

## 1.09 End stage renal disease

The number of Aboriginal and Torres Strait Islander people with treated end-stage renal disease (ESRD) as registered by the Australia and New Zealand Dialysis and Transplant Registry, expressed as a rate by age group, age-standardised rate and ratio

### Data sources

Data for this indicator come from the Australia and New Zealand Dialysis and Transplant Registry, the National Mortality Database and the AIHW National Hospital Morbidity Database.

### Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)

The data reported here on Indigenous persons with end-stage renal disease (ESRD) have been supplied by ANZDATA. The interpretation and reporting of these data are the responsibility of the authors and in no way should be seen as an official policy or interpretation of the registry.

In Australia, persons who develop ESRD and undertake dialysis or kidney transplantation are registered with ANZDATA. The Registry is the most comprehensive and reliable source of information on persons treated for ESRD. It compiles data on incidence and prevalence, renal complications, co-morbidities and patient deaths. The current Registry began in 1977 and is coordinated by the Queen Elizabeth Hospital in Adelaide. All relevant hospitals and related satellite units in Australia and New Zealand participate.

Indigenous identification in the Registry is based on self-identification in hospital records. However, because of the heightened awareness of the extent of renal disease in Indigenous Australians and the prolonged and repeated contact with renal units in hospitals, it is believed that Indigenous identification in the Registry is more complete than in general hospital data (Cass et al. 2001).

### National Mortality Database

The National Mortality Database is a national collection of de-identified unit record level data. It comprises most of the information recorded on death registration forms and medical (cause of death) certificates, including Indigenous status. The database is maintained by the Australian Institute of Health and Welfare (AIHW). Information on the characteristics and causes of death of the deceased is provided by the Registrars of Births, Deaths and Marriages and coded nationally by the Australian Bureau of Statistics (ABS). Information on the cause of death is supplied by the medical practitioner certifying the death, or by a coroner. The data are updated each calendar year and are presented by state/territory of usual residence rather than state/territory where death occurs.

It is considered likely that most deaths of Aboriginal and Torres Strait Islander people are registered. However, a proportion of these deceased are not reported as Aboriginal or Torres Strait Islander by the family, health worker or funeral director during the death registration process. That is, while data are provided to the ABS for the Indigenous status question for 99% of all deaths, there are concerns regarding the accuracy of the data. The Indigenous

status question is not always directly asked of relatives and friends of the deceased by the funeral director. Detailed breakdowns of Aboriginal and Torres Strait Islander deaths are therefore only provided for five jurisdictions – New South Wales, Queensland, South Australia, Western Australia and the Northern Territory (AIHW 2010).

Deaths for which the Indigenous status of the deceased was not reported have been excluded from the analysis.

Additional revised 2007 and preliminary 2008 mortality data for this indicator was supplied by the ABS from the ABS Cause of Death database. For further information see *Causes of Death, Australia, 2008* (ABS 2010).

Data have been combined for the five-year period 2004–2008 because of the small number of deaths from some conditions each year. Data have been analysed using the year of registration of death for all years. Note that the 2006 edition of this report used year of occurrence of death for all years of analysis except for the latest year of available data for which year of registration of death was used. Data published in this report may therefore differ slightly from those published in the previous edition for comparable years of data.

## **National Hospital Morbidity Database**

The National Hospital Morbidity Database is a compilation of episode-level records from admitted patient morbidity data collection systems in Australian hospitals in each state and territory. Information on the characteristics, diagnoses and care of admitted patients in public and private hospitals is provided annually to the AIHW by state and territory health departments.

Data are presented for the six jurisdictions that have been assessed by the AIHW as having adequate identification of Indigenous hospitalisations in 2006–08 – New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory. These six jurisdictions represent approximately 96% of the Indigenous population of Australia. Data are presented by state/territory of usual residence of the patient.

In the period 2007–08, there were 276,000 hospital separations (episodes of care for admitted patients) for Aboriginal and Torres Strait Islander patients, around 3.5% of all separations. The proportion of separations of Aboriginal and Torres Strait Islander persons was higher in public hospitals (5.4% or 256,425 separations) compared with private hospitals (0.6% or 20,015 separations). Of all Aboriginal and Torres Strait Islander separations, nearly 93% occurred in public hospitals (AIHW 2009).

Hospitalisations for which the Indigenous status of the patient was not reported have been included with hospitalisations data for non-Indigenous people under the 'other' category. This is to enable consistency across jurisdictions, because public hospitals in some states and territories do not have a category for the reporting of 'not stated' or inadequately recorded/reported Indigenous status.

Hospitalisation data are presented for the two-year period from July 2006 to June 2008. An aggregate of two years of data has been used, because the number of hospitalisations for some conditions is likely to be small for a single year.

The principal diagnosis is the diagnosis established to be the problem that was chiefly responsible for the patient's episode of care in hospital. The additional diagnosis is a condition or complaint either coexisting with the principal diagnosis or arising during the episode of care. The term 'hospitalisation' has been used to refer to a separation, which is the

episode of admitted patient care. This can include a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change in the type of care (for example, from acute to rehabilitation). 'Separation' also means the process by which an admitted patient completes an episode of care by being discharged, dying, transferring to another hospital or changing type of care.

## Analyses

Age-standardised rates and ratios have been used as a measure of morbidity in the Indigenous population relative to other Australians. Ratios of this type illustrate differences between the rates of morbidity among Indigenous people and those of other Australians, taking into account differences in age distributions.

## Registration data

Information is available on Indigenous persons with ESRD from the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA).

ESRD is a complete or near-complete failure of the kidneys to excrete wastes, concentrate urine, and regulate electrolytes. ESRD occurs when the kidneys are no longer able to function at a level that is necessary for day-to-day life. It usually occurs as chronic renal failure worsens to the point where kidney function is less than 10% of normal. Common associated complications include inflammation of the tissue layers surrounding the heart, bleeding in the gastrointestinal tract, altered brain function and structure, disturbances or structural or functional changes in the peripheral nervous system.

