea	ast 1 linked r	ecord
		Male	Female	Total	Male	Female	Total	Male	Female	Total
Cause of dea	th									
	Cancer ^b	64.4	63.6	64.3	64.6	62.5	63.8	65.2	64.4	65.0
	Cardio-vascular disease ^c	61.1	72.0	65.9	64.8	73.5	69.1	66.0	76.5	71.2
	External Causes ^d	36.8	40.4	39.5	39.9	39.7	39.7	38.0	40.4	39.7
	Potentially avoidable deaths ^e	54.1	55.9	54.6	54.6	55.8	55.0	54.7	55.9	55.5
Geographic r	emoteness (ARIA+) ^f								
	Major cities	59.5	66.1	61.7	61.0	66.3	62.8	62.4	67.1	64.9
	Inner regional	62.5	61.9	62.1	61.9	65.2	63.0	62.9	68.8	65.1
	Outer regional	56.0	65.7	59.9	57.8	63.4	60.5	59.6	65.0	61.1
	Remote	60.0	58.8	59.9	61.2	60.6	61.2	63.2	63.0	63.2
	Very remote	63.2	65.0	64.4	62.9	65.0	63.9	63.2	69.1	64.7
Total ^g		59.5	63.5	61.1	60.8	65.1	62.6	62.1	67.0	63.9

Source: ABS death data linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Records of deaths reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

b Cancer cause of death codes ICD-10: C00-C96.

c Cardiovascular diseases cause of death codes ICD-10: I00–I99

d External causes of death codes ICD-10: V00–Y98.

e Page et al.16

f ARIA+: Accessibility/Remoteness Index of Australia.

g Total includes records with missing information on ARIA+ or cause of death.

than females up to 84 years, and higher for females than males aged 85 years and over (Figure 3.3). For external causes of death, the death rates are higher for males than females at all ages and are most striking at 85 years and over (Figure 3.4). For potentially avoidable deaths, the death rates are higher for males than females at all ages (Figure 3.5). Enhancement using both the algorithm and "At least one linked record" retains these patterns and makes them more evident.

Enhancement resulted in higher SMRs for all causes of death examined and for both sexes (Table 3.4). As expected, enhancement based on "At least one linked record" resulted in higher standardised mortality ratios compared with enhancement based on the algorithm. For males, the largest absolute increase in SMR was for cancer followed by cardiovascular diseases; for females, the largest absolute increase in SMR was for cardiovascular diseases, followed by potentially avoidable deaths.

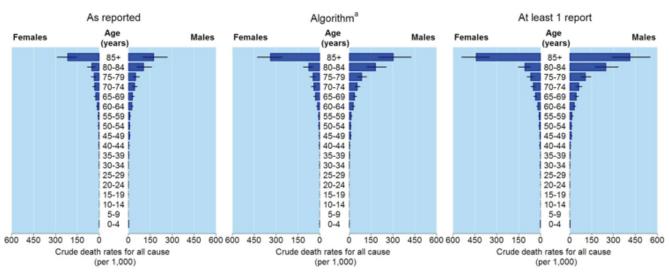
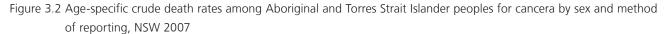
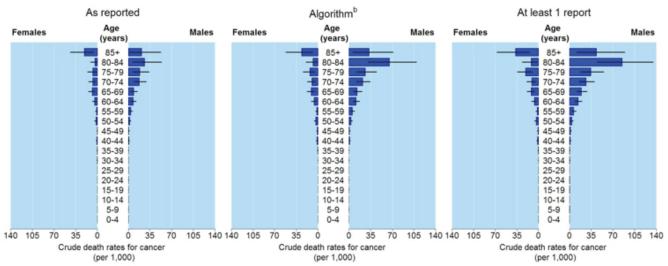


Figure 3.1 Age-specific crude death rates among Aboriginal and Torres Strait Islander peoples by sex and method of reporting, NSW 2007

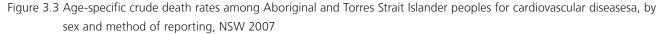
Source: ABS death data linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data. Denominator population for calculation of rates: Series B of the ABS estimated NSW Aboriginal and Torres Strait Islander population for 2007.² a Records of deaths reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

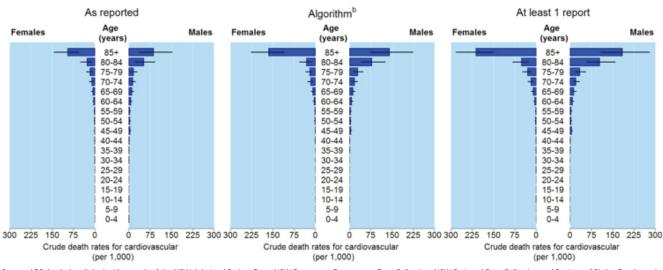




Source: ABS death data linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data. Denominator population for calculation of rates: Series B of the ABS estimated NSW Aboriginal and Torres Strait Islander population for 2007.² a Cancer cause of death codes ICD-10: C00–C96.

b Records of deaths reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

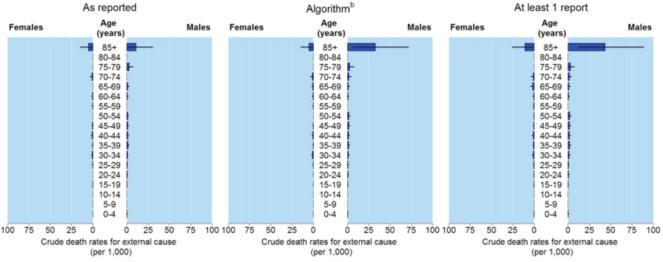




Source: ABS death data linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data. Denominator population for calculation of rates: Series B of the ABS estimated NSW Aboriginal and Torres Strait Islander population for 2007.² a Cardiovascular cause of death codes ICD-10: 100–199.

b Records of deaths reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

Figure 3.4 Age-specific crude death rates among Aboriginal and Torres Strait Islander peoples for external causesa by sex and method of reporting, NSW 2007



Source: ABS death data linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data. Denominator population for calculation of rates: Series B of the ABS estimated NSW Aboriginal and Torres Strait Islander population for 2007.² a External causes cause of death codes ICD-10: V00–Y98.

b Records of deaths reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

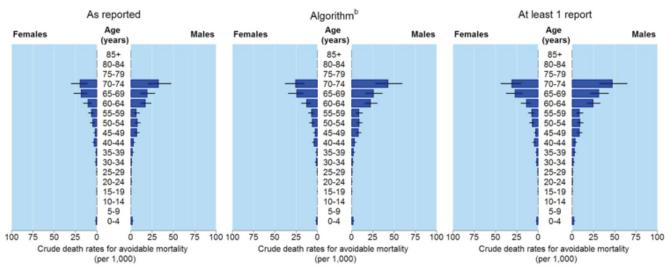


Figure 3.5 Aboriginal and Torres Strait Islander age-specific crude deaths rates for potentially avoidable deathsa by sex and method of reporting, NSW 2007

Source: ABS death data linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data. Denominator population for calculation of rates: Series B of the ABS estimated NSW Aboriginal and Torres Strait Islander population for 2007.² a Page et al.¹⁶

b Records of deaths reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

Table 3.4 Standardised mortality ratios for Aboriginal and Torres Strait Islander peoples by method of reporting, sex and cause of death, NSW 2007

Cause of death –		ales	Fen	nales	Тс	otal
method of reporting	SMR	95% CI	SMR	95% CI	SMR	95% CI
Cancer ^a						
As reported	152.3	119.6–191.2	130.3	97.9–170.1	141.1	117.7–167.8
Algorithme	223.3	182.3–268.4	193.1	153.1–240.3	207.2	178.7–239.1
At least one linked record	275.8	231.1–326.6	224.5	181.2–275.0	250.2	218.7–285.0
Cardiovascular diseases ^b						
As reported	261.6	212.8–318.1	252.9	200.8–314.3	254.7	219.0–294.6
Algorithm ^e	329.6	274.6–392.4	337.2	276.6-407.1	329.3	288.5–374.3
At least 1 linked record	368.8	310.5-435.0	412.1	344.8-488.7	384.2	340.0-432.6
External causes ^c						
As reported	126.8	88.3–176.3	205.8	127.4–314.6	146.6	110.7–190.4
Algorithme	173.9	128.2–230.6	245.0	158.5–361.6	191.1	149.8–240.3
At least 1 linked record	195.6	147.0–255.3	303.8	206.4-431.2	222.5	177.7–275.2
Potentially avoidable deaths ^d						
As reported	223.4	192.1–258.3	279.3	234.5-330.2	242.4	216.5–270.5
Algorithme	284.7	249.3–323.8	352.7	302.1-409.4	307.7	278.4–339.2
At least 1 linked record	310.5	273.4–351.2	391.5	338.1–450.9	338.1	307.4–371.0
All causes						
As reported	190.6	170.0–213.0	213.0	188.3–240.1	198.7	182.9–215.6
Algorithm ^e	257.4	233.4–283.3	285.1	256.4–316.1	267.3	248.8–286.7
At least 1 linked record	297.9	272.0-325.6	334.2	303.0–367.6	311.1	291.2–332.1

Source: ABS death data linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

SMR = standardised mortality ratio. For methods see Section 2.14.

CI = Confidence interval.

a Cancer cause of death codes ICD-10: C00-C97.

b Cardiovascular diseases cause of death codes ICD-10: I00–I99.

c External causes of death codes ICD-10: V00-Y98.

d Page et al.¹⁶

e Records of deaths reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

CHAPTER 4

Registry of Births, Deaths and Marriages Birth Registration Data

4.1 Babies

The development of the datasets for analysis of the enhancement of reporting of Aboriginal and Torres Strait Islander babies on the RBDM birth registration data is described in detail in Section 2.7 of the Methods chapter.

