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Chronic kidney disease

Regional variation in Australia



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*Authoritative information and statistics
to promote better health and wellbeing*

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Regional variation in Australia

Australian Institute of Health and Welfare
Canberra

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Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ANZDATA Registry	Australian and New Zealand Dialysis and Transplant Registry
ASGC	Australian Standard Geographical Classification
AusDiab	Australian Diabetes, Obesity and Lifestyle Study
CD	Collection District
CKD	chronic kidney disease
eGFR	estimated glomerular filtration rate
ERP	estimated residential population
ESKD	end-stage kidney disease
FaHCSIA	The Department of Families, Housing, Community Services and Indigenous Affairs
HILDA Survey	The Household, Income and Labour Dynamics in Australia (HILDA) Survey
ICD-10	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision
ICD-10-AM	International Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
KRT	kidney replacement therapy
METeOR	Metadata Online Registry
NHMD	National Hospital Morbidity Database
NMD	National Mortality Database
SLA	Statistical Local Area

Summary

Chronic kidney disease (CKD) is a common and serious problem in Australia and its management can be resource intensive. Those with CKD's most severe form, end-stage kidney disease (ESKD), usually require kidney replacement therapy (KRT) to survive, either in the form of dialysis or kidney transplantation.

As with other chronic conditions, the prevalence and incidence of CKD varies by where people live. This report provides a detailed picture of how CKD varies in Australia according to geographic location. Differences are explored in the incidence, prevalence, treatment, hospitalisations, deaths and the effect of Indigenous status on CKD and ESKD. This report also examines the relocation of patients when undergoing treatment for ESKD.

The mortality rate for CKD-related deaths was higher in *Remote and very remote* areas than in other regions

In 2010, the age-standardised rate of deaths with an underlying cause of CKD was considerably higher in more remote areas than in urban areas for both males and females. For males the death rate was 19 deaths per 100,000 population in *Remote and very remote* areas, compared to 13 deaths per 100,000 in *Major cities*. For females the comparable figures were 29 and 10 deaths per 100,000 population.

***Remote and Very remote* areas have higher rates of new cases of treated-ESKD than other areas**

In 2008–10, the rate of new cases of treated-ESKD was highest in *Remote and Very remote* areas (19 and 44 cases per 100,000 population respectively, compared to 10 per 100,000 population in *Major cities*).

Hospitalisations rates for regular dialysis in *Remote and very remote* areas were higher than other areas

In 2010–11, hospitalisation rates for regular dialysis for people in *Remote and very remote* areas were at least twice the rates in other areas.

Aboriginal and Torres Strait Islander people are more likely than other Australians to be hospitalised with CKD

In 2010–11, across all remoteness categories, the Indigenous age-standardised rate for regular dialysis hospitalisations was at least 7 times the rate for other Australians. This difference increased substantially in *Outer regional* and *Remote and very remote* areas.

Incompleteness of Indigenous identification means that the number of hospitalisations, treated-ESKD cases, and deaths recorded are likely to underestimate the true level of morbidity and mortality in Aboriginal and Torres Strait Islander people.

Introduction

The prevalence of certain diseases, including chronic kidney disease (CKD), can be correlated with where people live. It is known that those living in rural and remote areas have a higher incidence of hospitalisation for CKD and CKD-related deaths (AIHW 2009).

This report uses the Australian Bureau of Statistics (ABS) Australian Standard Geographical Classification (ASGC) system to group Australia into areas such as *Major cities*, *Remote* and *Very remote* (see Appendix B for more detail).

The prevalence and incidence of end-stage kidney disease (ESKD) varies with location (Cass et al. 2001). ESKD occurs when kidney function has deteriorated to such an extent that kidney replacement therapy (KRT), in the form of dialysis or kidney transplantation, is required for patient survival.

Box 1.1: Terminology

Chronic kidney disease

All kidney conditions where a person has evidence of kidney damage and/or reduced kidney function, lasting at least 3 months, regardless of the specific diagnosis of disease or condition causing the disease.

End-stage kidney disease

The most severe form of chronic kidney disease, also known as Stage 5 chronic kidney disease or kidney failure.

Incidence

The number of new cases (of an illness, disease or event) occurring during a given period.

Prevalence

The number or proportion (of cases, instances) present in a population at a given time.

In Australia, ESKD rates are higher for those living in remote areas than for urban dwellers (Cass et al. 2001). This finding is strongly linked to the high proportion of Aboriginal and Torres Strait Islander people in these areas, for whom the incidence rate of treated-ESKD is around 20 times as high as for non-Indigenous people in the same areas. In *Major cities*, the Indigenous rate of treated-ESKD, although still unacceptably high, falls to 4 times the non-Indigenous rate (AIHW 2011b).

There are a number of different CKD and ESKD data sources that include information on Indigenous status. However, the accuracy of identification may vary by data collection and region, and data collection methods may also vary. Incompleteness of Indigenous identification means that the number of hospitalisations and deaths recorded are an underestimate of the true level of morbidity and mortality of Aboriginal and Torres Strait Islander people.

Socioeconomic factors can also influence disease rates and treatment status, and location can be a proxy measure of socioeconomic position. While more people living in socioeconomically disadvantaged areas are from major urban centres, they tend to be over-represented in smaller towns and in geographically isolated communities (ABS 2000).

Treatment can also vary by location due to a combination of service availability and patient factors. For example, it is known that patients living in *Remote* and *Very remote* areas are less likely to receive a kidney transplant (ANZDATA 2012). This may be due to the combination of a higher proportion of Aboriginal and Torres Strait Islander people (who have lower transplant rates) in these areas (AIHW 2012a) and greater distance from major hospitals.

Box 1.2: Aboriginal and Torres Strait Islander people

Aboriginal and Torres Strait Islander people have higher rates of chronic kidney disease and other chronic conditions compared to other Australians.

Population distribution

Aboriginal and Torres Strait Islander people make up 2.5% of the total Australian population and are more likely to live in *Remote* and *Very remote* areas compared to non-Indigenous Australians (see Chapter 5).

To further complicate analyses, it is likely that some patients move to receive treatment, and it is not always possible to account for this in the analysis of available data. In addition, treatment practices in Australia vary by state and territory, due to a combination of remoteness, socioeconomic factors, physician preferences and availability of local training (George 2009).

Across all remoteness categories, most KRT-treated-ESKD patients are treated with dialysis rather than a kidney transplant (AIHW 2012a). Dialysis treatment is usually performed 'in-centre', rather than in the home, and one of the main issues these patients face is the burden of travel. Apart from those who have dialysis delivered in their homes, most dialysis patients must travel to a hospital or specialist centre several times a week.

For many people, particularly those from rural and remote areas, a diagnosis of ESKD means relocating to live within a reasonable travel time of where their dialysis will be provided. A large international study has shown that longer travel time is significantly associated with greater mortality risk and decreased health-related quality of life (Moist et al. 2008). While the full significance of travel burden is yet to be measured in the Australian context, it is recognised as one of the main reasons why some patients choose not to receive KRT (Morton et al. 2012).

Purpose of the report

The purpose of this report is to provide a detailed picture of the geographic distribution of CKD across Australia and to investigate the burden that travel and relocation places upon the ESKD patient population. Hospitalisation, deaths and treatment data are used to illustrate the distribution of the disease. Patient movement during the course of KRT treatment is also explored. Of particular interest is the disease burden on patients from rural and remote areas, particularly those areas with a higher proportion of Aboriginal and Torres Strait Islander people.

1 Chronic kidney disease

Key points

- People from *Remote and very remote* areas are more likely to be hospitalised for CKD than people from other areas.
- The mortality rate for CKD-related deaths was higher in *Remote and very remote* areas than in other regions.

While the prevalence of CKD in several countries has been reported at both national and state levels (McClellan et al. 2012), there is little information about its prevalence at sub-state levels. In contrast, ESKD has been reported at regional levels (see chapters 2–5).

In the Australian context, the 1999–2000 Australian Diabetes, Obesity and Lifestyle Study (AusDiab) provides national information on CKD prevalence. For more information on the AusDiab study, see Appendix B. This study included a biomedical component thereby allowing estimates of the prevalence of CKD to be made based on measured data. Biomedical data in the Australian Health Survey 2011–13 will enable future updates to this information.