- Between 2006 and 2008, there were 7,279 new patients registered with ANZDATA, of whom 696 (10%) identified as Aboriginal or Torres Strait Islander. This is higher than the proportion of Indigenous people in the total population (2.6%).
- Indigenous people starting ESRD treatment were substantially younger than non-Indigenous Australians starting ESRD treatment. Over half (63%) of new Indigenous patients registered with ANZDATA were aged less than 55 years, whereas less than a third (30%) of non-Indigenous Australians registered were below that age (Table 1.09.1).
- Incidence rates of treated ESRD for Indigenous Australians were higher than for non-Indigenous Australians across all age groups. The difference was marked at ages 45–54 years and 55–64 years where incidence rates for Indigenous Australians were between 12 and 15 times those for non-Indigenous Australians.
- After adjusting for differences in age structure, the incidence rate of treated ESRD for Indigenous Australians was around eight times the incidence rate of non-Indigenous Australians.
- Between 2006 and 2008, Indigenous males and females were 6 and 12 times as likely to register for treatment of ESRD as non-Indigenous males and females (Table 1.09.2).
- Incidence rates of treated ESRD for Indigenous Australians were higher than for non-Indigenous Australians in all states and territories. Rate ratios ranged from three in New South Wales to 26 in the Northern Territory (Table 1.09.3).
- Incidence rates for ESRD among Indigenous Australians were higher in remote areas of Australia than in *Major cities*. Indigenous Australians were 18 and 20 times as likely to register for treatment of ESRD as non-Indigenous Australians in *Remote* and *Very remote*

areas respectively, and 11 times as likely to register for treatment of ESRD in outer regional areas. In *Major cities* and *Inner regional* areas, incidence rates for Indigenous Australians were around four times those for non-Indigenous Australians living in these areas (Table 1.09.4).

The reasons for the high incidence of treated ESRD among Indigenous Australians are probably related to the high proportion of the Indigenous population with factors which contribute to the increased risk of kidney impairment and lack of access to services for detection and treatment of chronic kidney disease (AIHW 2005a).

**Table 1.09.1: Incidence of end-stage renal disease, by Indigenous status and age group, 2006–2008<sup>(a)</sup>**

	Number		Per cent <sup>(b)</sup>		No. per 100,000 <sup>(c)</sup>		Rate ratio <sup>(d)</sup>
	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous	
0–24	16	219	2.3	3.3	1.8	1.1	1.6
25–44	195	857	28.0	13.0	46.4	4.9	9.5*
45–54	225	926	32.3	14.1	160.7	10.8	14.9*
55–64	180	1,353	25.9	20.6	233.8	19.5	12.0*
65+	80	3,228	11.5	49.0	161.6	39.2	4.1*
<b>Total<sup>(e)</sup></b>	<b>696</b>	<b>6,583</b>	<b>100.0</b>	<b>100.0</b>	<b>80.4</b>	<b>10.1</b>	<b>8.0*</b>

\* Represents results with statistically significant differences in the Indigenous/non-Indigenous Australians comparisons.

(a) Calendar year reporting. Data are presented in three-year groupings because of small numbers each year.

(b) Proportion of Indigenous and non-Indigenous patients in each age group.

(c) Age-specific rates per 100,000 population.

(d) Rate ratio Indigenous: non-Indigenous.

(e) Total rates are directly age-standardised using the Australian 2001 standard population. Age standardised rates have been calculated using the direct method, age standardised by five year age group to 65+.

Source: AIHW analysis of ANZDATA data.

**Table 1.09.2: Incidence of end-stage renal disease for Indigenous Australians, by age group and sex, 2006–2008<sup>(a)</sup>**

Age group years	Male						Female						Total					
	No.	Per cent <sup>(b)</sup>	No. per 100,000 <sup>(c)</sup>	LCL 95% <sup>(d)</sup>	UCL 95% <sup>(e)</sup>	Rate ratio <sup>(f)</sup>	No.	Per cent	No. per 100,000 <sup>(c)</sup>	LCL 95% <sup>(d)</sup>	UCL 95% <sup>(e)</sup>	Rate ratio <sup>(f)</sup>	No.	Per cent	No. per 100,000 <sup>(c)</sup>	LCL 95% <sup>(d)</sup>	UCL 95% <sup>(e)</sup>	Rate ratio <sup>(f)</sup>
0–14	n.p.	n.p.	n.p.	n.p.	n.p.	1.0	n.p.	n.p.	n.p.	n.p.	n.p.	0.6	n.p.	n.p.	n.p.	n.p.	n.p.	0.8
15–24	n.p.	n.p.	n.p.	n.p.	n.p.	2.2*	n.p.	n.p.	n.p.	n.p.	n.p.	2.7*	n.p.	n.p.	n.p.	n.p.	n.p.	2.4*
25–34	24	7.5	21.9	13.2	30.7	5.7*	28	7.4	25.0	15.8	34.3	7.8*	52	7.5	23.5	17.1	29.9	6.7*
35–44	70	22.0	73.4	56.2	90.6	9.6*	73	19.3	70.2	54.1	86.3	15.2*	143	20.5	71.7	60.0	83.5	11.7*
45–54	106	33.3	157.2	127.3	187.1	11.2*	119	31.5	164.0	134.5	193.4	21.5*	225	32.3	160.7	139.7	181.7	14.9*
55–64	74	23.3	202.7	156.5	248.9	8.0*	106	28.0	261.9	212.0	311.7	19.0*	180	25.9	233.8	199.7	268.0	12.0*
65 +	35	11.0	165.9	110.9	220.9	3.1*	45	11.9	158.5	112.2	204.8	5.9*	80	11.5	161.6	126.2	197.1	4.1*
<b>Total<sup>(g)</sup></b>	<b>318</b>	<b>100.0</b>	<b>77.5</b>	<b>67.8</b>	<b>87.2</b>	<b>5.9*</b>	<b>378</b>	<b>100.0</b>	<b>83.0</b>	<b>73.9</b>	<b>92.0</b>	<b>11.5*</b>	<b>696</b>	<b>100.0</b>	<b>80.4</b>	<b>73.8</b>	<b>86.9</b>	<b>8.0*</b>

\* Represents results with statistically significant differences in the Indigenous/non-Indigenous Australians comparisons.

(a) Calendar year reporting. Data are presented in three-year groupings because of small numbers each year.

(b) Proportion of male, female and total registration rates for Indigenous persons in the period 2006–2008.

(c) Age-specific rates per 100,000 population.

(d) LCL = lower confidence limit.

(e) UCL = upper confidence limit.

(f) Rate ratio Indigenous: non-Indigenous.

(g) Total rates are directly age-standardised using the Australian 2001 standard population. Age standardised rates have been calculated using the direct method, age standardised by five year age group to 65+.