The analysis dataset for 2008 comprised 98 264 birth records linked to 190 549 records from population datasets: APD n = 95 529, and PDC records (infants) n = 95 020. There was at least one linked record for 97 409 (99.1%) births.

There were 5465 births with Aboriginal and Torres Strait Islander mothers or fathers registered in NSW in 2008 (Table 4.1). After record linkage, enhancement resulted in 5688 births using the algorithm and 5986 births using "At least one linked record" where the person was reported as Aboriginal or Torres Strait Islander, representing increases of 4.1% and 9.5% respectively.

Table 4.1 Birth registrations for Aboriginal and Torres Strait Islander babies by demographic characteristics and method of reporting, NSW 2008

Demographic			Reporting method		
characteristics	As reported		Enhanced	l reporting	
		Algori	ithm ^a	At least 1 lir	nked record
	No.	No.	%b	No.	%b
Sex					
Male	2840	2933	3.3	3036	6.9
Female	2624	2727	3.9	2816	7.3
Geographic remoter	ness ^c				
Major cities	2484	2582	3.9	2643	6.4
Inner regional	1318	1370	3.9	1431	8.6
Outer regional	1249	1285	2.9	1343	7.5
Remote	273	279	2.2	287	5.1
Very remote	69	69	0.0	70	1.4
Total ^d	5465	5688	4.1	5986	9.5

Source: RBDM birth registration data linked with records of the NSW Admitted Patient Data and the NSW Perinatal Data Collection.

a Records of births among babies born to Aboriginal and Torres Strait Islander mothers or fathers accepted as reported; for remaining records, if there were 3 units of information 2 are

required to report a baby as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

b Difference between the number of enhanced births and "As reported" births as a percentage of "As reported" births.

c ARIA+: Accessibility/Remoteness Index of Australia.

d Total includes records with missing information on demographic characteristics.

4.2 Mothers

The development of the datasets for analysis of the enhancement of reporting of Aboriginal and Torres Strait Islander mothers on the RBDM birth registration data is described in detail in Section 2.7 of the Methods chapter.

The analysis dataset comprised 158 103 RBDM birth registrations (2000–2008) for the 95 872 mothers that had a registered birth in 2008. These data linked to 589 573 records from population datasets: APD n = 320 269, EDDC n = 111 039, ABS death records n = 5, and PDC records (mothers) n = 158 260. There was more than one birth registration record for 92 639 (96.6%) mothers.

There were 3084 birth registrations for Aboriginal and Torres Strait Islander mothers where the mother was always reported as Aboriginal or Torres Strait Islander over the registration period 2000–2008 (Table 4.2). After record linkage, enhancement resulted in 3777 birth registrations to Aboriginal and Torres Strait Islander mothers using the algorithm and 4603 using "At least one linked record" where the person was reported as Aboriginal or Torres Strait Islander, representing increases of 22.5% and 49.3% respectively.

Enhancement resulted in a trend of greater proportional increase in reporting of Aboriginal or Torres Strait Islander mothers with increasing maternal age, and a greater proportional increase in reporting of Aboriginal or Torres Strait Islander mothers resident in urban compared to rural areas.

Demographic	Reporting method						
characteristics	As reported ^a	Enhanced reporting					
		Algorithm ^b		At least 1 linked record			
	No.	No.	% ^c	No.	% ^c		
Age (years)							
<20	604	696	15.2	736	21.9		
20–24	901	1104	22.5	1261	40.0		
25–29	712	914	28.4	1126	58.1		
30–34	518	629	21.4	862	66.4		
35–39	275	339	23.3	477	73.5		
40+	74	95	28.4	141	90.5		
Geographic remote	ness ^d						
Major cities	1391	1716	23.4	2182	56.9		
Inner regional	677	861	27.2	1051	55.2		
Outer regional	727	872	19.9	1011	39.1		
Remote	195	219	12.3	235	20.5		
Very remote	49	53	8.2	58	18.4		
Total ^e	3084	3777	22.5	4603	49.3		

Table 4.2 Birth registrations for Aboriginal and Torres Strait Islander mothers by demographic characteristics and method of reporting, NSW 2008

Source: RBDM birth registration data linked with records of ABS death data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and NSW Admitted Patient Data. a Aboriginal or Torres Strait Islander mothers reported on birth registrations in 2008, who were always reported as Aboriginal or Torres Strait Islander on all birth registrations for the period 2000–2008.

b Where a mother is always reported as Aboriginal or Torres Strait Islander in the RBDM birth registration data this is accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report a mother as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

c Difference between the number of mothers using enhanced reporting and the "As reported" number of mothers as a percentage of the "As reported" number of mothers.

d ARIA+: Accessibility/Remoteness Index of Australia.

e Total includes records with missing information on demographic characteristics.

CHAPTER 5

Perinatal Data Collection

5.1 Babies

The development of the dataset for analysis of the enhancement of reporting of Aboriginal and Torres Strait Islander babies on the PDC is described in detail in Section 2.9 of the Methods chapter.

The analysis dataset for 2008 comprised 96 223 birth records linked to 174 860 records from population datasets: APD n = 93 007, and RBDM birth registration records (infants) n = 81 853. There was at least one linked record for 94 512 (98.2%) births.

In 2008, the PDC collected information on whether the mother was Aboriginal or Torres Strait Islander, and did not collect information on whether the baby was Aboriginal or Torres Strait Islander.

There were 3013 Aboriginal and Torres Strait Islander babies reported to be born to Aboriginal or Torres Strait Islander mothers according to the PDC (Table 5.1). After record linkage, enhancement resulted in 3237 births using the algorithm and 4381 births using "At least one linked record", representing increases of 7.4% and 45.4% respectively. Enhancement using record linkage resulted in a slightly greater proportional increase in reporting of Aboriginal or Torres Strait Islander male babies compared to female babies, and a greater proportional increase in reporting of Aboriginal and Torres Strait Islander babies in urban compared to rural areas.

Table 5.1 Babies born to Aboriginal and Torres Strait Islander mothers by demographic characteristics and method of reporting, NSW 2008^a

Demographic characteristics			Reporting method		
	Enhanced	As reported ^b			
	reporting	Algorithm ^c		At least 1 linked record	
	No.	No.	% ^d	No.	%d
Sex					
Male	1525	1647	8.0	2254	47.8
Female	1485	1587	6.9	2124	43.0
Geographic remoter	ness ^e				
Major cities	898	962	7.1	1695	88.8
Inner regional	1132	1204	6.4	1463	29.2
Outer regional	676	745	10.2	859	27.1
Remote	200	211	5.5	227	13.5
Very remote	78	84	7.7	92	17.9
Total ^f	3013	3237	7.4	4381	45.4

Source: NSW Perinatal Data Collection records linked with records of NSW Admitted Patient Data and Registry of Births, Deaths and Marriages birth registration data.

b Babies where the mother was reported as Aboriginal or Torres Strait Islander.

c Records of babies born to Aboriginal or Torres Strait mothers accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal or Torres Strait Islander, otherwise 1 is sufficient.

d Difference between the number of enhanced births and "As reported" births as a percentage of "As reported" births.

e ARIA+: Accessibility/Remoteness Index of Australia.

f Total includes records with missing information on demographic characteristics.

a Year of birth

The analysis was carried out a second time to estimate the number of babies born to Aboriginal and Torres Strait Islander mothers or fathers, using the additional information on Aboriginal and Torres Strait Islander fathers available on the RBDM birth registration data (Table 5.2). Enhancement resulted in 3471 births using the algorithm and 5451 births using "At least one linked record", representing increases of 15.2% and 80.9% respectively. Enhancement using record linkage resulted in a greater proportional increase in reporting of Aboriginal and Torres Strait Islander male babies compared to female babies; and a marked increase in reporting of Aboriginal and Torres Strait Islander babies born to mothers resident in urban compared to rural areas.

5.2 Mothers

The development of the dataset for analysis of the enhancement of reporting of Aboriginal and Torres Strait Islander mothers on the RBDM birth registration data is described in detail in Section 2.10 of the Methods chapter.

The analysis dataset comprised 162 482 PDC data birth records (2000–2008) for the 94 703 mothers that gave

birth in 2008. These data linked to 583 738 records from population datasets: APD n = 325 562, EDDC n = 114 292, ABS death records n = 0, and RBDM birth registration records (mothers) n = 143 884. There was at least one linked record for 94 396 (99.6%) of mothers.

In 2008, there were 2472 Aboriginal or Torres Strait Islander mothers who gave birth in 2008, and were always reported as Aboriginal or Torres Strait Islander in all their PDC birth records for the period 2000–2008. After record linkage, enhancement resulted in 3469 reported births to Aboriginal and Torres Strait Islander mothers using the algorithm and 4718 reported births using "At least one linked record", representing increases of 40.3% and 90.9% respectively. Enhancement using record linkage resulted in a trend of a greater proportional increase in reporting of births to Aboriginal and Torres Strait Islander mothers with increasing maternal age. There was a greater proportional increase in reporting in urban compared to rural areas, with an almost doubling in the reported number of Aboriginal and Torres Strait Islander mothers in major cities.

Table 5.2 Babies born to Aboriginal and Torres Strait Islander mothers or fathers by demographic characteristics and method of reporting, NSW 2008^a

Demographic	Reporting method				
characteristics	As reported ^b	Enhanced reporting			
		Algorithm ^c		At least 1 linked record	
	No.	No.	%d	No.	%d
Sex					
Male	1525	1788	17.2	2808	84.1
Female	1485	1680	13.1	2640	77.8
Geographic remote	ness ^e				
Major cities	898	1023	13.9	2123	136.4
Inner regional	1132	1304	15.2	1867	64.9
Outer regional	676	803	18.8	1065	57.5
Remote	200	218	9.0	242	21.0
Very remote	78	90	15.4	99	26.9
Total ^f	3013	3471	15.2	5451	80.9

Source: NSW Perinatal Data Collection birth records linked with records of NSW Admitted Patient Data and Registry of Births, Deaths and Marriages birth registration data.

a Year of birth.

b Babies where the mother or father was reported as Aboriginal and Torres Strait Islander

c Records of babies born to Aboriginal or Torres Strait mothers or fathers accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

d Difference between the number of enhanced births and "As reported" births as a percentage of "As reported" births.

e ARIA+: Accessibility/Remoteness Index of Australia.

f Total includes records with missing information on demographic characteristics.