The AusDiab study collected information on people from urban and rural areas (Table 1.1), but due to the sampling methodology it under sampled from rural areas. Indigenous Australians were also under represented in the survey, making up only 0.8% of the AusDiab sample (Dunstan et al. 2002), compared to the national proportion of 2.5%. As a result of the sampling methodology, the AusDiab study may underestimate geographical differences in CKD prevalence. The survey found no difference across regions in the prevalence of earlier stages (1–2) of CKD, but the prevalence for stages 3–5 was 1.2 times as high in rural than in urban areas (see Box A1 in Appendix A for CKD staging).

Table 1.1: Prevalence of chronic kidney disease in Australia by location, 1999–2000

Stage of chronic kidney disease ^(a)	Prevalence ^(b) (%)		
	Urban	Rural	Total
Stages 1–2	5.6	5.6	5.6
Stages 3–5	7.1	8.6	7.8

(a) Stages of CKD were developed by the United States Kidney Disease Outcome Quality Initiative (K/DOQI) (National Kidney Foundation of America 2002).

(b) Prevalence estimates were determined by calculating estimated glomerular filtration rates based on blood creatinine levels. The Modification of Diet in Renal Disease '175' formula was used as recommended by the Australasian Creatinine Consensus Working Group (Mathew et al. 2007).

Note: Evidence of kidney damage for stages 1 and 2 was determined by presence of albuminuria or proteinuria.

Source: AIHW analysis of the 1999–2000 AusDiab study.

CKD hospitalisations

Hospitalisation data is another source of regional information on CKD as it includes diagnosis information and the geographic location of the patient's residence. It is important to note that people who are hospitalised with CKD will most likely have a more advanced form of the disease. While the hospitalisation data presented here do not capture all cases of CKD, they do provide an indication of the level of serious disease requiring hospitalisation. These data do not include non-admitted patient activity in hospitals. For information on the scope and coverage of hospitalisation data, see Appendix B.

Data for each hospitalisation are based on information provided at the end of an episode of care, when the length of stay and procedures carried out are known and diagnostic information is more accurate.

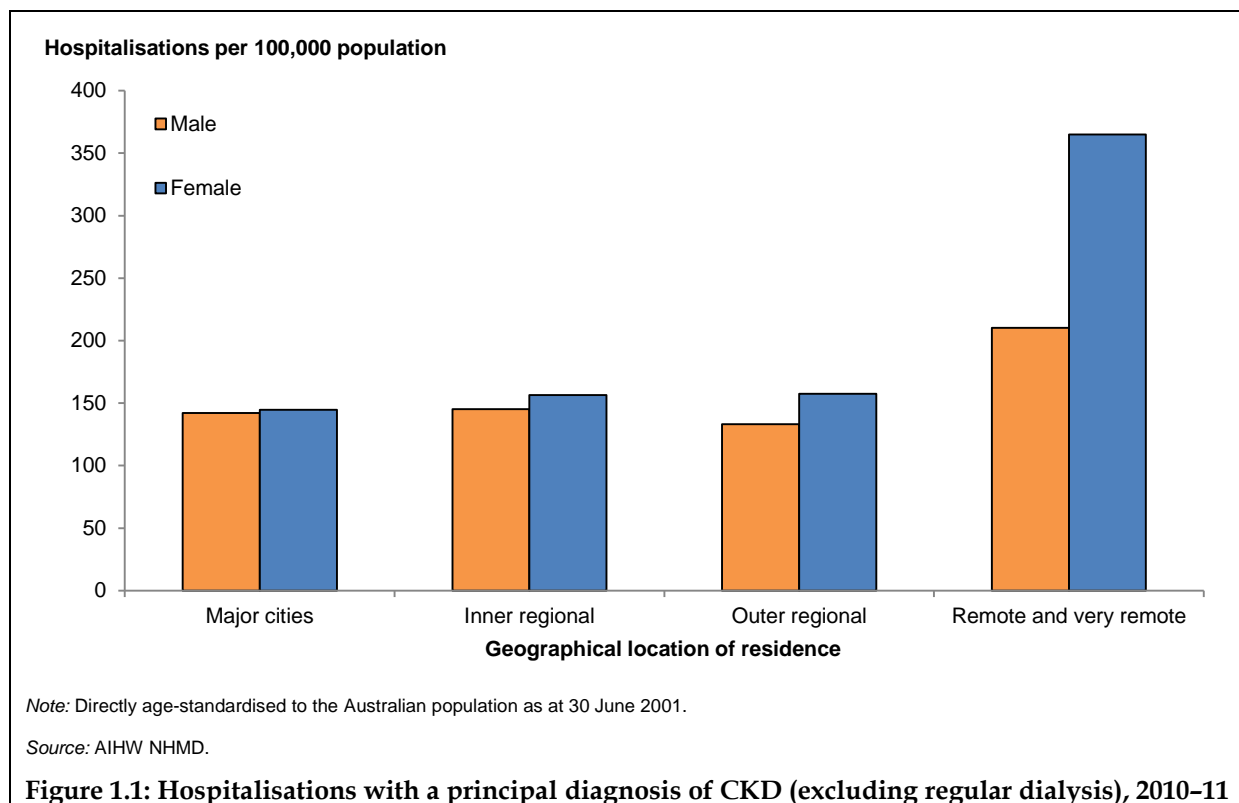
There are two distinct types of diagnoses recorded in the database – principal and additional. The principal diagnosis is the diagnosis established after study to be chiefly responsible for occasioning the patient's episode of admitted patient care. An additional diagnosis is a condition or complaint that either coexists with the principal diagnosis or arises during the episode of care. Additional diagnoses are recorded if the conditions affect patient management (AIHW 2012b). For more information on hospitalisation data, see Appendix B.

Regional variation

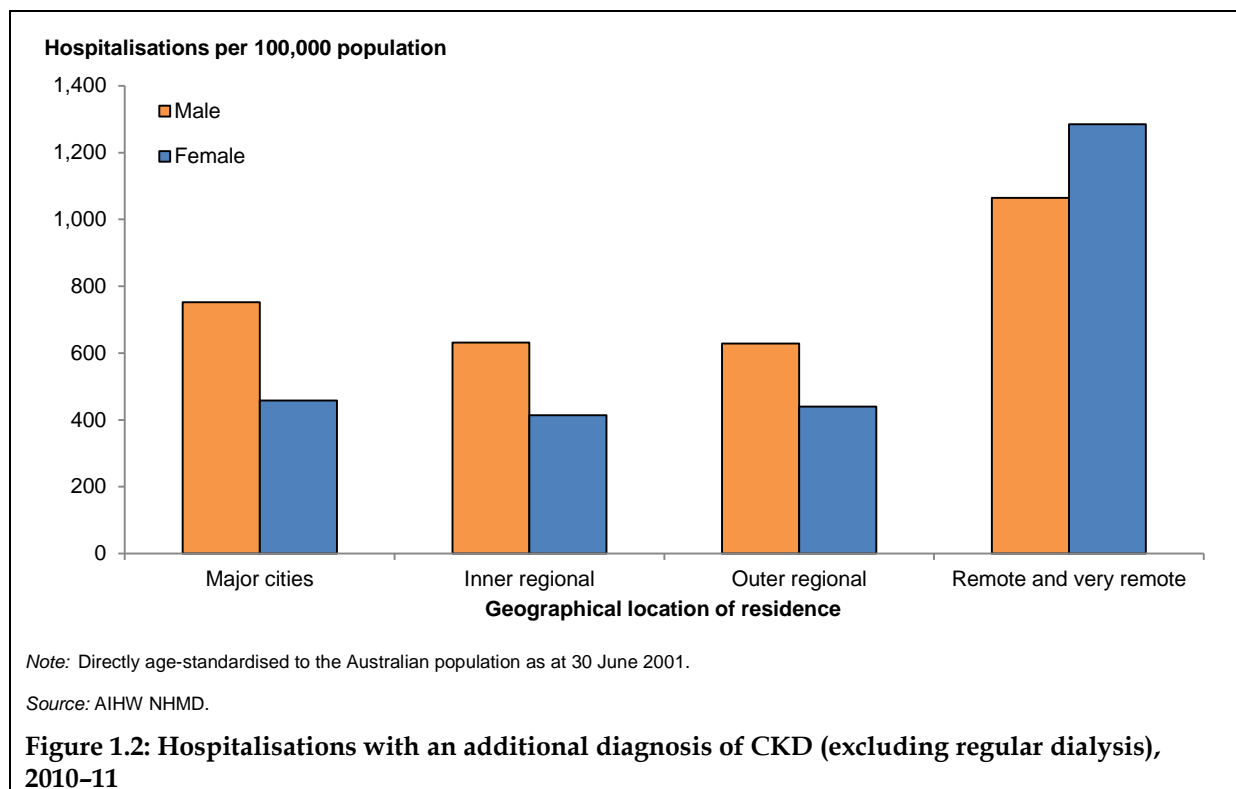
In 2010–11, there were 33,882 hospitalisations for CKD as a principal diagnosis (excluding regular dialysis – refer to Appendix B for definition). Rates were similar for *Major cities*, *Inner regional* and *Outer regional* areas (close to 150 hospitalisations per 100,000 people) but higher in *Remote and very remote* areas; men in *Remote and very remote* areas were hospitalised at 1.5 times the rate of those from *Major cities* (210 hospitalisations per 100,000 people compared to 142) and women were hospitalised at 2.5 times the rate of those from *Major cities* (365 hospitalisations per 100,000 people compared to 145) (Figure 1.1 and Table A1). The higher rates observed in *Remote and very remote* areas possibly reflects the higher proportion of Aboriginal and Torres Strait Islander people living in these areas.