Source: AIHW analysis of ANZDATA data.

**Table 1.09.3: Incidence of end-stage renal disease, by Indigenous status, sex and state/territory, 2006–2008<sup>(a)</sup>**

	Males			Females			Persons		
	No.	No. per 100,000 <sup>(b)</sup>	Ratio <sup>(c)</sup>	No.	No. per 100,000 <sup>(b)</sup>	Ratio <sup>(c)</sup>	No.	No. per 1,000 <sup>(b)</sup>	Ratio <sup>(c)</sup>
<b>NSW</b>									
Indigenous	39	35.4	2.7*	41	31.2	4.1*	80	33.1	3.2*
Non-Indigenous	1,369	13.2	..	869	7.6	..	2,238	10.3	..
<b>Vic</b>									
Indigenous	12	61.8	4.6*	11	42.7	6.7*	23	51.2	5.2*
Non-Indigenous	1,060	13.6	..	553	6.4	..	1,613	9.8	..
<b>Qld</b>									
Indigenous	90	81.1	6.3*	94	82.5	10.3*	184	82.2	8.0*
Non-Indigenous	769	12.8	..	515	8.0	..	1,284	10.3	..
<b>WA</b>									
Indigenous	66	108.2	8.1*	80	127.7	20.0*	146	118.9	12.2*
Non-Indigenous	401	13.4	..	205	6.4	..	606	9.7	..
<b>SA</b>									
Indigenous	18	80.6	6.5*	25	93.3	14.5*	43	87.3	9.5*
Non-Indigenous	313	12.4	..	178	6.4	..	491	9.2	..
<b>Tas</b>									
Indigenous	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.
Non-Indigenous	91	11.6	..	66	7.7	..	157	9.5	..
<b>ACT</b>									
Indigenous	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	6	131.0	7.1*
Non-Indigenous	106	25.7	..	60	12.5	..	166	18.5	..
<b>NT</b>									
Indigenous	88	168.9	18.1*	125	204.7	42.7*	213	188	25.7*
Non-Indigenous	20	9.3	..	8	4.8	..	28	7.3	..
<b>Australia</b>									
<b>Indigenous</b>	<b>318</b>	<b>77.5</b>	<b>5.9*</b>	<b>378</b>	<b>83.0</b>	<b>11.5*</b>	<b>696</b>	<b>80.4</b>	<b>8.0*</b>
<b>Non-Indigenous</b>	<b>4,129</b>	<b>13.2</b>	<b>..</b>	<b>2,454</b>	<b>7.2</b>	<b>..</b>	<b>6,583</b>	<b>10.1</b>	<b>..</b>

\* Represents results with statistically significant differences in the Indigenous/non-Indigenous Australian comparisons.

(a) Calendar year reporting. Data are presented in three-year groupings because of small numbers each year.

(b) Directly age-standardised using the Australian 2001 standard population. Age standardised rates have been calculated using the direct method, age standardised by five year age group to 65+.

(c) Rate ratio Indigenous: non-Indigenous.

Source: AIHW analysis of ANZDATA data.

**Table 1.09.4: Incidence of end-stage renal disease, by Indigenous status and remoteness, 2006–2008<sup>(a)</sup>**

	Number		Per cent <sup>(b)</sup>		No. per 100,000 <sup>(c)</sup>		Rate ratio <sup>(d)</sup>
	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous	
Major Cities	95	4,685	13.7	71.2	39.5	10.9	3.6*
Inner Regional	64	1,275	9.3	19.4	40.0	9.3	4.3*
Outer Regional	179	536	25.7	8.1	98.2	8.7	11.3*
Remote	126	64	18.1	1.0	148.6	8.4	17.7*
Very Remote	232	22	33.3	0.3	167.9	8.5	19.9*
<b>Australia<sup>(e)</sup></b>	<b>696</b>	<b>6,583</b>	<b>100.0</b>	<b>100.0</b>	<b>80.4</b>	<b>10.1</b>	<b>8.0*</b>

\* Represents results with statistically significant differences in the Indigenous/non-Indigenous Australian comparisons.

(a) Calendar year reporting. Data are presented in three-year groupings because of small numbers each year.

(b) Proportion of Indigenous and non-Indigenous patients in each remoteness category.

(c) Directly age-standardised using the Australian 2001 standard population. Age standardised rates have been calculated using the direct method, age standardised by five year age group to 65+.

(d) Rate ratio Indigenous: non-Indigenous.

(e) Australia total includes cases where remoteness category was not known.

Source: AIHW analysis of ANZDATA data.



## Time series analysis

Data on the incidence of ESRD among Indigenous and non-Indigenous Australians for the period 1991–2008 are presented below (Table 1.09.5; Figure 1.09.1).

- The number of Indigenous patients starting ESRD treatment has more than quadrupled since 1991 (from 54 in 1991 to 242 in 2008).
- Over the period 1991–2008, there were significant increases in the incidence rate of ESRD among Indigenous Australians. The fitted trend implies an average yearly increase in the rate of around 2.4 per 100,000, which is equivalent to a 130% increase in the rate over the period. The fitted trend showed significant increases in the incidence of ESRD for both Indigenous males and females.
- Over the same period, there were also significant increases in the incidence rates of ESRD among non-Indigenous males and females, but these increases were not as rapid as in the Indigenous population (increase of 96% for males and 48% for females).
- There was a significant increase in the incidence rate difference and a non-significant increase in the rate ratio between Indigenous and non-Indigenous Australians for ESRD over the period 1991–2008 (143% in the rate difference and 23% in the rate ratio for persons), reflecting both a relative and absolute increase in the gap between incidence rates for Indigenous and non-Indigenous Australians for ESRD over the period.

The early rapid increase in the incidence of ESRD in the Indigenous population may reflect both real growth and the increasing availability and acceptability of kidney replacement therapy by Indigenous people. In recent years rates of ESRD in the Indigenous population appear to have stabilised.

Fluctuations in the incidence rates of ESRD for Indigenous Australians over time may also reflect changing levels of identification of Indigenous registrations in the ANZDATA Registry and Indigenous population estimates. Caution should be exercised in assessing trends in Indigenous ESRD rates over time and comparisons with the non-Indigenous population.