Table 5.3 Aboriginal and Torres Strait Islander mothers reported on the Perinatal Data Collection by demographic characteristics and method of reporting, NSW 2008^a

Demographic			Reporting method			
characteristics	As reported ^b	Enhanced reporting				
		Algo	Algorithm ^c		At least 1 linked record	
	No.	No.	% ^d	No.	%d	
Age (years)						
<20	563	634	12.6	721	28.1	
20–24	839	1108	32.1	1337	59.4	
25–29	521	843	61.8	1153	121.3	
30–34	337	540	60.2	864	156.4	
35–39	174	275	58.0	501	187.9	
40+	38	67	76.3	140	268.4	
Geographic remote	ness ^e					
Major cities	687	1118	62.7	1933	181.4	
Inner regional	921	1269	37.8	1543	67.5	
Outer regional	584	759	30.0	886	51.7	
Remote	182	204	12.1	220	20.9	
Very remote	72	86	19.4	88	22.2	
Total ^f	2472	3469	40.3	4718	90.9	

Source: NSW Perinatal Data Collection linked with records of the ABS death data, NSW Admitted Patient Data, NSW Emergency Department Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Year of birth.

b Aboriginal and Torres Strait Islander mothers reported on the PDC and who gave birth in 2008, and were always reported as Aboriginal and Torres Strait Islander on all PDC records for the period 2000–2008.

c Records of births reported to Aboriginal and Torres Strait mothers accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

d Difference between the number of mothers using enhanced reporting and the "As reported" number of mothers as a percentage of the "As reported" number of mothers.

e ARIA+: Accessibility/Remoteness Index of Australia.

f Total includes records with missing information on demographic characteristics.

5.3 Reporting by hospital

Table 5.4 shows the estimated level of reporting of births to Aboriginal and Torres Strait Islander mothers by hospital and LHD in NSW, using the number of reported births according to the algorithm as the standard. The estimated level of reporting varied between hospitals from 80% to 100%, with higher levels of reporting in hospitals in more rural areas compared to urban areas. While we have used reporting based on the algorithm for comparison, it is important to note that some Aboriginal or Torres Strait Islander people may not be reported on either the original data or after enhancement using the algorithm, and true levels of reporting may be lower than shown in Table 5.4.

Table 5.4 Level of reporting of babies born to Aboriginal and Torres Strait Islander mothers in the Perinatal Data Collection by Local Health District and hospital, NSW 2008

Local Health Dis	strict–hospital ^a	Method of	Method of reporting		
		As reported	Algorithm ^b		
		No.	No	%	
Sydney					
	Royal Prince Alfred	101	104	97.1	
	Other	2	3	66.7	
	Total	103	107	96.3	
South Western S	Sydney				
	Fairfield	17	18	94.4	
	Liverpool	53	59	89.8	
	Campbelltown	67	72	93.1	
	Bankstown / Lidcombe	9	11	81.8	
	Bowral and District	10	10	100.0	
	Other	0	0	0	
	Total	156	170	91.8	
South Eastern S	ydney				
	St George	8	10	80.0	
	Royal Hospital for Women	55	59	93.2	
	Other	4	5	80.0	
	Total	67	74	90.5	
Illawarra Shoalh	aven				
	Shoalhaven and District Memorial	70	74	94.6	
	Wollongong	124	129	96.1	
	Other	1	1	100.0	
	Total	195	204	95.6	
Western Sydney	,				
	Blacktown	85	98	86.7	
	Westmead	36	37	97.3	
	Other	4	4	100.0	
	Total	125	139	89.9	
Nepean Blue Mo	ountains				
	Blue Mountains District Anzac Memorial	5	5	100.0	
	Nepean	166	172	96.5	
	Hawkesbury District Health Service	37	38	97.4	
	Lithgow Health Service	20	20	100.0	
	Total	228	235	97.0	
Northern Sydne	у				
	Hornsby and Ku-Ring-Gai	8	9	88.9	
	Royal North Shore	10	10	100.0	
	Other	8	9	88.9	
	Total	26	28	92.9	
Central Coast					
	Gosford	103	105	98.1	
	Other	4	4	100.0	
	Total	107	109	98.2	

Local Health Di	strict–hospital ^a	Method of	Method of reporting		
		As reported	Algorithm ^b		
		No.	No		
	Armidale and New England	54	56	96.4	
	Gunnedah District	32	35	91.4	
	Inverell District	29	31	93.5	
	Moree District	66	72	91.7	
	Narrabri District	28	29	96.6	
	Tamworth Base	123	130	94.6	
	Manning Base	70	73	95.9	
	Maitland	63	68	92.6	
	Muswellbrook District	24	24	100.0	
	Belmont	7	7	100.0	
	Singleton District	10	10	100.0	
	John Hunter	224	230	97.4	
	Other	10	10	100.0	
	Total	740	775	95.5	
Northern NSW					
	Casino and District Memorial	10	10	100.0	
	Grafton Base	39	42	92.9	
	Lismore Base	110	117	94.0	
	Murwillumbah District	17	18	94.4	
	The Tweed	59	66	89.4	
	Other	3	3	100.0	
	Total	238	256	93.0	
Mid North Coas	t				
	Coffs Harbour Base	85	86	98.8	
	Kempsey	55	57	96.5	
	Macksville District	18	18	100.0	
	Port Macquarie Base	44	48	91.7	
	Other	3	3	100.0	
	Total	205	212	96.7	
Southern NSW					
	Bega District	8	11	72.7	
	Goulburn Base	8	9	88.9	
	Moruya District	31	37	83.8	
	Queanbeyan Health Service	10	13	76.9	
	Other	3	6	50.0	
	Total	60	76	78.9	
Murrumbidgee					
-	Deniliquin Health Service	12	13	92.3	
	Griffith Base	38	45	84.4	
	Leeton Health Service	13	14	92.9	
	Narrandera Health Service	11	12	91.7	
	Wagga Wagga Base	62	70	88.6	
	Other	10	16	62.5	
	Total	146	170	85.9	

Local Health District–hospital ^a		Method o	f reporting	Level of reporting ^c	
		As reported	Algorithm ^b		
		No.	No		
Western NS	N				
	Bourke Multi-Purpose Service	15	17	88.2	
	Dubbo Base	280	294	95.2	
	Mudgee District	10	13	76.9	
	Walgett District	6	6	100.0	
	Bathurst Base	36	38	94.7	
	Cowra District	13	17	76.5	
	Forbes District	27	28	96.4	
	Orange Base	77	95	81.1	
	Parkes District	17	21	81.0	
	Other	14	16	87.5	
	Total	495	545	90.8	
Far West					
	Broken Hill Base	53	56	94.6	
	Total	53	56	94.6	
Private Hosp	pitals				
	Mater Misericordiae Private	5	5	100.0	
	Sydney Adventist Private	8	8	100.0	
	North Gosford Private	9	9	100.0	
	The Hills Private	5	5	100.0	
	Sydney Southwest Private	6	6	100.0	
	Newcastle Private	16	21	76.2	
	Other	20	26	76.9	
	Total	69	80	86.3	
Total		3013	3237	93.1	

Source: NSW Perinatal Data Collection linked with records of the ABS death data, NSW Admitted Patient Data, NSW Emergency Department Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Hospitals with 5 or more births reported to Aboriginal or Torres Strait mothers shown individually.

b Records of births to Aboriginal or Torres Strait mothers accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

c The number of babies born to Aboriginal and Torres Strait Islanders mothers that were reported on the PDC as a percentage of the estimated number of births according to the algorithm.

5.4 Selected indicators

Enhancement with the algorithm resulted in similar rates of preterm birth and low birth weight among babies born to Aboriginal and Torres Strait Islander mothers than was observed in the original PDC data (Table 5.5). Enhancement using "At least one linked record" resulted in a decrease in both these rates. Both before and after enhancement, rates of preterm birth and low birth weight are substantially higher in very remote areas compared to less remote areas. While enhancement resulted in an increase in the numbers of births reported, the pattern of the relationship between these indicators and geographic remoteness showed little variation.

For babies born to Aboriginal and Torres Strait Islander mothers or fathers enhancement with the algorithm also resulted in similar rates of preterm birth and low birth weight among babies born to Aboriginal and Torres Strait Islander mothers than was observed in the original PDC data (Table 5.5). Enhancement using "At least one linked record" resulted in an overall decrease in these rates, together with a widening differential in rates between urban and rural areas.