Compared to Indigenous males, Indigenous women have higher levels of albuminuria (the early marker of CKD) (Hoy et al. 2012) and also have higher rates of CKD and treated-ESKD (AIHW 2011b). The sex trend difference between Aboriginal and Torres Strait Islander women and men in non-urban areas is also reflected in other comparisons of CKD and ESKD rates presented in this report.

The possible reasons for increased CKD rates in Aboriginal and Torres Strait Islander females compared to Aboriginal and Torres Strait Islander males from non-urban areas are complex and likely due to several factors. Lower numbers of nephrons (the functional units of the kidney) in females, combined with lower birth weight and excessive childhood infections are likely to play a role. These features are more common in female Aboriginal and Torres Strait Islanders from remote areas (Hoy et al. 2010; Hoy et al. 2012), as are higher rates of diabetes and obesity (both key CKD risk factors) (Hoy et al. 2012).



In 2010-11, there were 140,136 hospitalisations where CKD was recorded as an additional diagnosis (excluding regular dialysis) and where a remoteness category could be allocated. As with hospitalisations where CKD was the principal diagnosis, rates were similar for *Major cities*, *Inner regional* and *Outer regional* areas at around 550 hospitalisations per 100,000 people but higher in *Remote and very remote* areas – almost twice the rate of *Major cities* (1,160 hospitalisations per 100,000 people). Whereas men in non-remote areas were 1.4 to 1.6 times more likely to be hospitalised than women, in *Remote and very remote* areas women were 1.2 times more likely to be hospitalised than men (1,285 hospitalisations per 100,000 people compared to 1,064) (Figure 1.2 and Table A2).



CKD deaths

Data from the National Mortality Database (NMD) also provide information on geographical differences in CKD. The NMD maintains cause of death information for all deaths registered in Australia. CKD can be recorded as the underlying cause (the condition that initiated the train of morbid events leading directly to death), or an associated cause (causes, other than the underlying cause, that were instrumental in causing death). For more information on the NMD, see Appendix B.

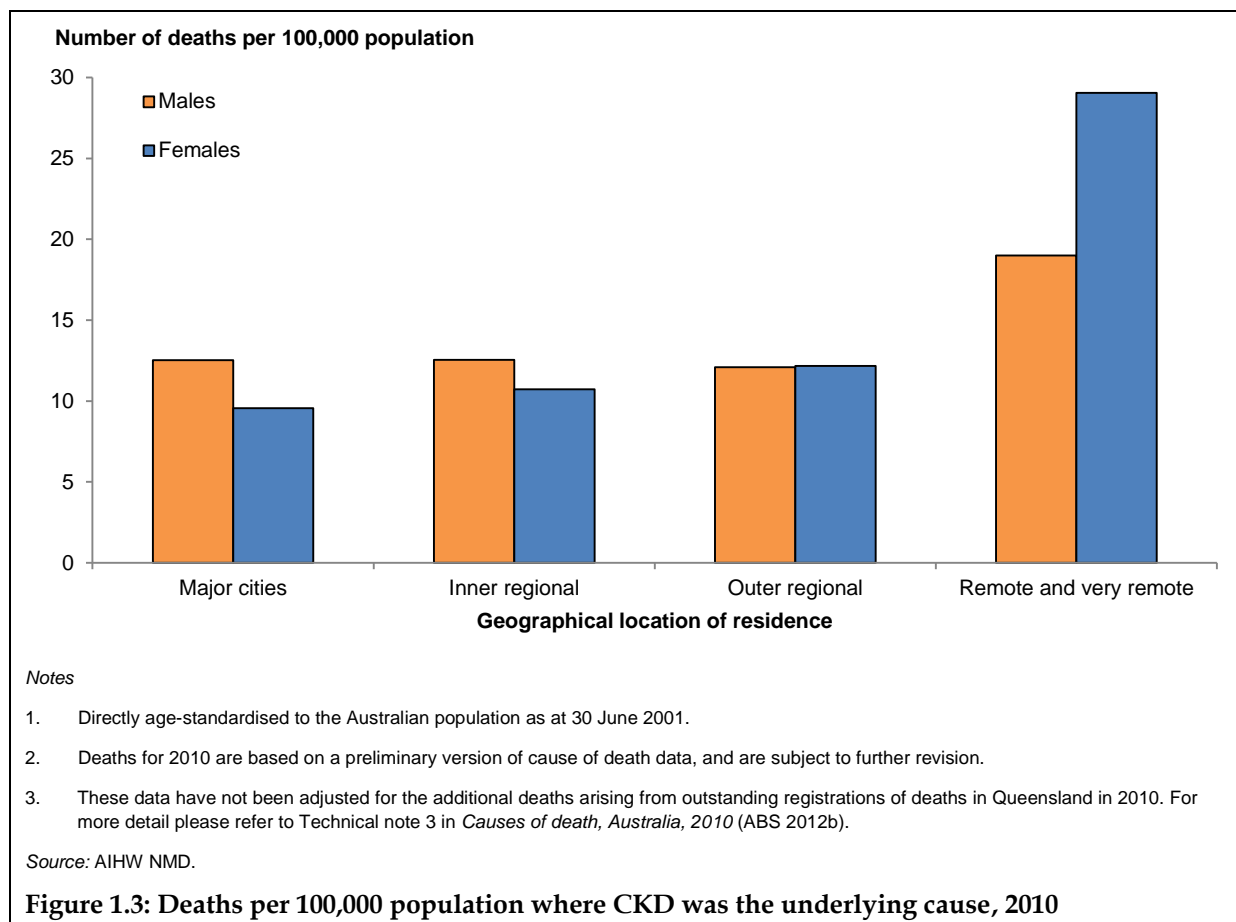
In 2010, CKD was recorded as an underlying or associated cause of death in 14,278 cases. CKD was recorded as the underlying cause of death in about one-fifth of these cases (1,331 male and 1,652 female). There were 11,295 deaths where CKD was recorded as an associated cause of death—6,137 male deaths and 5,158 female deaths.

Regional variation

In 2010, there was clear regional variation in deaths where CKD was recorded as an underlying (Figure 1.3 and Table A3) or associated cause of death (Figure 1.4 and Table A4).