**Table 1.09.5: Age-standardised incidence rates, rate ratios and rate differences for end-stage renal disease, 1991-2008**

	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Annual change <sup>(a)</sup>	Per cent change over period <sup>(b)</sup>
<b>Indigenous</b>																				
Males	26	25	41	45	58	46	57	67	59	66	71	81	81	88	90	103	105	110	4.7*	309.2*
Females	28	39	49	67	70	57	95	70	98	84	104	91	92	105	125	117	129	132	5.4*	330.1*
Persons	54	64	90	112	128	103	152	137	157	150	175	172	173	193	215	220	234	242	10.2*	320.0*
<b>Non-Indigenous</b>																				
Males	540	591	596	704	738	760	782	883	950	928	1,045	1,059	1,085	1,089	1,260	1,375	1,362	1,392	51.2*	161.1*
Females	385	429	473	499	507	563	551	586	644	672	692	661	725	673	808	842	770	842	25.4*	112.1*
Persons	925	1,020	1,069	1,203	1,245	1,323	1,333	1,469	1,594	1,600	1,737	1,720	1,810	1,762	2,068	2,217	2,132	2,234	76.6*	140.7*
<b>Indigenous rate (no. per 100,000)<sup>(c)</sup></b>																				
Males	27.8	28.5	44.4	50.7	61.7	42.9	48.2	69.8	54.5	64.9	59.7	71.8	73.4	68.1	68.1	78.8	74.6	73.6	2.6*	156.8*
Females	34.0	44.1	47.9	67.5	68.9	55.0	87.4	67.1	89.5	68.5	92.9	75.1	69.1	76.9	91.3	81.7	79.7	79.1	2.2*	112.0*
Persons	31.2	36.8	45.8	59.1	65.2	49.7	69.2	67.9	73.1	66.2	77.8	73.7	70.4	72.6	80.7	80.1	77.0	76.4	2.4*	130.1*
<b>Non-Indigenous<sup>(c)</sup> rate (no. per 100,000)</b>																				
Males	6.9	7.4	7.5	8.7	9.0	9.1	9.2	10.3	10.9	10.5	11.5	11.5	11.5	11.3	12.9	13.7	13.2	13.2	0.4*	95.6*
Females	4.7	5.2	5.6	5.8	5.7	6.2	6.0	6.3	6.7	6.9	6.9	6.5	7.0	6.4	7.4	7.6	6.8	7.3	0.1*	47.8*
Persons	5.7	6.2	6.5	7.1	7.3	7.6	7.5	8.1	8.6	8.5	9.0	8.8	9.1	8.7	9.9	10.4	9.8	10.0	0.2*	74.1*
<b>Rate ratio<sup>(d)</sup></b>																				
Males	4.0	3.9	5.9	5.9	6.9	4.7	5.2	6.8	5.0	6.2	5.2	6.3	6.4	6.0	5.3	5.8	5.6	5.6	0.1	21.8
Females	7.2	8.5	8.5	11.5	12.0	8.8	14.6	10.7	13.3	9.9	13.4	11.6	9.9	12.1	12.3	10.7	11.7	10.8	0.1	34.8
Persons	5.4	5.9	7.1	8.3	9.0	6.6	9.2	8.4	8.5	7.8	8.6	8.4	7.8	8.4	8.1	7.7	7.8	7.6	0.1	22.7

(continued)

**Table 1.09.5 (continued): Age-standardised incidence rates, rate ratios and rate differences for end-stage renal disease, 1991–2008**

	1991	1992	1993	1994	1995	1996	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006	2007	2008	Annual change <sup>(a)</sup>	Per cent change over period <sup>(b)</sup>
<b>Rate difference<sup>(e)</sup></b>																				
Males	20.9	21.1	36.9	42.0	52.7	33.8	38.9	59.5	43.6	54.4	48.1	60.4	61.9	56.8	55.3	65.2	61.4	60.5	2.2*	177.0*
Females	29.3	38.9	42.3	61.6	63.1	48.7	81.4	60.9	82.8	61.6	86.0	68.6	62.1	70.6	83.8	74.1	72.9	71.8	2.1*	122.3*
Persons	25.5	30.5	39.4	52.0	57.9	42.1	61.7	59.8	64.5	57.7	68.8	65.0	61.4	64.0	70.8	69.7	67.2	66.4	2.1*	142.7*

\* Represents results with statistically significant increases or declines at the  $p < 0.05$  level over the period 1991–2008.

(a) Average annual change in rates, rate ratios and rate differences determined using linear regression analysis.