Enhancement with the algorithm and using "At least one linked record" resulted in increased rates of first antenatal visit less than 20 weeks gestation (Table 5.7). Both enhanced reporting methods resulting in increased reported rates of first antenatal visit less than 20 weeks gestation in major cities and decreased rates in very remote areas, effectively decreasing the urban-rural differential for this indicator. Table 5.5 Low birth weight and preterm babies born to Aboriginal and Torres Strait Islander mothers by geographic remoteness and method of reporting, NSW 2008

		ia or reporti	119, 119 17 20						
Indicator-				Met	hod of repo	rting			
geographic remoteness ^a		As reported	1			Enhanced	l reporting		
Temoteness					Algorithm ^b		At lea	ast 1 linked	record
	Cases	Total		Cases	Total		Cases	Total	
	No.	No.		No.	No.		No.	No.	
Low birth weight ^c									
Major cities	117	898	13.0	127	962	13.2	189	1695	11.2
Inner regional	130	1132	11.5	140	1204	11.6	166	1463	11.3
Outer regional	85	676	12.6	92	745	12.3	103	859	12.0
Remote	19	200	9.5	20	211	9.5	20	227	8.8
Very remote	14	78	17.9	14	84	16.7	15	92	16.3
Total ^e	368	3013	12.2	396	3237	12.2	496	4381	11.3
Preterm birth ^d									
Major cities	98	898	10.9	106	962	11.0	161	1695	9.5
Inner regional	130	1132	11.5	138	1204	11.5	160	1463	10.9
Outer regional	78	676	11.5	88	745	11.8	96	859	11.2
Remote	19	200	9.5	19	211	9.0	20	227	8.8
Very remote	17	78	21.8	17	84	20.2	18	92	19.6
Total ^e	347	3013	11.5	373	3237	11.5	460	4381	10.5

Source: NSW Perinatal Data Collection linked with records of the ABS death data, NSW Admitted Patient Data, NSW Emergency Department Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a ARIA+: Accessibility/Remoteness Index of Australia.

b Records of births to Aboriginal or Torres Strait mothers accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report a baby as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

c Low birth weight: less than 2,500 grams.

d Preterm birth: Less than 37 weeks gestation.

e Total includes records with missing information on ARIA+.

Table 5.6 Low birth weight and preterm babies born to Aboriginal and Torres Strait Islander mothers or fathers by geographic remoteness and method of reporting, NSW 2008

Indicator-				Re	oorting met	hod			
geographic remoteness ^a		As reported				Enhanced	l reporting		
					Algorithm ^b		At lea	ast 1 linked	record
	Cases	Total		Cases	Total		Cases	Total	
	No.	No.		No.	No.		No.	No.	
Low birth weight ^c									
Major cities	117	898	13.0	135	1023	13.2	223	2123	10.5
Inner regional	130	1132	11.5	153	1304	11.7	195	1867	10.4
Outer regional	85	676	12.6	96	803	12.0	120	1065	11.3
Remote	19	200	9.5	20	218	9.2	20	242	8.3
Very remote	14	78	17.9	15	90	16.7	19	99	19.2
Total ^e	368	3013	12.2	422	3471	12.2	580	5451	10.6
Preterm birth ^d									
Major cities	98	898	10.9	114	1023	11.1	189	2123	8.9
Inner regional	130	1132	11.5	147	1304	11.3	187	1867	10.0
Outer regional	78	676	11.5	93	803	11.6	109	1065	10.2
Remote	19	200	9.5	20	218	9.2	20	242	8.3
Very remote	17	78	21.8	18	90	20.0	22	99	22.2
Total ^e	347	3013	11.5	397	3471	11.4	532	5451	9.8

Source: NSW Perinatal Data Collection linked with records of the ABS death data, NSW Admitted Patient Data, NSW Emergency Department Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a ARIA+: Accessibility/Remoteness Index of Australia.

b Records of births to Aboriginal or Torres Strait mothers or fathers accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report a baby as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

c Low birth weight: less than 2,500 grams.

d Preterm birth: Less than 37 weeks gestation.

e Total includes records with missing information on ARIA+.

Table 5.7 First antenatal visit less than 20 weeks gestation among Aboriginal and Torres Strait Islander mothers by demographic characteristics and method of reporting, NSW 2008

			1 3,					
			Rej	porting met	hod			
	As reported ^l				Enhance	d reporting		
				Algorithm ^c		At least 1 linked record		
Cases	Total		Cases	Total		Cases	Total	
No.	No.		No.	No.		No.	No.	
577	699	82.5	954	1147	83.2	1696	1968	86.2
806	934	86.3	1112	1291	86.1	1360	1567	86.8
487	593	82.1	639	770	83.0	751	899	83.5
145	183	79.2	163	206	79.1	176	222	79.3
51	74	68.9	59	88	67.0	60	90	66.7
2090	2510	83.3	2954	3536	83.5	4083	4795	85.2
	Cases No. 577 806 487 145 51	Cases Total No. No. 577 699 806 934 487 593 145 183 51 74	No. No. % 577 699 82.5 806 934 86.3 487 593 82.1 145 183 79.2 51 74 68.9	Cases Total Cases No. No. No. 5777 699 82.5 954 806 934 86.3 1112 487 593 82.1 639 145 183 79.2 163 51 74 68.9 59	Reporting met As reported ^b Algorithm ^C Cases Total Cases Total Cases Total No. % No. No. 577 699 82.5 954 1147 806 934 86.3 1112 1291 487 593 82.1 639 770 145 183 79.2 163 206 51 74 68.9 59 88	Reporting method As reported ^b Cases Total Cases Total Cases Total Cases Total Cases Total Cases Total % No. No. % No. No. % 577 699 82.5 954 1147 83.2 806 934 86.3 1112 1291 86.1 487 593 82.1 639 770 83.0 145 183 79.2 163 206 79.1 51 74 68.9 59 88 67.0	Reporting method As reported ^b Enhanced reporting Algorithm ^c At lease Cases Total Cases Total Cases No. No. % No. No. % No. 577 699 82.5 954 1147 83.2 1696 806 934 86.3 1112 1291 86.1 1360 487 593 82.1 639 770 83.0 751 145 183 79.2 163 206 79.1 176 51 74 68.9 59 88 67.0 60	Reporting method As reported ^b Enhanced reporting Algorithm ^c At least 1 linked At least 1 linked Cases Total Cases Total Cases Total No. No. No. % No. No. % No. No. No. 577 699 82.5 954 1147 83.2 1696 1968 806 934 86.3 1112 1291 86.1 1360 1567 487 593 82.1 639 770 83.0 751 899 145 183 79.2 163 206 79.1 176 222 51 74 68.9 59 88 67.0 60 90

Source: NSW Perinatal Data Collection linked with records of the ABS death data, NSW Admitted Patient Data, NSW Emergency Department Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a ARIA+: Accessibility/Remoteness Index of Australia.

b Aboriginal and Torres Strait Islander mothers reported on the Perinatal Data Collection and who gave birth in 2008, and were always reported as Aboriginal and Torres Strait Islander on all Perinatal Data Collection records for the period 2000–2008.

c Records of Aboriginal or Torres Strait mothers accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report a mother as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

d Total includes records with missing information on ARIA+.

Emergency Department Data Collection

6.1 Persons

The linked dataset for analysis of the enhancement of reporting of Aboriginal and Torres Strait Islander peoples on the EDDC is described in detail in Section 2.11 of the Methods chapter.

The dataset comprised 2 008 663 records of emergency department attendances in 2007-08 linked to a total of 7 737 948 records of the APD, EDDC (2005 to 2008), PDC, RBDM birth registration data, and ABS death data. The 2 008 663 EDDC records for 2007-08 related to 1 259 730 persons.

There were 24 135 Aboriginal or Torres Strait Islander people who were always reported as Aboriginal or Torres Strait Islander on all their EDDC records for the 2007-08 financial year (Table 6.1). Using the algorithm to enhance reporting, the number of Aboriginal or Torres Strait Islander people rose to 41 775, an increase of 73%. Using "At least one linked record" to enhance reporting, the number of Aboriginal or Torres Strait Islander people rose to 50 442, an increase of 109%.

For both methods of enhancement, there was a greater increase in reporting for: females compared to males; for people less than 5 years and over 60 years compared to other age groups; for more urban areas of residence compared to more rural and remote areas of residence. The most striking effect of enhancement was the more than two-fold increase in the number of reported emergency department attendances among Aboriginal or Torres Strait Islander people living in major cities.

6.2 Reporting by hospital

Overall, 70% of people reported as Aboriginal or Torres Strait Islander using the algorithm were reported as Aboriginal or Torres Strait Islander on the original EDDC data (Table 6.2). The level of reporting varied substantially across hospitals, and tended to be better in hospitals in rural and remote LHDs than hospitals in metropolitan LHDs. While reporting based on the algorithm was used for comparison, it is important to note that some Aboriginal or Torres Strait Islander people may not be reported on either the original data or after enhancement using the algorithm, and true levels of reporting may be lower than shown in Table 6.2.

Demographic			Reporting method	1			
characteristics	As reported ^a		Enhanced reporting				
		Alg	Jorithm ^b	At least 1 linked record			
	No.	No.	% ^c	No.	% ^c		
Sex							
Male	12 288	20 958	70.6	25 211	105.2		
Female	11 847	20 817	75.7	25 211	112.8		
Age (years)							
0–4	3964	7156	80.5	9605	142.3		
5–9	2364	3664	55.0	4483	89.6		
10–14	2516	3565	41.7	3937	56.5		
15–19	2662	4537	70.4	5111	92.0		
20–24	2155	3956	83.6	4569	112.0		
25–29	1680	3135	86.6	3696	120.0		
30–34	1527	2822	84.8	3286	115.2		
35–39	1493	2675	79.2	3174	112.6		
40–44	1324	2291	73.0	2631	98.7		
45–49	1086	1847	70.1	2136	96.7		
50–54	800	1402	75.3	1605	100.6		
55–59	551	999	81.3	1179	114.0		
60–64	410	778	89.8	951	132.0		
65–69	330	621	88.2	742	124.8		
70–74	211	432	104.7	575	172.5		
75–79	135	319	136.3	439	225.2		
80–84	56	160	185.7	307	448.2		
85+	148	285	92.6	422	185.1		
Geographic remote	ness ^d						
Major cities	5335	11 051	107.1	148 10	177.6		
Inner regional	10 722	18 212	69.9	21 651	101.9		
Outer regional	5761	9135	58.6	10290	78.6		
Remote	1287	1918	49.0	2056	59.8		
Very remote	352	444	26.1	459	30.4		
Total ^e	24 135	41 775	73.1	50 422	108.9		

Table 6.1 Aboriginal and Torres Strait Islander persons reported on the Emergency Department Data Collection by demographic characteristics and method of reporting, NSW 2007-08

Source: NSW Emergency Department Data Collection linked with records of the ABS death data, NSW Admitted Patient Data, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Records of persons who attended an emergency department in 2007-08 and were always reported as Aboriginal and Torres Strait Islander on the EDDC for all presentations in the period 2005–2008.

b Where a person is always reported as Aboriginal and Torres Strait Islander in the Emergency Department Data Collection this is accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

c Difference between the number of enhanced EDDC records and the "As reported" EDDC records as a percentage of the "As reported" EDDC records.

d ARIA+: Accessibility/Remoteness Index of Australia.

e Total includes records with missing information on demographic characteristics.