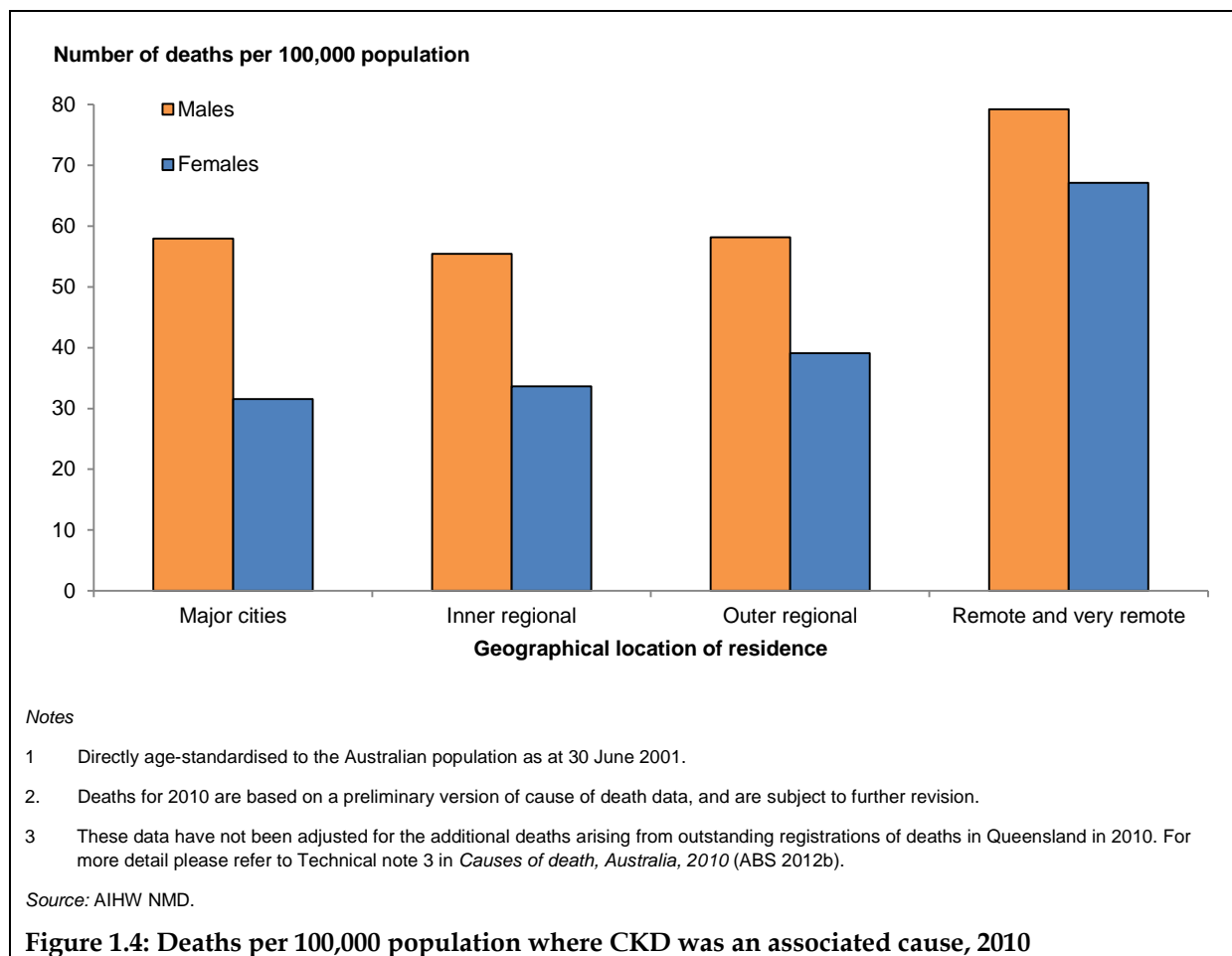
The age-standardised mortality rate where CKD was the underlying cause was higher in *Remote and very remote* regions than in other regions. Differences between male and female rates varied across regions:

- the rate was higher for males than females in *Major cities* and *Inner regional* areas, and approximately equal in *Outer regional* areas
- the mortality rate was considerably higher for females (29 deaths per 100,000 population) than males (19 deaths per 100,000 population) in *Remote and very remote* areas.



The mortality rate for CKD as an associated cause of death was higher for males than females across all regions. However, while the rate for males was roughly consistent across *Major cities*, *Inner regional* and *Outer regional* areas at just under 60 deaths per 100,000 population, it increased in *Remote and very remote* areas to almost 80 deaths per 100,000 population.

The mortality rate for females increased gradually as remoteness increased from 32 deaths per 100,000 population in *Major cities* to 39 deaths per 100,000 population in *Outer regional* areas, but also spiked in *Remote and very remote* areas to 67 deaths per 100,000 population. Again, this possibly reflects the higher proportion of Aboriginal and Torres Strait Islander people (with correspondingly higher rates of CKD) living in *Remote and very remote* areas (Figure 1.4 and Table A4).



2 Incidence of ESKD

Key points

During 2008–2010:

- rates of new cases of treated-ESKD increased with increasing remoteness.

During 2005–2007:

- about two-thirds of all new cases of ESKD (both KRT-treated and non-KRT-treated) were in *Major cities*.
- those living in *Very remote* areas had much higher overall incidence rates of ESKD.
- people living in *Remote* and *Very remote* areas were more likely to receive KRT for their ESKD.
- age-specific treatment rates did not differ systematically by remoteness.

This next section gives an overview of geographical differences in the incidence of treated-ESKD and in the total incidence of ESKD. As with the CKD results in Chapter 1, each data source shows higher rates in *Remote* and *Very remote* areas. However, it is important to note that the majority of cases are actually in *Major cities*, due to the higher number of people living in these areas.

New cases of treated-ESKD

This section presents information on individuals commencing treatment with KRT. Due to the small number of cases in *Remote* and *Very remote* areas, 2008–2010 data have been combined in this section.

In 2008–2010, more than half (65%) of the new cases of treated-ESKD were for people living in *Major cities* and only 6% of cases were from *Remote* and *Very remote* areas. After accounting for population size, and adjusting for differences in age-structures, the rate of new cases was highest in *Remote* and *Very remote* areas (19 and 44 per 100,000 population, respectively, compared to 10 per 100,000 population in *Major cities*) (Table 2.1 and Figure 2.1).

Differences between male and female rates varied across regions:

- In *Major cities*, male rates were almost 2 times as high as female rates (14 compared to 7 per 100,000 population).
- In *Inner regional* areas, male rates were around 1.8 times female rates (12 compared to 7 per 100,000 population, respectively).
- In *Outer regional* areas, male rates were around 1.5 times female rates (13 compared to 9 per 100,000 population, respectively).
- In *Remote* areas, rates for males and females were similar (around 19 per 100,000 population).
- In *Very remote* areas, female rates were around 1.7 times male rates (58 compared to 33 per 100,000 population).

Table 2.1: New cases of treated-ESKD by geographical location of first treatment, 2008–2010

	Major cities		Inner regional		Outer regional		Remote		Very remote	
	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)
Male	2,902	13.5	874	12.3	442	13.1	101	19.6	92	33.4
Female	1,787	7.4	505	6.7	292	8.8	84	18.8	121	57.9
Persons	4,689	10.2	1,379	9.3	735	11.0	185	19.2	213	44.0

(a) Treated-ESKD patients per 100,000 population, directly age-standardised to the 2001 Australian population.

Source: AIHW analysis of ANZDATA Registry data.