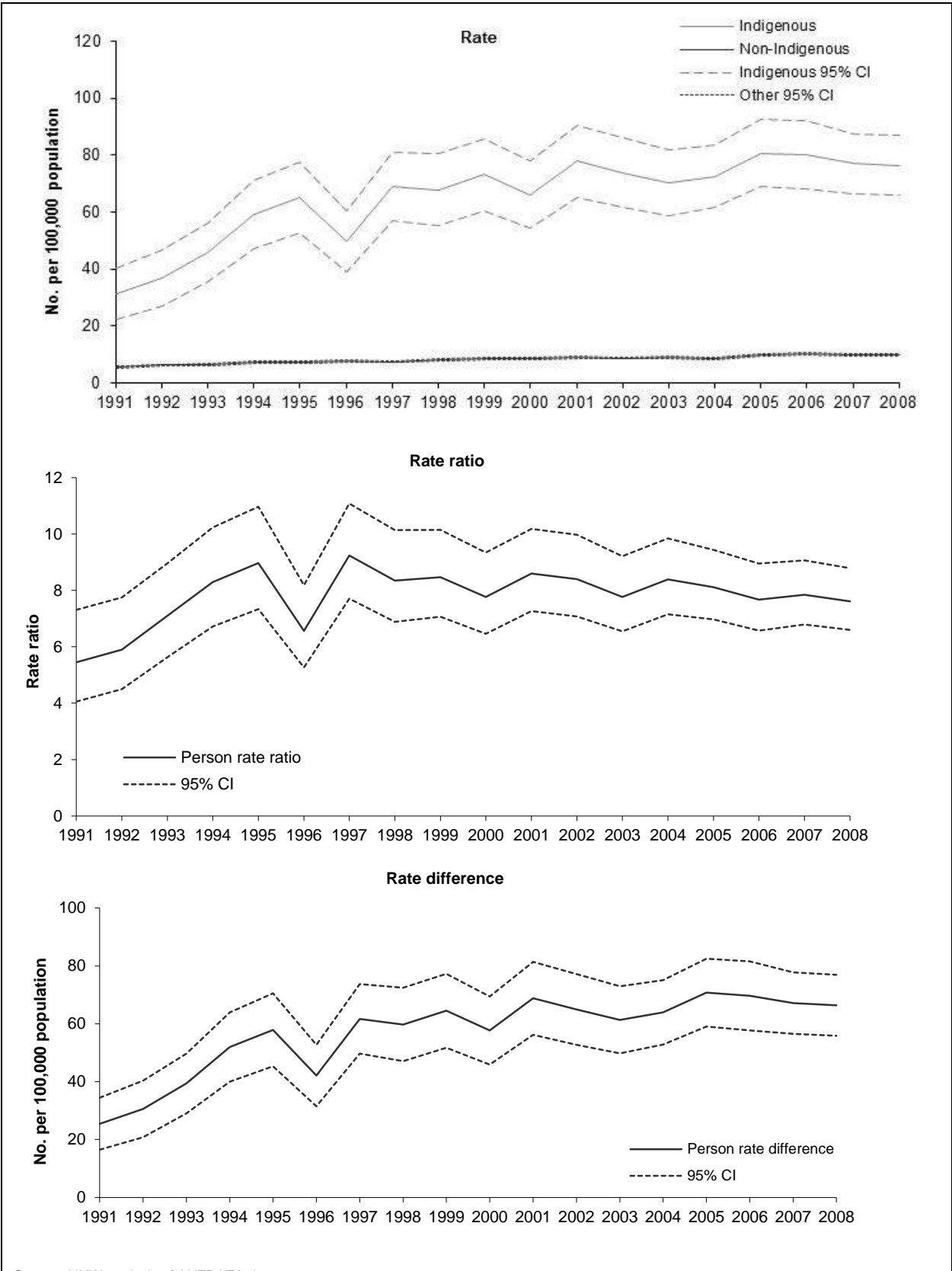
(b) Per cent change between 1991 and 2008 based on the average annual change over the period.

(c) Rates have been directly age-standardised using the 2001 Australian standard population. Age standardised rates have been calculated using the direct method, age standardised by five year age group to 75+.

(d) Incidence rate for Indigenous people divided by the rate for non-Indigenous Australians.

(e) Incidence rate for Indigenous people minus the rate for non-Indigenous Australians.

Source: AIHW analysis of ANZDATA data



Source: AIHW analysis of ANZDATA data.

**Figure 1.09.1: Age-standardised registration rates, rate ratios and differences for end-stage renal disease, by Indigenous status, 1991–2008**

## Management of end-stage renal disease

ESRD patients require either a kidney transplant or dialysis to maintain the functions normally performed by the kidneys. Patterns of treatment for ESRD differ between Indigenous and non-Indigenous patients.

- As at 31 December 2008, of all Indigenous ESRD patients registered, 88% relied on dialysis and only 12% had received a kidney transplant. In contrast, 55% of non-Indigenous Australians living with ESRD relied on dialysis and 45% had received a kidney transplant (Table 1.09.6).
- Indigenous Australians with ESRD were 10 times as likely as non-Indigenous Australians to rely on dialysis.

Once dialysis treatment has started, Indigenous people are less likely than other Australians to be placed on the active transplant waiting list and less likely to move from the waiting list to transplantation (McDonald & Russ 2003; Cass et al. 2003). Factors which may contribute to these disparities include miscommunication between Indigenous patients and health professionals, lack of understanding from Indigenous patients of their illness and its treatment, lower rates of well-matched kidney donors for Indigenous patients than for other patients and the higher rate of comorbidity among Indigenous Australians (Cass et al. 2003; McDonald & Russ 2003). Transplant outcomes are also substantially poorer for Indigenous Australians than for non-Indigenous Australians (McDonald & Russ 2003).

**Table 1.09.6: Total patients with end-stage renal disease, by Indigenous status and treatment, as at 31 December 2008<sup>(a)</sup>**

Treatment	Number		Per cent <sup>(b)</sup>		No. per 100,000 <sup>(c)</sup>		Ratio <sup>(d)</sup>
	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous	Indigenous	Non-Indigenous	
Dialysis	1,147	8,915	87.8	54.7	390.2	39.9	9.8*
Transplant	159	7,382	12.2	45.3	45.7	33.9	1.3*
<b>Total</b>	<b>1,306</b>	<b>16,297</b>	<b>100.0</b>	<b>100.0</b>	<b>435.9</b>	<b>73.8</b>	<b>5.9*</b>

\* Represents results with statistically significant differences in the Indigenous/non-Indigenous comparisons.

(a) Calendar year reporting.

(b) Proportion of Indigenous and non-Indigenous patients receiving dialysis and transplants.

(c) Directly age-standardised using the Australian 2001 standard population. Age standardised rates have been calculated using the direct method, age standardised by five year age group to 75+.

(d) Rate ratio Indigenous: non-Indigenous.

Source: AIHW analysis of ANZDATA data.

## Hospitalisations

- Over the period June 2006 to July 2008, there were 1,916,287 hospitalisations for chronic kidney disease and its sequelae in New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory combined, of which 224,457 (11.7%) were for Indigenous Australians.
- Approximately 43% of total hospitalisations of Indigenous Australians were for chronic kidney disease.

### Hospitalisations for chronic kidney disease

Chronic kidney disease includes diabetic nephropathy, hypertensive renal disease, glomerular disease, chronic renal failure and end-stage renal disease (ESRD).

Hospitalisations of Indigenous Australians for chronic kidney disease and its sequelae in New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory combined over the period June 2006 to July 2008 are presented in Tables 1.09.7 and 1.09.8.

- Of all hospitalisations for chronic kidney disease among Aboriginal and Torres Strait Islander people, the majority (98%) were for care involving dialysis.
- Indigenous Australians were hospitalised for both care involving dialysis and diabetic nephropathy at around 11 times the rate of other Australians, and chronic renal failure at around six times the rate of other Australians.
- Approximately 45% of Indigenous Australians hospitalised for chronic kidney disease and its sequelae were males (101,300) and 55% were females (123,157).
- Indigenous males were hospitalised for chronic kidney disease with dialysis at over eight times the rate of other males, and Indigenous females were hospitalised for chronic kidney disease at over 15 times the rate of other females (Table 1.09.8).
- Over the period June 2006 to July 2008, there were 224,457 bed-days associated with Indigenous chronic kidney disease hospitalisations in New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory combined, at an average of 1.1 days per separation. Excluding same-day separations for dialysis (220,763 hospitalisations), the average length of stay in hospital for Indigenous people with chronic kidney disease was 5.0 days compared with 4.9 days for other Australians.