Table 6.2 Level of reporting of Aboriginal and Torres Strait Islander peoples in the Emergency Department Data Collection by
Local Health District and hospital, NSW 2007-08

Local Health Di	istrict–hospital		g method	Level of reporting	
		As reported ^a	Algorithm ^b		
		No.	No.		
Sydney					
	Canterbury	224	308	72.7	
	Royal Prince Alfred	1860	2245	82.9	
	Concord	73	144	50.7	
	Total	2157	2697	80.0	
South Western	Sydney				
	Camden	84	148	56.8	
	Fairfield	202	307	65.8	
	Liverpool	524	1166	44.9	
	Campbelltown	774	1527	50.7	
	Bankstown / Lidcombe	197	367	53.7	
	Bowral and District	183	327	56.0	
	Total	1964	3842	51.1	
South Eastern S	Sydney				
	Sydney	182	378	48.1	
	Sydney Eye	50	109	45.9	
	Prince of Wales	352	751	46.9	
	St George	79	327	24.2	
	Sutherland	116	307	37.8	
	Total	779	1872	41.6	
Illawarra Shoall	haven				
	Bulli District	19	114	16.7	
	Milton and Ulladulla	61	211	28.9	
	Shoalhaven and District Memorial	2257	2696	83.7	
	Wollongong	1042	1524	68.4	
	Shellharbour	588	857	68.6	
	Total	3967	5402	73.4	
Western Sydne					
	Auburn	0	244	0.0	
	Blacktown	0	922	0.0	
	Mount Druitt	0	2027	0.0	
	Westmead	0	829	0.0	
	Total	0	4022	0.0	
Nepean Blue M	ountains				
	Blue Mountains District Anzac Memoriald	0	380	0.0	
	Nepean	624	1725	36.2	
	Lithgow Health Serviced	0	632	0.0	
	Total	624	2737	22.8	
Northern Sydne					
-		123		47.3	

Local Health Dist	rict–hospital		ng method	Level of reporting	
		As reported ^a	Algorithm ^b		
		No.	No.	%	
	Manly District	57	133	42.9	
	Mona Vale and District	58	126	46.0	
	Royal North Shore	76	182	41.8	
	Ryde	45	129	34.9	
	Total	359	830	43.3	
Central Coast					
	Gosford	1049	1495	70.2	
	Wyong	1581	2023	78.2	
	Total	2630	3518	74.8	
lunter New Engl	and				
	Armidale and New England	1594	1977	80.6	
	Glen Innes District	353	426	82.9	
	Gunnedah District	1268	1513	83.8	
	Inverell District	807	1187	68.0	
	Moree District	2015	3277	61.5	
	Narrabri District	1141	1248	91.4	
	Quirindi District	228	534	42.7	
	Tamworth Base	5275	5879	89.7	
	Wee Waa District	713	801	89.0	
	Bulahdelah District	45	48	93.8	
	Gloucester Soldier's Memorial	109	151	72.2	
	Manning Base	1808	2072	87.3	
	Cessnock District	592	715	82.8	
	Kurri Kurri District	259	297	87.2	
	Maitland	1432	1649	86.8	
	Muswellbrook District	576	653	88.2	
	Belmont	620	735	84.4	
	Scott Memorial, Scone	122	133	91.7	
	Singleton District	548	628	87.3	
	Wilson Memorial, Murrurundi	13	17	76.5	
	Nelson Bay and District Polyclinic	218	251	86.9	
	John Hunter	2433	2740	88.8	
	Total	22169	26931	82.3	
Northern NSW					
	Grafton Base	1524	2429	62.7	
	Lismore Base	1610	2807	57.4	
	Murwillumbah District	127	353	36.0	
	The Tweed	1407	1832	76.8	
	Total	4668	7421	62.9	
Vid North Coast					
	Coffs Harbour Base	1603	2072	77.4	
	Kempsey	2678	3600	74.4	
	Total	4281	5672	75.5	

Local Health Dist	rict–hospital	Reporting	method	Level of reporting
		As reported ^a	Algorithm ^b	
		No.	No.	
Southern NSW				
	Goulburn Base	256	403	63.5
	Total	256	403	63.5
Murrumbidgee				
	Griffith Base	1156	1325	87.2
	Wagga Wagga Base	2262	2565	88.2
	Total	3418	3890	87.9
Western NSW				
	Dubbo Base	4618	5584	82.7
	Bathurst Base	1135	1488	76.3
	Orange Base	2114	2408	87.8
	Total	7867	9480	83.0
Far West				
	Broken Hill Base	1839	2071	88.8
	Total	1839	2071	88.8
St Vincent's Hospi	tal Network			
	St Vincent's, Darlinghurst	458	1140	40.2
	Calvary Mater Newcastle	1070	1176	91.0
	Total	1528	2316	66.0
Sydney Children's	Hospital Network			
	The Children's Hospital at Westmead	706	959	73.6
	Sydney Children's	405	698	58.0
	Total	1111	1657	67.0
Other				
	Albury Base	1165	1294	90.0
Total		60 782	86 055	70.6

Source: NSW Emergency Department Data Collection linked with records of the ABS death data, NSW Admitted Patient Data, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Persons who attended an emergency department in 2007-08 and were always reported as Aboriginal and Torres Strait Islander on the EDDC for all presentations in the period 2005–2008. b Where a person is always reported as Aboriginal and Torres Strait Islander in the Emergency Department Data Collection this is accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

c The reported number of Aboriginal and Torres Strait Islander people who were always reported as Aboriginal and Torres Strait Islander on the EDDC as a percentage of the number of Aboriginal and Torres Strait Islander people estimated by the algorithm.

d Blacktown Hospital, Westmead Hospital, Auburn Hospital, Blue Mountains District Anzac Memorial Hospital, Mount Druitt Hospital and Lithgow Health Service were unable to provide information on emergency department attendances among Aboriginal and Torres Strait Islander persons.

CHAPTER 7

Hospitalisations

7.1 Persons

The development of the dataset for analysis of the enhancement of reporting of Aboriginal and Torres Strait Islander babies on the APD data is described in detail in Section 2.12 of the Methods chapter.

In summary, the dataset comprised 2 395 528 APD records (July 2000–December 2008) for the 1 297 222 persons that were separated from hospital in 2007-08. These data linked to 3 265 084 records from population datasets: EDDC n = 2 494 818, PDC (mothers) n = 238 666, PDC (infants) n = 148 917, RBDM birth registrations (mothers) n = 222 775, RBDM birth registrations (infants) n = 144 063, and ABS death records n = 15 845.

There were 17 103 Aboriginal or Torres Strait Islander people who were always reported as Aboriginal or Torres Strait Islander on the APD for the 2007-08 financial year (Table 7.1). Using the algorithm to enhance reporting, the number of Aboriginal or Torres Strait Islander people rose to 29 266, an increase of 71.1%. Using "At least one linked record" to enhance reporting, the number of Aboriginal or Torres Strait Islander people rose to 37 732, an increase of 120.6%.

For both methods of enhancement, reporting increased more for: females compared to males; older age groups compared to younger age groups; and for more urban areas of residence compared to more rural and remote areas of residence. After enhancement, the most striking result was the more than two-fold increase in the number of hospitalisations among Aboriginal or Torres Strait Islander people reported for major cities.

7.2 Reporting by hospital

The level of reporting of Aboriginal or Torres Strait Islander people for individual hospitals using the original APD records and compared to the algorithm is shown in Table 7.2. Overall, 85.8% of people reported as Aboriginal or Torres Strait Islander using the algorithm were reported on the original APD data. The level of reporting varied substantially across hospitals, and tended to be better in hospitals in rural and remote LHDs than hospitals in metropolitan LHDs. While reporting based on the algorithm was used for comparison, it is important to note that some Aboriginal or Torres Strait Islander people may not be reported on either the original data or after enhancement using the algorithm, and true levels of reporting may be lower than shown in Table 7.2.

Demographic			Reporting method				
characteristics	As reported ^a		Enhanced reporting				
			Algorithm ^b	At least 1 linked record			
	No.	No.	% ^c	No.	% ^c		
Sex							
Male	7640	12 870	68.5	16 382	114.4		
Female	9462	16 395	73.3	21 349	125.6		
Age (years)							
0-4	1749	2882	64.8	3689	110.9		
5–9	814	1382	69.8	1636	101.0		
10–14	881	1216	38.0	1348	53.0		
15–19	1645	2449	48.9	2782	69.1		
20–24	1562	2768	77.2	3307	111.7		
25–29	1202	2423	101.6	3074	155.7		
30–34	1098	2170	97.6	2812	156.1		
35–39	1099	2048	86.4	2630	139.3		
40-44	887	1714	93.2	2007	126.3		
45–49	821	1484	80.8	1753	113.5		
50–54	663	1299	95.9	1514	128.4		
55–59	533	1046	96.2	1286	141.3		
60–64	411	879	113.9	1114	171.0		
65–69	330	709	114.8	932	182.4		
70–74	229	535	133.6	763	233.2		
75–79	136	389	186.0	598	339.7		
80–84	55	203	269.1	398	623.6		
85+	29	115	296.6	255	779.3		
Geographic remote	ness ^d						
Major cities	4002	8159	103.9	12 462	211.4		
Inner regional	5959	10 182	70.9	12 749	113.9		
Outer regional	4483	7310	63.1	8541	90.5		
Remote	1491	1979	32.7	2136	43.3		
Very remote	776	974	25.5	1017	31.1		
Total ^e	17 103	29 266	71.1	37 732	120.6		

Table 7.1 Aboriginal and Torres Strait Islander persons reported on the Admitted Patient Data by demographic characteristics and method of reporting, NSW 2007-08

Source: NSW Admitted Patient Data linked with records of ABS death data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Persons who were admitted to hospital in 2007-08 and were always reported as Aboriginal and Torres Strait Islander on the APD for all hospital separations in the period July 2000– December 2008.

b Where a person is always reported as Aboriginal and Torres Strait Islander in the Admitted Patient Data this is accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

c Difference between the number of enhanced hospital separations and the "As reported" hospital admissions as a percentage of the "As reported" number of hospital separations .

d ARIA+: Accessibility/Remoteness Index of Australia.

e Total includes records with missing information on demographic characteristics.