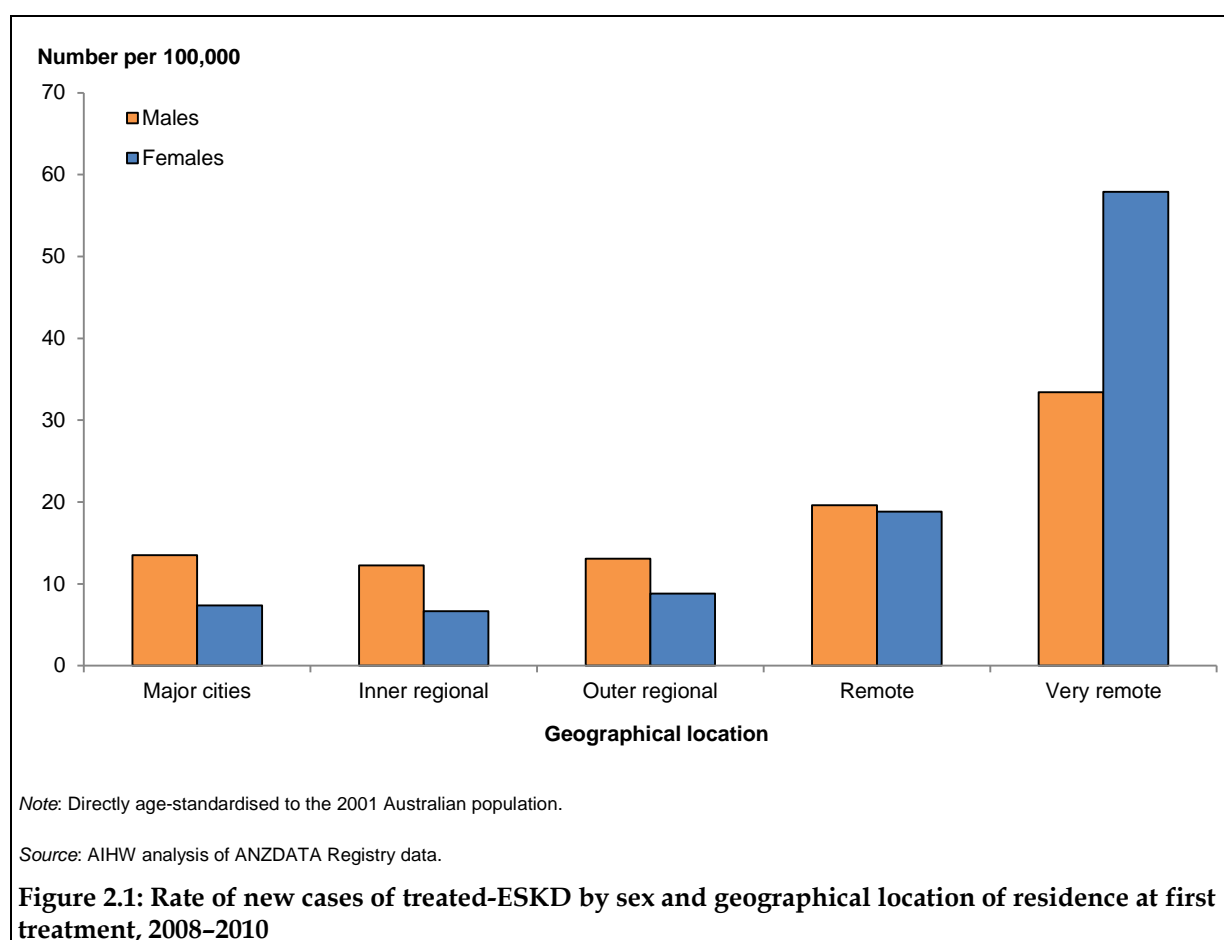


Figure 2.1: Rate of new cases of treated-ESKD by sex and geographical location of residence at first treatment, 2008–2010

The rate of new cases of treated-ESKD increased with age in *Major cities*, *Inner regional* and *Outer regional* areas, peaking in the oldest age group (70 and over). In *Remote* and *Very remote* areas, the rate of new cases of treated-ESKD also increased with age, but peaked in the 60–64 age group. The difference in age-related trends in *Remote* and *Very remote* areas compared to other areas, is likely due to the high proportion of Aboriginal and Torres Strait Islander people in these areas. Aboriginal and Torres Strait Islander people tend to start treatment for ESKD at an earlier age than non-Indigenous Australians (McDonald & Russ 2003).

Total incidence

Traditionally, incidence data for ESKD in Australia have only been available for those treated with KRT, with virtually all of these cases recorded in the Australian and New Zealand Dialysis and Transplant (ANZDATA) Registry. As not all people will be suitable candidates for KRT, and some may choose not to take it up, this method of measuring incidence of ESKD underestimates the total incidence in the community.

To estimate the total incidence of ESKD, the AIHW used data linkage to estimate the number of new cases of ESKD not treated with KRT (AIHW 2011a). The number of non-KRT-treated cases is estimated using a defined set of cause of death codes in the NMD, with the aim of counting people who died with ESKD in the study period but were not treated with KRT. This number is added to the number of dialysis and transplant cases recorded in the ANZDATA Registry. Data linkage is also used to ensure that people treated with dialysis or transplant who die during the study period are only counted once.

There are various reasons why some patients do not receive KRT treatment for their ESKD, including medical reasons (such as suitability for KRT), accessibility of services, and personal choice. KRT is a complex treatment, and individual patients make choices based on their particular circumstances.

For this analysis, patients are classified into areas of remoteness as specified in the ABS ASGC (see Appendix B for details). These areas are based on either a patient's postcode at their first treatment (for patients who were KRT-treated and did not die during the 2005–07 reference period) or their place of usual residence before their death (for non-KRT-treated patients or KRT-treated cases that died during the reference period).

In 2005–2007, when non-KRT-treated cases were added to treated cases from ANZDATA, the total number of new cases of ESKD increased by between 24.4% (in *Very remote* areas) and 55.0% (in *Inner regional* areas) (Table 2.2). About two-thirds (8,825) of all new cases of ESKD were in *Major cities* (Table 2.2).

Table 2.2: Total incidence of ESKD, by treatment status and geographical location, 2005–2007

	Major cities	Inner regional	Outer regional	Remote	Very remote
Number of cases					
KRT-treated	4,642	1,263	701	196	225
Non-KRT-treated	4,184	1,543	748	94	73
Total	8,825	2,806	1,449	290	299
Age-standardised rate (per 100,000 population)^(a)					
KRT-treated	10.9	9.2	11.3	21.5	52.0
Non-KRT-treated	9.0	10.2	12.1	14.2	29.2
Total	19.9	19.4	23.2	35.7	81.1

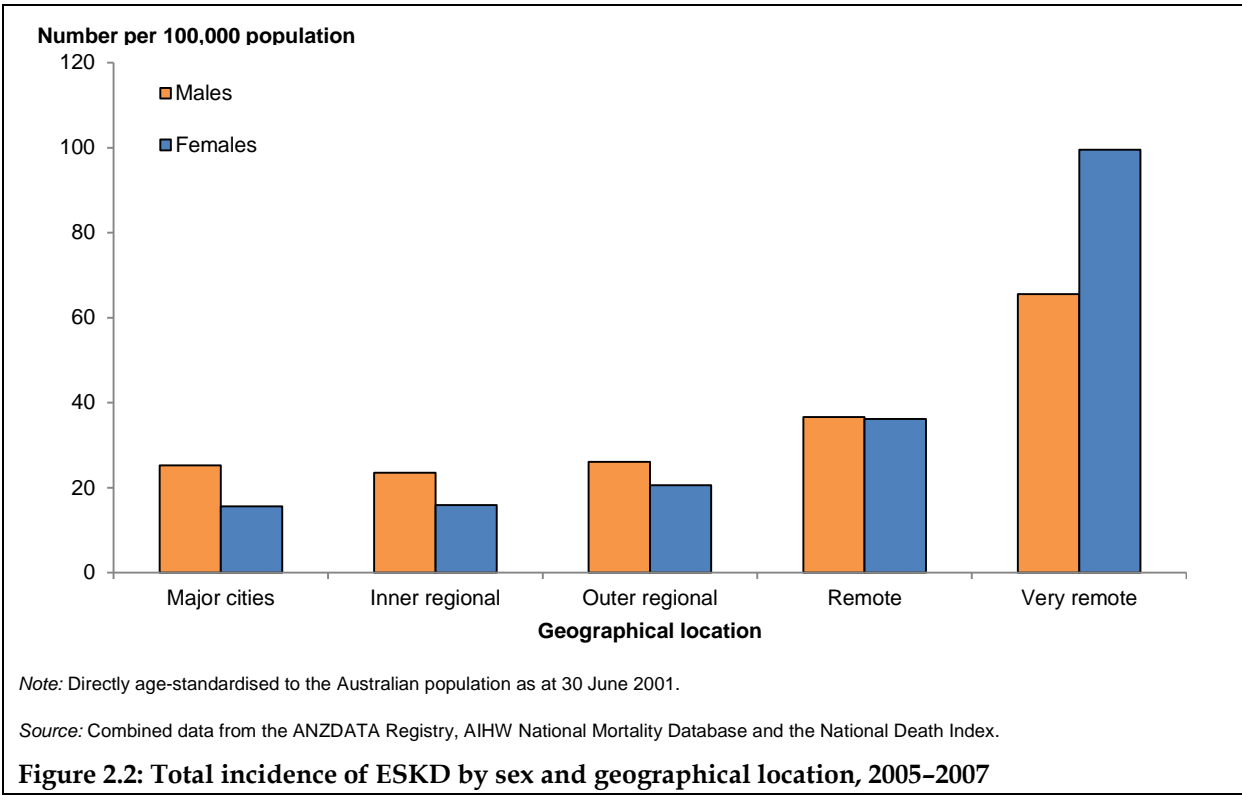
(a) Directly age-standardised to the Australian population as at 30 June 2001.

Note: Male and female counts may not add up to total numbers (persons) due to rounding associated with allocating cases to ASGC categories.

Source: Linked ANZDATA Registry, AIHW National Mortality Database and National Death Index.