**Table 1.09.7: Hospitalisations for chronic kidney disease and its sequelae, by Indigenous status and type of kidney disease, NSW, Vic, Qld, WA, SA and NT, July 2006 to June 2008<sup>(a)(b)(c)(d)</sup>**

	Number		Per cent <sup>(e)</sup>		Indigenous			Other <sup>(f)</sup>			Rate Ratio <sup>(j)</sup>
	Indigenous	Other <sup>(f)</sup>	Indigenous	Other <sup>(f)</sup>	No. per 1,000 <sup>(g)</sup>	95% LCL <sup>(h)</sup>	95% UCL <sup>(i)</sup>	No. per 1000 <sup>(g)</sup>	95% LCL <sup>(h)</sup>	95% UCL <sup>(i)</sup>	
Care involving dialysis (ESRD)	220,763	1,645,262	98.4	97.2	421.5	419.5	423.4	39.1	39.1	39.2	10.8*
Diabetic nephropathy	1,312	10,062	0.6	0.6	2.7	2.5	2.9	0.2	0.2	0.2	11.4*
Renal-tubulo interstitial diseases	966	12,780	0.4	0.8	1.2	1.1	1.3	0.3	0.3	0.3	3.6*
Chronic renal failure	626	9,448	0.3	0.6	1.2	1.1	1.3	0.2	0.2	0.2	5.5*
Glomerular diseases	459	4,904	0.2	0.3	0.3	0.3	0.4	0.1	0.1	0.1	2.6*
Hypertensive renal disease	55	1,395	–	0.1	0.1	0.1	0.1	–	–	–	2.7*
Other chronic diseases	276	7,979	0.1	0.5	0.3	0.3	0.4	0.2	0.2	0.2	1.7*
<b>Total</b>	<b>224,457</b>	<b>1,691,830</b>	<b>100.0</b>	<b>100.0</b>	<b>427.3</b>	<b>425.3</b>	<b>429.3</b>	<b>40.3</b>	<b>40.2</b>	<b>40.3</b>	<b>10.6*</b>

\* Represents results with statistically significant differences in the Indigenous/other comparisons.

- (a) Data are from public and most private hospitals. Data exclude private hospitals in the Northern Territory.
- (b) Categories are based on the ANZDATA for this measure. Other coding categories are based on the ICD-10-AM fifth edition (National Centre for Classification of Health 2006); ICD-10-AM codes Z49; E102, E112, E132 and E142; N11–N12 and N14–N16; N18–N19; N00–N08; I12–I13, I150 and I151; N25–N28, N391, N392, Q60–Q63, T824, T861, and Z940.
- (c) Financial year reporting.
- (d) Data are reported by state/territory of usual residence of the patient hospitalised and are for New South Wales, Victoria, Western Australia, South Australia, the Northern Territory and Queensland only. These six jurisdictions are considered to have adequate levels of Indigenous identification, although the level of accuracy varies by jurisdiction and hospital. Data for these six jurisdictions over-represent Indigenous populations in less urbanised and more remote locations. Hospitalisation data for these six jurisdictions should not be assumed to represent the hospitalisation experience in the other jurisdictions.
- (e) Proportion of hospitalisations of Indigenous and other people in the period 2006–07 to 2007–08.
- (f) 'Other' includes hospitalisations of non-Indigenous people and those for whom Indigenous status was not stated.
- (g) Directly age-standardised using the Australian 2001 standard population. Age standardised rates have been calculated using the direct method, age standardised by five year age group to 75+.
- (h) LCL = lower confidence limit.
- (i) UCL = upper confidence limit.
- (j) Rate ratio Indigenous: other.

*Notes*

- Population estimates are based on the 2006 Census.
- Care types 7.3, 9 & 10 (Newborn – unqualified days only; organ procurement; hospital boarder) excluded from analysis.

Source: AIHW analysis of National Hospital Morbidity Database.

**Table 1.09.8: Hospitalisations of Indigenous Australians for chronic kidney disease and its sequelae, by sex and type of kidney disease, NSW, Vic, Qld, WA, SA and NT, July 2006 to June 2008<sup>(a)(b)(c)(d)</sup>**

	Males						Females					
	No.	Per cent <sup>(e)</sup>	No. per 1,000 <sup>(f)</sup>	95% LCL <sup>(g)</sup>	95% UCL <sup>(h)</sup>	Rate ratio <sup>(i)</sup>	No.	Per cent <sup>(e)</sup>	No. per 1,000 <sup>(f)</sup>	95% LCL <sup>(g)</sup>	95% UCL <sup>(h)</sup>	Rate ratio <sup>(i)</sup>
Care involving dialysis (ESRD)	99,711	98.4	416.1	413.0	419.1	8.1*	121,052	98.3	430.8	428.2	433.4	14.9*
Diabetic nephropathy	636	0.6	2.7	2.5	3.0	8.9*	676	0.5	2.7	2.4	2.9	14.8*
Renal-tubulo interstitial diseases	114	0.1	0.3	0.3	0.4	3.0*	852	0.7	1.9	1.8	2.1	3.7*
Chronic renal failure	401	0.4	1.8	1.6	2.0	6.7*	225	0.2	0.7	0.6	0.9	4.0*
Glomerular diseases	263	0.3	0.4	0.3	0.4	2.4*	196	0.2	0.3	0.2	0.3	2.9*
Hypertensive renal disease	26	–	0.1	–	0.1	1.9*	29	–	0.1	0.1	0.1	4.0*
Other chronic diseases	149	0.1	0.4	0.3	0.5	1.7*	127	0.1	0.3	0.3	0.4	1.9*
<b>Total</b>	<b>101,300</b>	<b>100.0</b>	<b>421.8</b>	<b>418.8</b>	<b>424.9</b>	<b>8.1*</b>	<b>123,157</b>	<b>100.0</b>	<b>436.8</b>	<b>434.2</b>	<b>439.4</b>	<b>14.5*</b>

\* Represents results with statistically significant differences in the Indigenous/other comparisons.