Table 7.2 Level of reporting of Aboriginal and Torres Strait Islander peoples in Admitted Patient Data by Local Health District and hospital, NSW 2007-08

ocal Health District–hospital ^a	Reporting		Level of reporting	
	As reported ^b	Algorithm ^c		
	No.	No.		
/dney				
Canterbury	83	122	68.0	
Royal Prince Alfred	2059	2256	91.3	
Concord	64	193	33.2	
RPAH Institute of Rheumatology and Orthopaedics	19	19	100.0	
Other public hospitals	19	34	55.9	
Total	2244	2624	85.5	
outh Western Sydney				
Camden	55	69	79.7	
Fairfield	114	163	69.9	
Liverpool	525	849	61.8	
Campbelltown	562	724	77.6	
Bankstown / Lidcombe	140	220	63.6	
Bowral and District	114	132	86.4	
Other public hospitals	16	21	76.2	
Total	1526	2178	70.1	
outh Eastern Sydney				
Sydney/Sydney Eye	111	178	62.4	
Prince of Wales	658	859	76.6	
St George	488	711	68.6	
Sutherland	87	131	66.4	
Royal Hospital for Women	210	249	84.3	
Other public hospitals	18	29	62.1	
Total	1572	2157	72.9	
awarra Shoalhaven				
Bulli District	44	50	88.0	
Milton and Ulladulla	38	41	92.7	
Shoalhaven and District Memorial	1537	1757	87.5	
Wollongong	1108	1229	90.2	
Shellharbour	537	578	92.9	
Other public hospitals	44	56	78.6	
Total	3308	3711	89.1	
estern Sydney				
Auburn	131	186	70.4	
Blacktown	589	732	80.5	
Mount Druitt	608	672	90.5	
Westmead	1211	1476	82.0	
Total	2539	3066	82.8	
epean Blue Mountains				
Blue Mountains District Anzac Memorial	72	84	85.7	
Nepean	1522	1932	78.8	
Hawkesbury District Health Service	0	202	0.0	
Lithgow Health Service	143	206	69.4	
Other public hospitals	33	70	47.1	
Total	1770	2494	71.0	

Local Health District–hospital ^a		ig method	Level of reporting ^d	
	As reported ^b	Algorithm ^c		
	No.	No.	%	
Northern Sydney				
Hornsby and Ku-Ring-Gai	104	142	73.2	
Manly District	53	96	55.2	
Mona Vale and District	28	51	54.9	
Royal North Shore	188	300	62.7	
Ryde	31	46	67.4	
Other public hospitals	82	136	60.3	
Total	486	771	63.0	
Central Coast				
Other public hospitals	15	22	68.2	
Gosford	946	1130	83.7	
Wyong	543	934	58.1	
Hunter New England				
Armidale and New England	1101	1237	89.0	
Gunnedah District	231	291	79.4	
Inverell District	308	384	80.2	
Moree District	1214	1269	95.7	
Narrabri District	367	383	95.8	
Tamworth Base	1767	2072	85.3	
Manning Base	1296	1370	94.6	
Cessnock District	83	95	87.4	
Kurri Kurri District	46	48	95.8	
Maitland	508	579	87.7	
Muswellbrook District	133			
		148	89.9	
Calvary Mater Newcastle	267	306	87.3	
Belmont	159	173	91.9	
Singleton District	124	149	83.2	
John Hunter	2491	2704	92.1	
Other public hospitals	673	774	87.0	
Total	10 768	11 982	89.9	
Northern NSW				
Ballina District	867	897	96.7	
Casino and District Memorial	272	279	97.5	
Grafton Base	1259	1384	91.0	
Lismore Base	2362	2549	92.7	
Maclean District	101	114	88.6	
Murwillumbah District	85	146	58.2	
The Tweed	955	1197	79.8	
Other public hospitals	536	580	92.4	
Total	6437	7146	90.1	
Mid North Coast				
Bellinger River District	59	65	90.8	
Coffs Harbour Base	1365	1552	88.0	
Kempsey	1537	1699	90.5	
Macksville District	251	280	89.6	
Port Macquarie Base	655	935	70.1	
			84.0	
			84.0	
Other public hospitals Total	42 3909	50 4581		

Local Health District–hospital ^a	Reportin	Reporting method	
	As reported ^b	Algorithm ^c	
	No.	No.	
Southern NSW			
Bateman's Bay District	161	177	91.0
Bega District	337	372	90.6
Cooma Health Service	17	22	77.3
Goulburn Base	124	166	74.7
Moruya District	601	622	96.6
Queanbeyan Health Service	137	152	90.1
Other public hospitals	87	105	82.9
Total	1464	1616	90.6
<i>l</i> urrumbidgee			
Deniliquin Health Service	81	84	96.4
Young Health Service	61	68	89.7
Griffith Base	804	845	95.1
Tumut Health Service	89	98	90.8
Wagga Wagga Base	1134	1317	86.1
Other public hospitals	717	863	83.1
Total	2886	3275	88.1
Vestern NSW			
Dubbo Base	3865	4204	91.9
Mudgee District	90	118	76.3
Bathurst Base	393	442	88.9
Cowra District	184	219	84.0
Forbes District	324	354	91.5
Orange Base	1977	2078	95.1
Parkes District	199	223	89.2
Other public hospitals	4550	4968	91.6
Total	11 582	12 606	91.9
ar West			
Broken Hill Base	846	918	92.2
Other public hospitals	161	163	98.8
Total	1007	1081	93.2
t Vincent's Health Network			
St Vincent's, Darlinghurst	308	635	48.5
Other public hospitals	11	23	47.8
Total	319	658	48.5
ydney Children's Hospitals Network			
The Children's Hospital at Westmead	672	813	82.7
Sydney Children's	348	483	72.0
Total	1020	1296	78.7
ustice Health			
Total	823	987	83.4
Other			
Albury Base	255	297	85.9
Total	55 419	64 612	85.8

Source: NSW Admitted Patient Data linked with records of ABS death data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data. R

a Public Hospitals in Peer Group C2, District 2 and above are shown individually.

b Persons who were admitted to hospital in 2007-08 and were always reported as Aboriginal and Torres Strait Islander on the APD for all hospital separations in the period July 2000– December 2008.

c Where a person is always reported as Aboriginal and Torres Strait Islander in the Admitted Patient Data this is accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

d The reported number of Aboriginal and Torres Strait Islander people who were always reported as Aboriginal and Torres Strait Islander on the APD as a percentage of the number of Aboriginal and Torres Strait Islander peoples estimated by the algorithm.

Selected indicators 7.3

Overall, standardised hospital admission rates rose substantially after enhancement: from 248 to 641 per 1,000 population using the algorithm and to 803 per 1,000 using enhancement with "At least one linked record" (Table 7.3). Using the algorithm, enhancement of reporting resulted in over a two-fold increase in the standardised hospital admission rate for cardiovascular diseases, injury and poisoning, and diabetes. Similar increases in hospital admission rates were observed for males and females. Enhancement with "At least one linked record" resulted further increases in standardised hospital admission rates compared with the algorithm.

Table 7.3 Standardised hospital admission rates for Aboriginal and Torres Strait Islander peoples by method of reporting, sex and condition, NSW 2007-08

Condition-	Males		Females		Total	
method of reporting	Rate per 1,000 ^a	95% CI	Rate per 1,000 ^a	95% CI	Rate per 1,000 ^a	95% CI
Cardiovascular diseases ^b						
As reported	14.7	13.3–16.1	13.8	12.5–15.1	14.4	13.4–15.3
Algorithm ^e	43.4	40.6-46.2	35.1	32.9–37.3	39.0	37.3–40.7
At least 1 linked record	60.6	57.0-64.3	45.3	42.6-47.9	52.2	50.0-54.3
Diabetes ^c						
As reported	40.9	38.6-43.2	44.5	42.2-46.9	43.1	41.5–44.8
Algorithm ^e	93.0	89.3–96.8	97.4	94.0-100.9	95.8	93.2–98.3
At least 1 linked record	111.3	106.9–115.6	110.6	106.9–114.4	111.0	108.2–113.8
Injury and poisoning ^d						
As reported	22.9	21.6-24.2	15.2	14.1–16.2	19.0	18.2–19.8
Algorithm ^e	47.8	45.6-50.0	32.6	31.0–34.3	39.9	38.6-41.2
At least 1 linked report	59.3	56.7-62.0	41.7	39.7–43.7	50.2	48.5–51.8
All admissions						
As reported	223.6	219.0-228.3	271.7	267.0-276.4	248.4	245.1–251.7
Algorithm ^e	677.0	667.1–686.9	620.4	612.8-628.0	640.7	634.7–646.6
At least 1 linked record	843.3	831.6-855.0	781.3	772.5–790.2	802.6	795.6-809.7

Source: NSW Admitted Patient Data linked with records of the NSW Emergency Department Data, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data, and ABS Aboriginal and Torres Strait Islander estimated resident population NSW 20072. Standard hospitalisation rates were obtained using ABS Australian death CI = Confidence interval.

a Directly standardised rate

b Cardiovascular diseases: Primary diagnosis in the ICD-10-AM range: I00-I99.

c Diabetes: Any diagnosis in the ICD-10-AM range: E10-E14 and O24

d Injury and poisoning: Primary diagnosis in the ICD-10-AM range: S00–T99

e Where a person is always reported as Aboriginal and Torres Strait Islander in the Admitted Patient Data this is accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

CHAPTER 8

Cancer Registrations

8.1 Persons

The development of the dataset for analysis of the enhancement of reporting of Aboriginal and Torres Strait Islander persons on the CCR data is described in detail in Section 2.13 of the Methods chapter.