Those living in *Remote* and *Very remote* areas had much higher incidence rates of ESKD (Figure 2.2), particularly in younger age groups (AIHW 2011a). The higher overall rates seen in *Very remote* areas are likely to be driven by the relatively higher proportion of Aboriginal and Torres Strait Islander people in these areas – 48% compared to 6% or less in *Major cities* and *Regional* areas (AIHW 2011b).

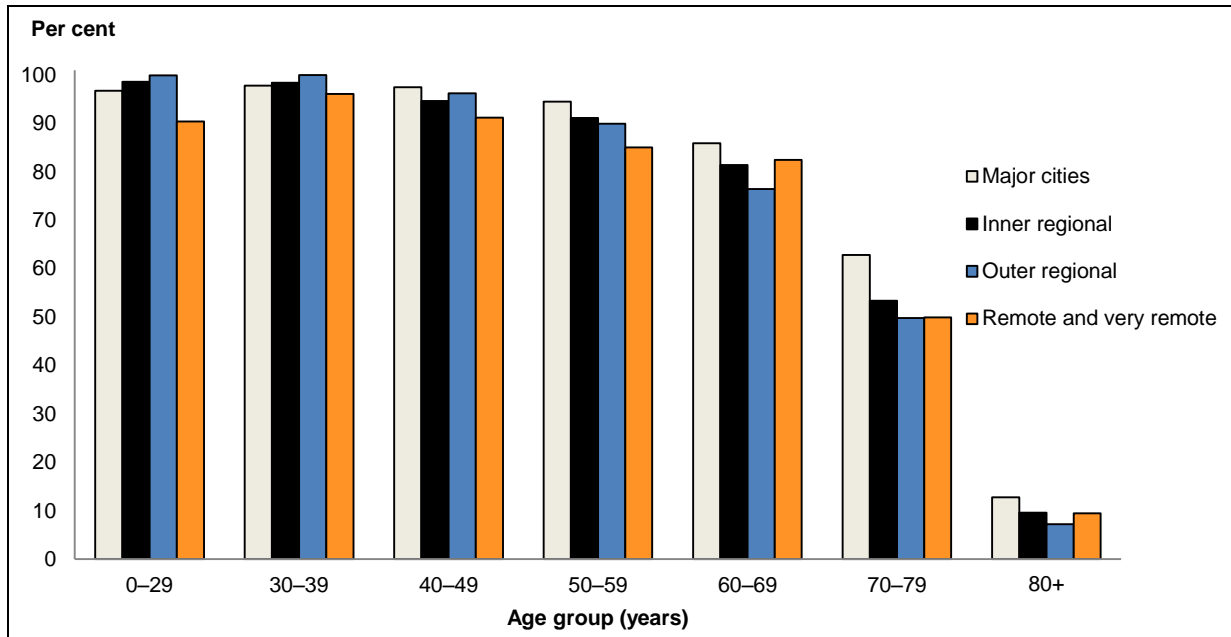
Aboriginal and Torres Strait Islander females are more likely than Aboriginal and Torres Strait Islander males to develop ESKD in *Remote* and *Very remote* areas (AIHW 2011b). In contrast, non-Indigenous males are more likely to develop ESKD than non-Indigenous females. The higher proportion of Aboriginal and Torres Strait Islander people in *Very remote* areas (48% versus 2.5% of the total Australian population) likely contributes to the higher female rates seen in *Very remote* areas (Figure 2.2) (AIHW 2011a, 2011b). Conversely, in *Major cities*, *Inner* and *Outer regional* areas, males had higher rates of ESKD than females and similar rates to females in *Remote* areas (Figure 2.2 and Table A5).



KRT treatment rates by geographical location

In 2005–2007, the proportion of people with ESKD who were KRT-treated varied across geographic locations. People living in *Remote* and *Very remote* areas were more likely to be treated than those in *Major cities*, *Inner* and *Outer regional* areas (Table 2.2).

In addition, it is also important to look at treatment rates by age, as younger patients are more likely to receive treatment (AIHW 2011a). This is reflected in the higher proportion of ESKD cases treated with KRT in *Remote* and *Very remote* areas where more than half (58%) of the new cases of ESKD are under the age of 60 compared to 19–27% of new cases in other areas. Consequently, when treatment rates are examined by age group, people from *Remote* and *very remote* areas do not have higher treatment rates (Figure 2.3). Comparisons are further complicated due to the small number of cases in *Remote* and *very remote* areas.



Source: Combined data from the ANZDATA Registry, AIHW National Mortality Database and the National Death Index.

Figure 2.3: Proportion of new cases of ESKD treated with KRT, by geographical location and age group, 2005-2007

3 Prevalence and type of treatment for ESKD

Key points

At the end of 2010:

- *Remote* and *Very remote* areas have higher prevalence rates of treated-ESKD than other areas.
- The proportion of treated-ESKD patients treated with a functioning kidney transplant was lowest in *Remote* and *Very remote* areas.
- Satellite haemodialysis was the most common form of dialysis treatment in all geographical locations.

In 2010–11:

- Hospitalisation rates for regular dialysis in *Remote and very remote* areas were at least twice as high as other areas.

Treated-ESKD prevalence

The ANZDATA Registry data records the postcode where KRT-treated-ESKD patients are currently living. This information has been used to assign a remoteness category based on the ASGC system (see Appendix B for details).

At the end of December 2010, the rate of treated-ESKD was highest for people living in *Remote* and *Very remote* areas (142 and 175 per 100,000 population, respectively) (Table 3.1), after taking into account population size and adjusting for differences in age structure.

Males had higher rates of treated-ESKD than females in *Major cities*, *Inner regional* and *Outer regional* areas. In contrast, the opposite trend occurred in *Remote* and *Very remote* areas. As with the incidence of treated-ESKD (Figure 2.1) and the total incidence of ESKD (Figure 2.2), higher rates of treated-ESKD for females in *Remote* and *Very remote* areas are likely due to the relatively high proportion of Aboriginal and Torres Strait Islander people making up the population in these areas.

It is worth noting that a different pattern is seen for people starting treatment, as opposed to those currently receiving treatment. In 2008–10, the age-standardised rate for people starting KRT treatment in *Very remote* areas was 2.3 times the rate in *Remote* areas (see Chapter 2). The reason why the same level of difference was not seen for people currently receiving treatment for ESKD (Figure 3.1) may be due to patients from *Very remote* areas moving to access services or moving as their treatment becomes more complex (see Chapter 4 for more detail on patient movement).