(a) Data are from public and most private hospitals. Data exclude private hospitals in the Northern Territory.

(b) Categories are based on the ANZDATA for this measure. Other coding categories are based on the ICD-10-AM fifth edition (National Centre for Classification in Health 2006); ICD-10-AM codes Z49; E102, E112, E132 and E142; N11–N12 and N14–N16; N18–N19; N00–N08; I12–I13, I150 and I151; N25–N28, N391, N392, Q60–Q63, T824, T861, and Z940.

(c) Financial year reporting.

(d) Data are reported by state/territory of usual residence of the patient hospitalised and are for New South Wales, Victoria, Western Australia, South Australia, the Northern Territory and Queensland only. These six jurisdictions are considered to have adequate levels of Indigenous identification, although the level of accuracy varies by jurisdiction and hospital. Data for these six jurisdictions over-represent Indigenous populations in less urbanised and more remote locations. Hospitalisation data for these six jurisdictions should not be assumed to represent the hospitalisation experience in the other jurisdictions.

(e) Proportion of hospitalisations of Indigenous and other people in the period 2006–07 to 2007–08.

(f) Directly age-standardised using the Australian 2001 standard population. Age standardised rates have been calculated using the direct method, age standardised by five year age group to 75+.

(g) LCL = lower confidence limit.

(h) UCL = upper confidence limit.

(i) Rate ratio Indigenous: other.

#### Notes

1. Population estimates are based on the 2006 Census.

2. Care types 7.3, 9 & 10 (Newborn – unqualified days only; organ procurement; hospital boarder) excluded from analysis.

Source: AIHW analysis of National Hospital Morbidity Database.



## Mortality

Data for this section come from the forthcoming report *Chronic kidney disease in Aboriginal and Torres Strait Islander people 2011* (AIHW forthcoming) report.

- Over the period 2003–2007, in New South Wales, Queensland, Western Australia, South Australia and the Northern Territory combined, there were 8,976 deaths for which chronic kidney disease was recorded as the underlying cause of death, of which 356 deaths (4.0%) were for Indigenous Australians.
- Approximately 45% of all Indigenous Australians who died from chronic kidney disease were males and 55% were females.
- After adjusting for differences in age structure, Indigenous Australians were 4.2 times as likely as non-Indigenous Australians to have died from chronic kidney disease between 2003 and 2007.
- Indigenous males died from chronic kidney disease at almost four times the rate of non-Indigenous males, and Indigenous females died from chronic kidney disease at almost five times the rate of non-Indigenous females.

## **Data quality issues**

### **Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)**

The data reported here on Indigenous persons with end-stage renal disease (ESRD) have been supplied by the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). Datasets provided for analysis are de-identified. The interpretation and reporting of these data are the responsibility of the authors and in no way should be seen as an official policy or interpretation of the registry. Data is collected from all dialysis and transplant units in Australia and New Zealand at 31st December. This encompasses virtually all patient events that have occurred in the previous twelve months as well as a "snapshot" of all dialysis and transplants patients on those dates.

### **Indigenous status question**

Patients in the Registry are identified according to 'racial origin'. Aboriginal people and Torres Strait Islanders are identified separately, but separate results are not always published for Torres Strait Islanders because of small numbers of patients.

### **Under-identification**

The completeness of identification of Indigenous people in the registry is not known. However the nature of the illness means that treatment centres have prolonged contact with patients and, therefore, have a considerable opportunity to collect accurate information (Disney et al. 1997).

Indigenous identification is based on self-identification and discussion with the treating physician. There is often significant concern about the quality of Indigenous identification in morbidity, mortality and demographic data sets. However, racial identification in the ANZDATA Registry is reported to be good. A survey form is completed for all patients at the commencement of haemodialysis; this survey has a question about 'Racial origin' and includes a prompt regarding Indigenous status. ESRD patients have regular contact with renal services from the time of diagnosis, through intensive maintenance therapy until death. There is heightened awareness of renal disease in Indigenous Australians and multiple opportunities exist to reconfirm data accuracy (Cass et al. 2001).

## **National Mortality Database**

### **Deaths**

The mortality rate for Indigenous Australians can be influenced by identification of Indigenous deaths, late registration of deaths, and changes to death forms and/or processing systems. Because of the small size of the Indigenous population, these factors can significantly affect trends over time and between jurisdictions. At present, there is considerable variation across the states and territories in the completeness of mortality and hospital data for Indigenous people.

### **Indigenous status question**

All jurisdictions comply with the standard wording for the Indigenous status question and categories for their death registration forms. However, although data are provided to the ABS for the Indigenous status question for 99% of all deaths, there are concerns regarding the accuracy of the data.

The Indigenous status question is not always directly asked. Detailed breakdowns of Indigenous deaths are therefore provided for only five jurisdictions – New South Wales, Queensland, South Australia, Western Australia and the Northern Territory.

Indigenous status information from the two sources is kept in the database, although this may not be consistent for an individual.

In 2004, a new range of codes were introduced as part of the effort to standardise and improve indigenous identification in data collection nationally.

### **Indigenous Mortality Quality Study**

The ABS conducted a number of quality studies based on the 2006 Census of Population and Housing and other datasets as part of the Census Data Enhancement (CDE) project (ABS 2008). The CDE Indigenous Mortality Quality Study linked Census records with death registration records and examined differences in the reporting of Indigenous status across the two datasets.

There were 106,945 registered death records available to be linked in the study. Of these, 1,800 (1.7%) were identified as Indigenous on the death registration. Of the total registered deaths, 98,898 (92%) were linked to a Census record. However, a much lower linkage rate was achieved for Indigenous deaths, with more than one quarter of all Indigenous death registrations (26% or 473) unable to be linked to a Census record. As a result, Indigenous death records were over-represented in the unlinked death registrations.

As well as being over-represented in unlinked death registrations, unlinked Indigenous death records had different characteristics to linked Indigenous death registrations. Indigenous death records with older ages at death and from non-remote regions were more likely to be linked.

### **Under-identification**

Almost all deaths in Australia are registered. However, the Indigenous status of the deceased is not always recorded/recorded correctly. The incompleteness of Indigenous identification means the number of deaths registered as Indigenous is an underestimate of deaths occurring in the Aboriginal and Torres Strait Islander population (ABS 2009a). As a result, the observed differences between Indigenous and non-Indigenous mortality are under-estimates of the true differences.