In summary, the analysis dataset comprised 36 039 cases for the 35 472 persons diagnosed with cancer in 2007. These records linked to 100 576 records from the

following datasets: APD n = 28 351, EDDC records n = 70 364, PDC (mothers) n = 858, PDC (infants) n = 88, RBDM birth registrations (mothers) n = 826, and RBDM birth registrations (infants) n = 89.

There were 305 Aboriginal or Torres Strait Islander people reported in the CCR in 2007 (Table 8.1). Using the algorithm to enhance reporting, the number of Aboriginal or Torres Strait Islander people rose to 381, an increase of 24.9%. Using "At least one linked record" to enhance reporting,

Table 8.1 Aboriginal and Torres Strait Islander persons reported on the Central Cancer Registry by demographic characteristic	S
and method of reporting, NSW 2007	

Demographic			Reporting method				
characteristics	As reported ^a		Enhanced reporting				
		Algorithm ^a		At least 1 li	nked record		
	No.	No.	%b	No.	%b		
Sex							
Male	173	212	22.5	257	48.6		
Female	132	169	28.0	198	50.0		
Age (years)							
0-4	3	4	33.3	6	100.0		
5–14	3	4	33.3	4	33.3		
15–24	4	7	75.0	8	100.0		
25–59	140	170	21.4	197	40.7		
60+	109	137	25.7	168	54.1		
Geographic remote	ness ^c						
Major cities	131	167	27.5	204	55.7		
Inner regional	97	118	21.6	142	46.4		
Outer regional	65	82	26.2	94	44.6		
Remote	9	11	22.2	12	33.3		
Very remote	3	3	0.0	3	0.0		
Cancer							
Lung cancer ^d	61	65	6.6	70	14.8		
Breast cancer ^e	33	38	15.2	41	24.2		
Colon cancer ^f	20	26	30.0	33	65.0		
Total ^g	305	381	24.9	455	49.2		

Source: NSW Central Cancer Registry data linked with records of the NSW Admitted Patient Data, NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data.

a Records of cancer cases reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

b Difference between the number of enhanced cancer cases and the "As reported" cancer cases as a percentage of the "As reported" number of cases.

c ARIA+: Accessibility/Remoteness Index of Australia.

d ICD-10-AM codes: C33-C34.

e ICD-10-AM code: C50.

f ICD-10-AM code: C18.

g Total includes all cancers and records with missing information on demographic characteristics.

Cancer type-	Males		Ea	Females		Total	
method of reporting	DSRa	95% CI	DSR ^a	95% CI	DSR ^a	95% CI	
Lung cancer ^b							
As reported	169.6	105.8–251.2	64.3	39.2–98.5	105.9	76.8–141.2	
Algorithmf	177.4	112.8–259.2	66.4	41.0-100.8	110.7	81.2–146.3	
At least 1 linked record	188.9	122.6–272.2	73.7	46.3 –110.2	119.9	89.1–156.7	
Breast cancer ^C							
As reported	_	_	88.3	58.0–127.8	47.9	30.8–70.2	
Algorithm ^f	_	_	102.0	69.1–144.0	55.4	36.8–79.0	
At least 1 linked record	_	-	117.4	80.3–164.3	64.8	43.3–92.0	
Colon cancer ^d							
As reported	46.6	17.0–93.3	35.1	14.1–69.8	40.2	22.0-65.7	
Algorithm ^f	52.2	21.4–99.1	49.9	24.4-88.7	51.2	30.7–78.6	
At least 1 linked record	67.7	30.7 –121.7	71.7	38.8–119.1	71.4	45.3–105.2	
All cancers ^e							
As reported	701.9	572.1-847.1	351.1	286.5-424.6	492.8	429.1–562.1	
Algorithm ^f	857.8	714.7–1016.1	459.1	382.6-544.7	622.4	549.7–700.8	
At least 1 linked record	1044.0	886.2–1217.1	563.1	475.3-660.7	764.8	682.7–852.8	

Table 8.2 Standardised cancer incidence rates for Aboriginal and Torres Islander peoples by method of reporting, sex and type of cancer, NSW 2007

Source: NSW Central Cancer Registry linked with records of NSW Admitted Patient Data, , NSW Emergency Department Data Collection, NSW Perinatal Data Collection and Registry of Births, Deaths and Marriages birth registration data. ABS Aboriginal and Torres Strait Islander estimated resident population NSW 20072 and the Australian population 2001 (HOIST). DSR = Directly standardised cancer incidence rate per 100,000 population.

CI = Confidence interval.

a Directly standardised rate (Rates were age-adjusted using the Australian population as at 30 June 2001)

b ICD-10-AM codes: C33-C34.

c ICD-10-AM code: C50.

d ICD-10-AM code: C18.

e ICD-10-AM codes: C00–C96, D45, D46, D47.1, D47.3, L41.2 and excluding non-melanoma skin cancer (C44).

f Records of cancer cases reported among Aboriginal or Torres Strait people accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

the number of Aboriginal or Torres Strait Islander people rose to 455, an increase of 49.2%.

For both methods of enhancement, reporting of cancer registrations among Aboriginal or Torres Strait Islander peoples increased more for: females compared to males; older age groups compared to younger age groups; and for more urban areas of residence compared to more rural and remote areas of residence. The effect of enhancement on the number of reported cases of lung, breast and colon cancer was calculated. The number of cases increased for all cancers examined, ranging from 6.6% for lung cancer to 30.0% for colon cancer using the algorithm, and from 14.8% for lung cancer to 65.0% for colon cancer using "At least one linked record".

8.2 Selected indicators

Overall, standardised cancer incidence rates increased after enhancement: from 493 per to 622 per 100,000 population using the algorithm and to 765 per 100,000 population using enhancement with "At least one linked record" (Table 8.2). There were increases in standardised incidence rates for lung cancer, breast cancer and colon cancer for both methods of enhancement, with the greatest increase observed for colon cancer.

CHAPTER 9

Discussion

This project developed a method to improve reporting of Aboriginal and Torres Strait Islander peoples on administrative data collections using record linkage, a process that we have termed "enhanced" reporting. Enhanced reporting relies on having independent sources of information on whether a person is Aboriginal or Torres Strait Islander. Each independent report was counted as a "unit of information" that contributed to the weight of evidence as to whether a person will be reported as Aboriginal or Torres Strait Islander.

The following approach was used to report a person as Aboriginal or Torres Strait Islander:

- where a person is reported as Aboriginal or Torres Strait Islander on the dataset of interest this is accepted as reported;
- 2. otherwise:
 - i) if the person has 3 or more units of information, at least 2 indicating that the person is Aboriginal or Torres Strait Islander are required to report the person as Aboriginal or Torres Strait Islander; or
 - ii) if the person has 1 or 2 units of information, 1 is sufficient to report the person as Aboriginal or Torres Strait Islander.

This approach is modified slightly in the case of datasets where there may be more than one unit of information for a person, such as multiple records of hospitalisations for one person in the APD. Where there are multiple units of information in the same data collection for the same person, the above approach is modified so that part 1 of the algorithm reads: "where a person is always reported as Aboriginal or Torres Strait Islander on the dataset of interest this is accepted as reported".

We found that the level of enhancement achieved by the algorithm varied markedly between data collections (Table 9.1). When the findings of this project were compared with other published studies, we found:

The level of reporting of deaths among Aboriginal and Torres Strait Islander peoples in NSW on ABS death data based on enhancement with the algorithm (74.4%) is similar to that found by ABS for NSW deaths in a eleven-month period in 2006 and 2007 using linked death and Census records (76.3%).³ The pattern of increased enhancement for deaths among older persons and non-remote regions observed in this project was also observed by Briffa et al²⁰ in Western Australia.

- The level of reporting of Aboriginal and Torres Strait Islander peoples on the APD was 85% for 2007-08 using the algorithm. This is similar to a level of 88% (95% CI: 84%–93%) found in a survey of hospital inpatients carried out by the Australian Institute of Health and Welfare (AIHW) in 200721; and a level of 91% (95% CI: 85–94%) found in the 2010 Data Quality Survey of the APD.²²
- The level of reporting on the PDC was 55.3% for babies and 85.2% for mothers. This is higher than was previously found using record linkage with RBDM birth registration data and using capture-recapture methods;²³ and is related to births to Aboriginal or Torres Strait Islander mothers that are not reported as Aboriginal and Torres Strait Islander on either linked dataset being estimated and included in the capturerecapture process.

There is no published literature with which to compare the reporting of Aboriginal and Torres Strait Islander peoples on the EDDC, RBDM birth registration data or CCR. For the CCR, the level of enhancement will vary according to the pattern of sources of notifications; for example, there will be a greater level of enhancement for cancers that are notified primarily by pathology notification (such as melanoma), where no information is provided on whether a person is Aboriginal or Torres Strait Islander, compared to cancers notified from hospital services.