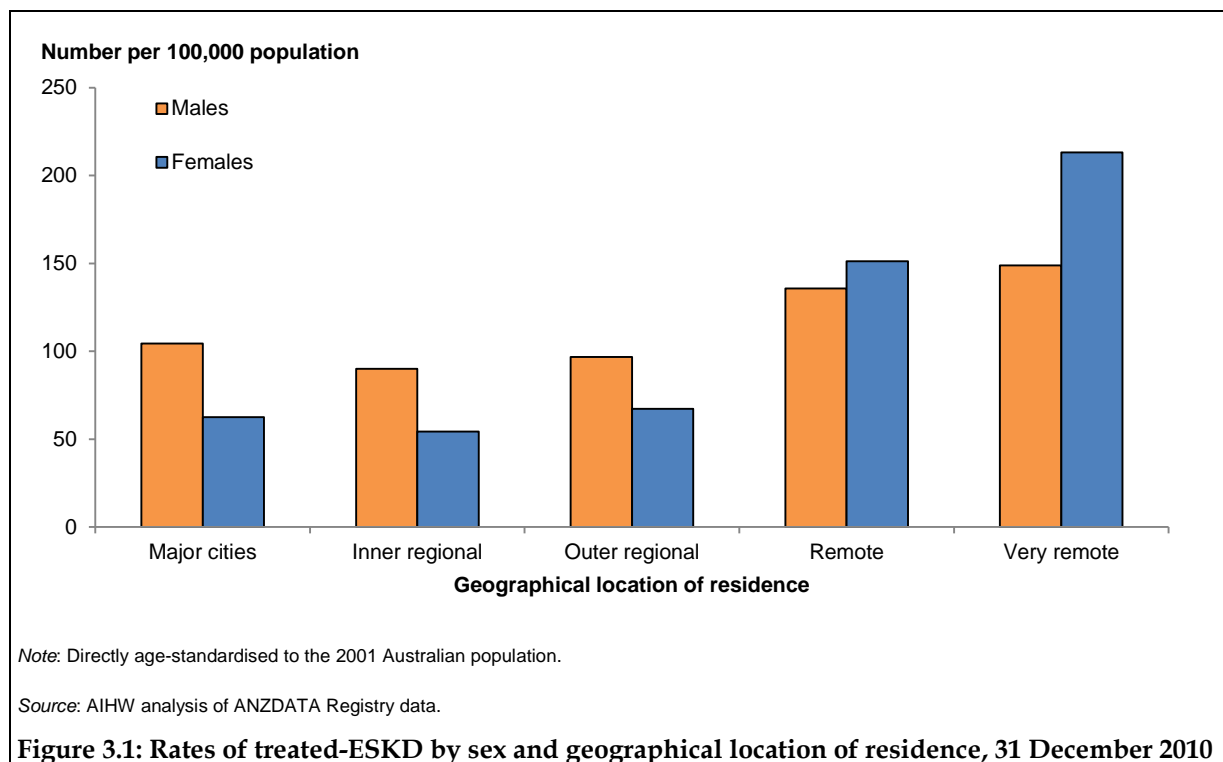


Table 3.1: Treated-ESKD by geographical location of residence, 31 December 2010

	Major cities		Inner regional		Outer regional		Remote		Very remote	
	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)
Male	7,844	104.5	2,155	90.0	1,086	96.7	242	135.7	138	148.9
Female	5,054	62.5	1,339	54.2	739	67.1	236	151.3	148	213.2
Persons ^(b)	12,898	82.3	3,493	71.5	1,825	81.8	477	142.3	286	175.5

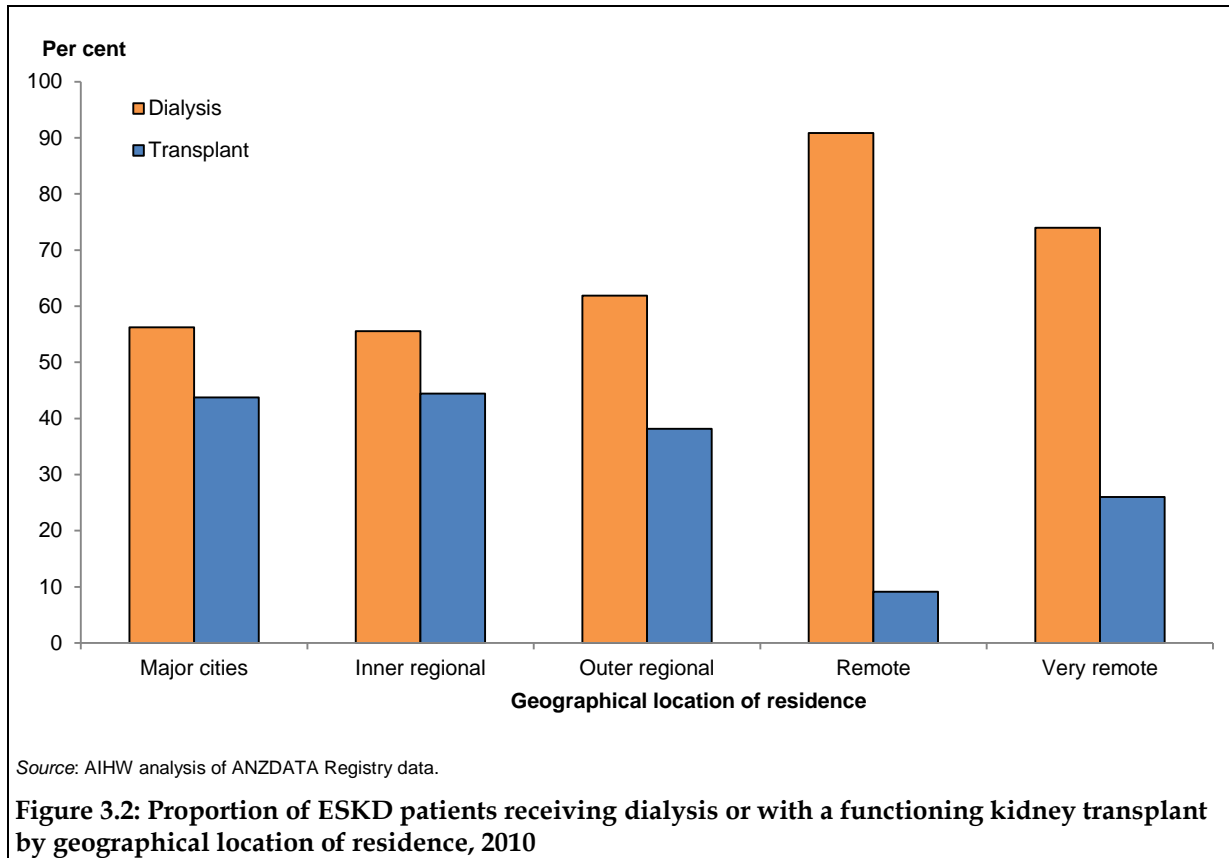
(a) Treated-ESKD patients per 100,000 population, directly age-standardised to the 2001 Australian population.

(b) Male and female numbers may not add up to total numbers (persons) due to rounding associated with allocating postcodes of residence to ASGC categories.

Source: AIHW analysis of ANZDATA Registry data.

Type of kidney replacement therapy by geographical location

The proportion of treated-ESKD patients with a functioning transplant varied by geographical location of residence (Figure 3.2). At the end of 2010, around 44% of treated-ESKD patients living in *Major cities* or *Inner regional* areas and 38% of ESKD patients living in *Outer regional* areas had a functioning kidney transplant. This compared to 9% in *Remote* areas and 26% in *Very remote* areas.



Dialysis treatment by geographical location of residence

The treatment pattern for dialysis varied with geographical location (Figure 3.3). Satellite haemodialysis was the most common dialysis treatment in all geographical locations, but *Remote* areas had the highest proportion of patients receiving haemodialysis at satellite clinics (70%). The home haemodialysis rate was highest in *Very remote* areas (10%) but this was the least commonly used type of treatment in all areas. The peritoneal dialysis rate was also highest in *Very remote* areas (23%) and similar in all other areas (ranging from 16–20%). For more information on the modes of dialysis, see Box 1.

Box 1: Dialysis modalities

Haemodialysis

In haemodialysis, blood is diverted from the body to a dialysis machine, where it is filtered before being returned to the body. This type of dialysis can be done at home, in hospital, or in satellite clinics. The machine requires special plumbing and the patient must restrict their travel to places where dialysis facilities are available.

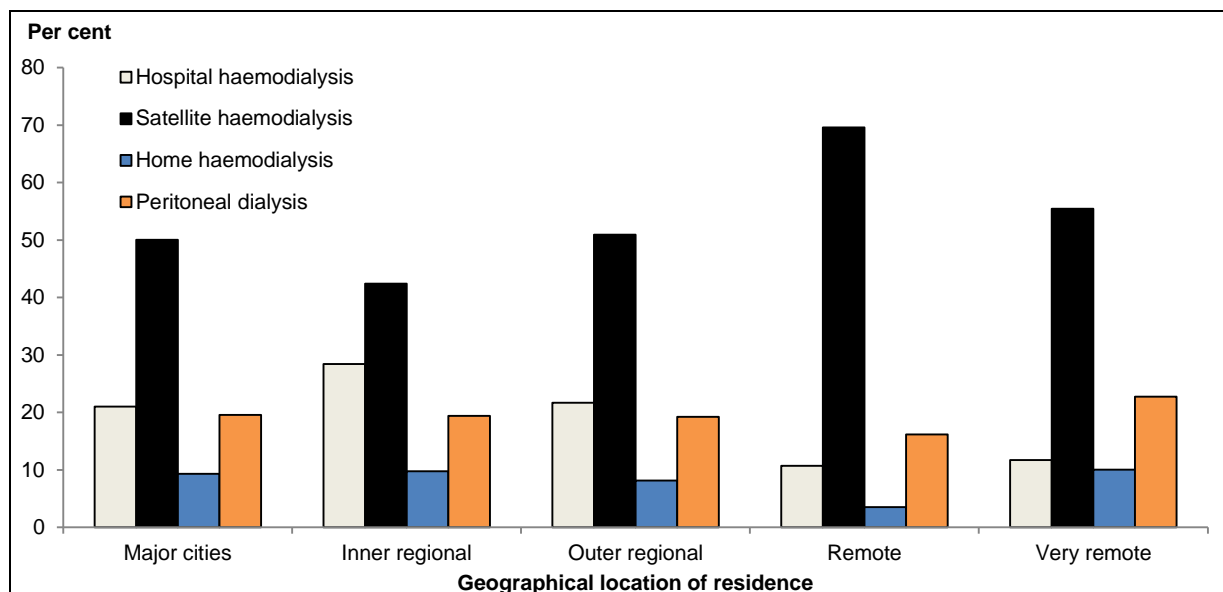
In most cases, the patient requires assistance connecting to the machine, and a partner, relative or friend can train to do this for home dialysis patients. During haemodialysis, the patient is usually connected to the machine for about 4–5 hours 3 times per week, when all their blood passes through the machine about 6 times.