Longer term mortality trend data are limited to three jurisdictions (Western Australia, South Australia and the Northern Territory) with 10 years of adequate identification of Indigenous deaths in their recording systems (ABS & AIHW 2005). The quality of the time series data is also influenced by the late inclusion of a 'not stated' category for Indigenous status in 1998. Before this time, the 'not stated' responses were probably included with the non-Indigenous.

The ABS calculated the implied coverage (identification) of Indigenous deaths for the period 2002–2006 using population estimates: New South Wales 45%, Victoria 32%, Queensland 51%, South Australia 62%, Western Australia 72%, Northern Territory 90%, Tasmania and the Australian Capital Territory were not calculated because of small numbers, Australia 55% (ABS 2007).

Note that different causes may have levels of under-identification that differ from the all-cause coverage estimates. Note also that the quality of the cause of death data depends on every step of the process of recording and registering deaths (including the documentation available at each step of the process) from certification to coding of cause of death.

There are also current concerns about data quality for causes of death, especially relating to external causes of death of all Australians (not just Indigenous) (ABS 2006).

Problems associated with identification result in an underestimation of deaths and hospital separations for Indigenous people.

### **Numerator and denominator**

Rate and ratio calculations rely on good numerator and denominator data. There are changes in the completeness of identification of Indigenous people in death records. These may take place at different rates from changes in the identification of Indigenous people in

other administrative collections and population censuses. Denominators used here are sourced from *Experimental estimates and projections: Aboriginal and Torres Strait Islander Australians 1991 to 2021* (ABS 2009b).

## **National Hospital Morbidity Database**

### **Hospital separations data**

The number and pattern of hospitalisations can be affected by differing admission practices among the jurisdictions and from year to year, and differing levels and patterns of service delivery.

In all states and territories, the proportion of Aboriginal and Torres Strait Islander separations in public hospitals increased over the 11-year period 1996–97 to 2007–08, from 3.7% to 5.4%. In private hospitals, it stayed around 0.2% to 0.3% until 2003–04, when there was a modest increase to 0.5%.

### **Indigenous status question**

Some jurisdictions have slightly different approaches to the collection and storage of the standard Indigenous status question and categories in their hospital collections. The ‘not stated’ category is missing from several collections. It is recommended that the standard wording and categories be used in all jurisdictions (AIHW 2005b).

‘Not stated’ responses to the Indigenous status question were around 1% in public hospitals and 4% in private hospitals in 2007–08. This is a reduction from 1998–99 when 2% of responses in public hospitals and 8% of responses in private hospitals had a ‘not stated’ Indigenous status (AIHW 2009).

### **Under-identification**

The incompleteness of Indigenous identification means the number of hospital separations recorded as Indigenous is an underestimate of hospitalisations involving Aboriginal and Torres Strait Islander people. Based on an analysis of a sample of data conducted in 2010, an estimated 89% of Indigenous patients were correctly identified in Australian public hospital admission records in 2007–08 (AIHW 2010). In other words, 11% of Indigenous patients were not identified, and the ‘true’ number of hospital admissions for Indigenous persons was about 12% higher than reported.

For several years, Queensland, South Australia, Western Australia and the Northern Territory reported that Indigenous status in their hospital separations data were of acceptable quality (AIHW 2007). The AIHW, however, has recently completed an assessment of the level of Indigenous under-identification in hospital data in all states and territories. Results from this assessment indicate that all hospitals in New South Wales, Victoria, Queensland, Western Australia and South Australia and public hospitals in the Northern Territory have adequate Indigenous identification (80% or higher overall levels of Indigenous identification in public hospitals only) in their separations data. For Tasmania and the Australian Capital Territory, the levels of Indigenous identification were not considered acceptable for analysis purposes. It has therefore been recommended that reporting of Indigenous hospital separations data be limited to information from New South Wales, Victoria, Queensland, Western Australia, South Australia and the Northern Territory, individually or in aggregate. The proportion of the Indigenous population covered by these six jurisdictions is 96%. The following caveats have also been recommended for analysis of hospitalisation data from selected jurisdictions (AIHW 2010):

- Interpretation of results should take into account the relative quality of the data from the jurisdictions included.

- Interpretation of time series analysis should take into account the possible contribution of changes over time in ascertainment of Indigenous status to changes in hospitalisation rates for Indigenous people.
- Bias may have been introduced due to the sampling method of hospitals used in the study. Hospitals with high proportions of Indigenous separations were used in the study to ensure sufficient numbers of Indigenous people were included in the study. Proportions of Indigenous separations should therefore not be taken to represent the NHMD overall.
- Hospitalisation data for these six jurisdictions are not necessarily representative of other jurisdictions.

From the AIHW study, it was possible to produce correction factors for the level of Indigenous under-identification in hospital data for each jurisdiction and at the national level.

#### **Remoteness areas**

There were acceptable levels of Indigenous identification for all remoteness areas, ranging from 80% in *Major cities* to 97% in *Remote* and *Very remote* areas. The quality of data supports analyses by remoteness areas, in aggregate, across states and territories. However, the sample size was insufficient to allow assessment of the quality of Indigenous identification by remoteness area within jurisdictions.

#### **Numerator and denominator**

Rate and ratio calculations rely on good numerator and denominator data. There are changes in the completeness of identification of Indigenous people in hospital records. These may take place at different rates from changes in the identification of Indigenous people in other administrative collections and population censuses. Denominators used in this analysis are sourced from *Experimental estimates and projections: Aboriginal and Torres Strait Islander Australians 1991 to 2010* (ABS 2009b).

#### **Data sources for injury emergency episodes**

The National Non-admitted Patient Emergency Department Care Database is a national collection of de-identified data on emergency department episodes based on the Non-admitted Emergency Department Care National Minimum Data Set. This data set includes the standard Indigenous status question but does not include injury coding (for example, ICD-10). The Injury Surveillance National Minimum Data Set includes injury coding (components of ICD-10) but does not include demographic details such as Indigenous status. Therefore, there is currently no national minimum data set containing both Indigenous status and injury coding.

## List of symbols used in tables

n.a.	not available
–	rounded to zero (including null cells)
0	zero
..	not applicable
n.e.c.	not elsewhere classified
n.f.d.	not further defined
n.p.	not available for publication but included in totals where applicable, unless otherwise indicated

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