We found that enhancement resulted in a substantially greater increase in reporting of older Aboriginal and Torres Strait Islander persons compared to younger persons, and this is probably due to the greater opportunity for enhancement from the relatively large number of linked records (primarily hospital admission records) available for Table 9.1 Enhancement of reporting of Aboriginal and Torres Strait Islander peoples by data source and method of reporting, NSW

Data source			Reporting metho	bd			
	As reported ^a		Enhanced reporting				
		Algo	Algorithm ^b		At least 1 linked record		
	No.	No.	% ^c	No.	% ^c		
ABS death registrations (2007)	580	780	34.5	908	56.6		
Registry of Births, Deaths and Marriages birth registration—babiesc (2008)	5465	5688	4.1	5986	9.5		
RBDM birth registration—mothers (2008)	3084	3777	22.5	4603	49.3		
Perinatal Data Collection-babies (2008)	3013	3471	15.2	5451	80.9		
Perinatal Data Collection–mothers (2008)	2472	3469	40.3	4718	90.9		
Emergency Department Data Collection (2007-08)	24 135	41 775	73.1	50 422	108.9		
Admitted Patient Data (2007-08)	17 103	29 266	71.1	37 732	120.6		
Central Cancer Registry	305	381	24.9	455	49.2		

a Number of records where persons were reported as Aboriginal and Torres Strait Islander on all records for each person on the data source.

b Where a person is always reported as Aboriginal and Torres Strait Islander in the data source this is accepted as reported; for remaining records, where there are 3 or more linked units of information 2 are required to report an individual as Aboriginal and Torres Strait Islander, otherwise 1 is sufficient.

c Difference between the number of enhanced records and the "As reported" records as a percentage of the "As reported" records.

older people. We found a greater increase in reporting of females compared to males, also likely to be related the greater opportunity for enhancement from the relatively larger number of linked records related to hospitalisation, first during the reproductive years, and second at older ages due to the longer survival of women compared to men.

We found a strong urban-rural gradient in the level of enhanced reporting achieved across all the data collections examined in this study, with greater enhancement occurring in urban versus rural and remote areas of residence. This indicates a greater relative under-reporting of Aboriginal and Torres Strait Islander peoples in urban compared to rural areas. Compared to baseline reporting of Aboriginal and Torres Strait Islander peoples on the source data collections, we found that enhancement with the algorithm resulted in a decrease in the urban-rural differential for median age at death, and the percentage of mothers with a first antenatal visit before 20 weeks gestation.

Record linkage has been used previously to enhance reporting of indigenous peoples or assess levels of underreporting on mortality data in Australia,^{3,14,21,24–26} New Zealand^{27,28} and Canada.²⁹ These studies used various approaches to enhance reporting of Indigenous peoples on administrative data collections, including reporting a person as Indigenous where:

- any linked record indicates the person is Indigenous;
- a person is reported as Indigenous on at least 50% of linked records;

- a person is reported as Indigenous on at least 2 linked records and/or records from at least 2 hospitals; or
- where information on whether the person is Indigenous is missing from the dataset of interest and a linked record reported that they are Indigenous.

Most of these approaches do not take into account the possibility of incorrect enhancement due to occasional incorrect links or data entry errors resulting in incorrect reports of a non-Indigenous person as Indigenous in the source datasets. While the overall rate of such problems may be low, where linked datasets are very large, and Indigenous populations are relatively small, a small percentage of incorrect links or data entry errors could make a substantial difference to the number of records reporting a person as Indigenous after enhancement using record linkage. For this reason we suggest that an approach incorporating a weight of evidence that a person is Aboriginal or Torres Strait Islander is preferable to "At least one linked record".

Various approaches are possible for algorithms incorporating a weight of evidence, such as a requirement that a certain percentage (e.g. 50%, 75% or 90%) of linked records report that the person is Aboriginal or Torres Strait Islander. Enhancement using a weight of evidence based on a proportion of records reporting a person as Aboriginal or Torres Strait Islander requires more evidence than a weight of evidence based on a minimum number of records, and would result in relatively smaller increases in the number of records reporting a person as Aboriginal or Torres Strait Islander. The weight of evidence used in this study allows the maximum number of people to be reported as Aboriginal or Torres Strait Islander without using an "At least one linked record" approach.

Enhancement of reporting of Aboriginal and Torres Strait Islander peoples on administrative data collections using record linkage does not define those persons as Aboriginal or Torres Strait Islander. Rather, record linkage enables us to create a statistical construct for the purposes of planning and research. Record linkage provides a mechanism to help reduce the under-reporting of Aboriginal and Torres Strait Islander peoples in official statistics, and allows adjustment of historical data to obtain improved estimates of morbidity and mortality among Aboriginal and Torres Strait Islander peoples. Importantly in this study, record linkage resulted in correction of some of the bias in health measures resulting from relative under-reporting of Aboriginal and Torres Strait Islander peoples resident in major cities and less remote geographic areas of NSW.

Limitations of the enhancement method used in this study include:

- Continued under-reporting of Aboriginal and Torres Strait Islander peoples after enhancement The Reference Group indicated that, even after enhancement, reporting of deaths among Aboriginal people was lower than they expected from their own experience. This suggests that there are some Aboriginal people who have not been reported as Aboriginal on any of their linked records.
- Restriction on enhancement of ABS death data to deaths registered in NSW

This project reports on deaths registered in NSW in 2007, and our analyses did not include deaths of NSW residents who died interstate—the personal identifiers that are used by the CHeReL for record linkage are supplied by the NSW RBDM, which is responsible for registration of deaths occurring in NSW. The ABS reports statistics on deaths in Australia by the state/ territory of residence. There is therefore a discrepancy between the number of deaths among Aboriginal and Torres Strait Islander peoples that we have presented "As reported" compared to ABS official statistics.

Units of information may not be completely independent.

Procedures for collecting information on whether a person is Aboriginal or Torres Strait Islander were not known for NSW private hospitals and some NSW public hospitals draw information on whether a person is Aboriginal or Torres Strait Islander for the PDC from the PAS—the same system that supplies information for the APD and EDDC. It is therefore possible that, for some people, one record that a person is Aboriginal or Torres Strait Islander may translate into multiple reports that a person is Aboriginal or Torres Strait Islander on the linked dataset. This would result in an increased weight of evidence that a person is Aboriginal or Torres Strait Islander in some cases. However, it is unlikely that this caused a substantial bias towards reporting people as Aboriginal or Torres Strait Islander in the linked dataset.

 Differential enhancement among the very young and the elderly.

The greatest enhancement in reporting was found in older people, followed by infants. As hospital records comprised 79% of the linked records and hospitalisation is more common among older people and almost universal for births, there was a greater opportunity to enhance reporting among babies and older Aboriginal or Torres Strait Islander people compared to young and middle-aged people.

Differential enhancement for those with chronic conditions.

There was greater enhancement of deaths and hospitalisations for those with chronic compared to acute conditions, which are likely to generate many hospital records. For example, enhanced reporting of deaths resulted in increases in SMRs, with a greater proportional increase in SMRs for cancer and cardiovascular diseases compared to external causes of death.

When planning a project that uses record linkage to enhance reporting of Aboriginal and Torres Strait Islander peoples on one or more data collections, we suggest the following should be considered:

 Enhancement of reporting of Aboriginal and Torres Strait Islander peoples does not define that a person is Aboriginal or Torres Strait Islander. Identifying as Aboriginal or Torres Strait Islander is something that Aboriginal and Torres Strait peoples decide about themselves. Enhancement using the algorithm developed during this project, or by any other method, aims to improve reporting on datasets collected for the purposes of research or management of health services.

- Enhancement of reporting of Aboriginal and Torres Strait Islander peoples using linked records creates a statistical construct for a specific purpose. Any statistical construct will depend on the purpose for which the data are intended to be used:
 - For the enhancement of the ABS death data, APD and EDDC, we chose to carry out enhancement using all available linked records. A smaller number of years of linked data could have been used, and would have resulted in a different number of reported deaths.
 - For the enhancement of the RBDM birth registration data and the PDC we chose to exclude linked death records from the enhancement, as this would have differentially enhanced reporting of Aboriginal and Torres Strait Islander babies who had died and possibly distort other measures of health status such as prematurity and low birth weight.
 - If the purpose of a project were to examine trends in mortality among Aboriginal and Torres Strait Islander peoples over several years, the range of datasets and the years of linked data used should be consistent for each year included in such a study to limit any bias from more recent years of data having more opportunity for enhancement.
- 3. Accuracy of recording of Aboriginal and Torres Strait Islander peoples on the source datasets. There may be evidence that Aboriginal and Torres Strait Islander peoples are reported more reliably on certain datasets. For example, linkage could include records from health services dedicated to providing services to Aboriginal and Torres Strait Islander peoples, and these records could provide a greater weight of evidence that a person is Aboriginal or Torres Strait Islander than records collected as part of universal health services.
- 4. The degree to which information on whether a person is Aboriginal or Torres Strait Islander people is collected independently on the linked datasets.
- 5. Numerator-denominator discordance When calculating rates or ratios, the relative level of reporting of Aboriginal and Torres Strait Islander peoples on the numerator and denominator datasets will affect the results. Changes in the relative level of reporting of Aboriginal and Torres Strait Islander peoples over time will also affect the results. The possible effects of numerator-denominator

discordance should be considered in the interpretation of results.

In conclusion, enhancement of reporting of Aboriginal and Torres Strait Islander peoples on administrative data through record linkage provides a mechanism to obtain improved estimates of morbidity and mortality of Aboriginal and Torres Strait Islander peoples. In this project, enhancement also resulted in correction of some of the bias inherent in indicators of morbidity and mortality resulting from relative under-reporting of Aboriginal and Torres Strait Islander peoples resident in major cities and less remote geographic areas. While record linkage may be used to improve reporting of Aboriginal and Torres Strait Islander peoples on historical data, it should not replace efforts to improve the quality of recording of information on Aboriginal and Torres Strait Islander persons at the point of care throughout the NSW health system.

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