If performed at home, patients may have the option of dialysing more frequently for a shorter period (5–7 times per week for about 2 hours) or nocturnally (6 nights per week for about 8 hours). During a haemodialysis session the patient is unable to move away from the machine, though they can sleep and perform activities such as reading, talking, or using a computer.

Peritoneal dialysis

In peritoneal dialysis, the abdomen is filled with sterile dialysis solution and the blood is filtered through the peritoneal membrane (which covers the abdominal cavity organs such as the stomach, liver and intestines). The dialysis solution contains a type of sugar (usually glucose or dextrose) which draws the waste products and extra fluid out of the blood, through the peritoneal membrane and into the solution. After a few hours, the used solution, now containing the wastes and extra fluid, is drained out of the body and replaced with fresh solution.

This process is called an exchange and takes about 30–45 minutes. In between exchanges, the patient is free to continue their usual activities. The patient can either perform peritoneal dialysis during the day (continuous ambulatory peritoneal dialysis), usually 3 or 4 times, or automatically at night using a machine for about 8–10 hours while the patient sleeps (automated peritoneal dialysis). As the necessary equipment is portable, peritoneal dialysis can be performed almost anywhere. The patient does not need to be in a hospital or clinic, and can usually manage the procedure without assistance.



Source: AIHW analysis of ANZDATA Registry data.

Figure 3.3: Dialysis treatment type by geographical location of residence, 2010

Irrespective of the mode of dialysis or where patients live, a very substantial time commitment is required for patients to receive adequate treatment. Satellite and hospital haemodialysis is usually carried out 3 times per week, each for 4–6 hours, whereas home haemodialysis can be carried out overnight (6–8 hours) on a more frequent basis. Continuous ambulatory peritoneal dialysis requires that the dialysis solution be exchanged every 4–6 hours, taking around 45 minutes each time. With an automated peritoneal dialysis, these exchanges can occur automatically overnight but an exchange may still be required during the day.

Patients living in isolated areas may be able to access in-home dialysis, or may need to travel long distances or relocate. There is some evidence that long travel times to dialysis treatment are associated with higher mortality rates (Moist et al. 2008).

The combination of time demands and physical constraints that those on dialysis treatment experience can lead to major changes in established patterns of social and economic participation. Dialysis patients can also face significant financial hardship from loss of income and higher out-of-pocket health costs. They also experience relatively high rates of depression and other psychological or interpersonal difficulties (Chilcot et al. 2008; Lew & Piraino 2005). Home life may be significantly disrupted and family members may be required to act as carers, particularly if people opt for home dialysis services.

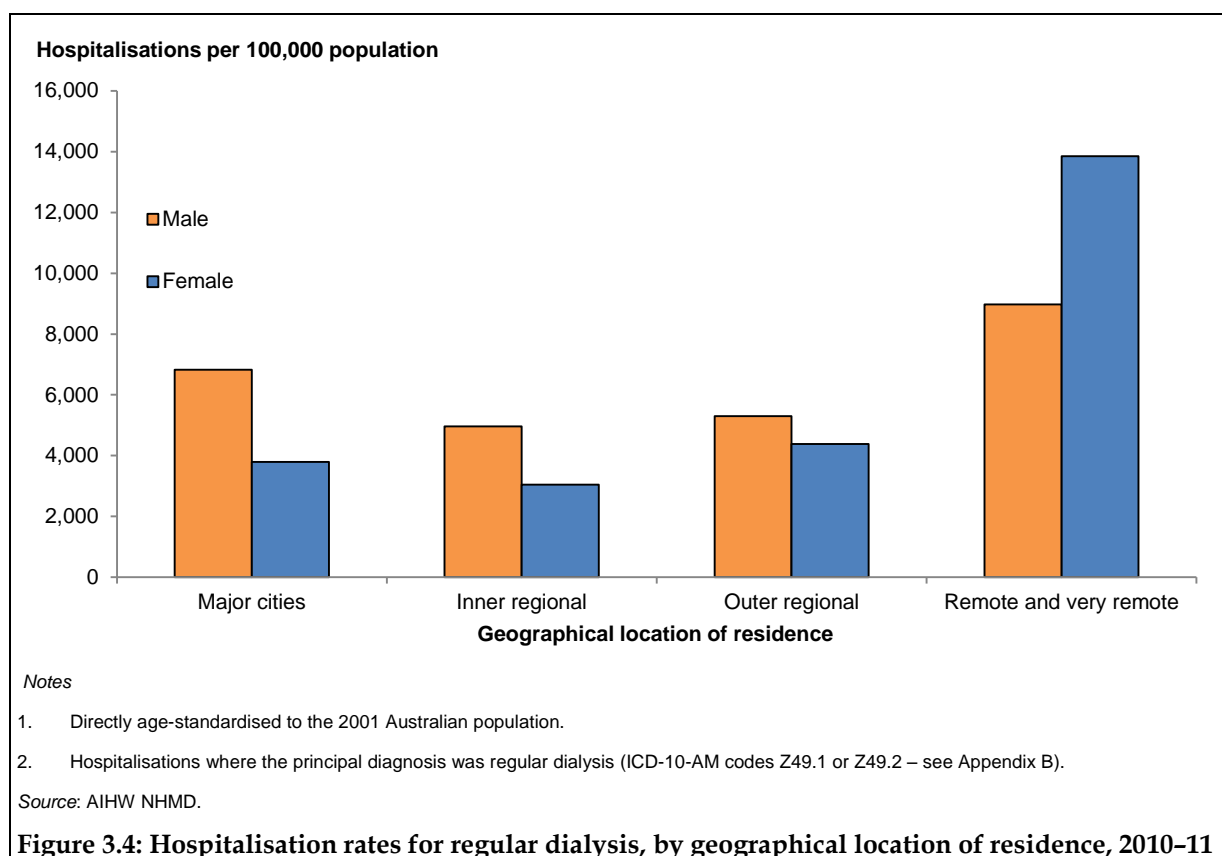
Hospitalisations for regular dialysis

People with CKD, particularly those with ESKD, often require hospital services – in fact regular dialysis treatment is the most common reason for hospitalisation in Australia (AIHW 2012b).

A regular dialysis hospitalisation is defined in this publication as a hospitalisation with a principal diagnosis of ICD-10-AM code Z49.1 (haemodialysis) or Z49.2 (peritoneal dialysis).

Hospitalisations for regular dialysis involve patients undergoing a formal hospital admission process, completing an episode of admitted patient care and being discharged from hospital. For a hospitalisation to record a principal diagnosis of ICD-10-AM codes Z49.1 or Z49.2, the intent for admission must be same day and the patient discharged on the same or next day of admission (NCCCH (National Centre for Classification in Health) 2010), see Appendix B for more information.

In 2010–11, the hospitalisation rate for regular dialysis (see Appendix B for definition) for people in *Major cities* was around 1.3 times as high as the rate in *Inner regional* areas (5,164 compared with 3,937 per 100,000 population) and similar to the rate in *Outer regional* areas (4,823 per 100,000 population). Hospitalisation rates in *Remote and very remote* areas were at least twice the rates in other areas. Males were hospitalised at higher rates in *Major cities*, *Inner regional* and *Outer regional* areas, while females had higher hospitalisation rates in *Remote and very remote* areas (Figure 3.4 and Table A6).



4 Movement for treatment

Key point

- ESKD patients from *Remote* and *Very remote* areas are more likely to change remoteness categories during the first year of their KRT treatment when compared to patients from other areas.

When commencing or undergoing KRT, some people move their place of residence closer to where they receive treatment for their ESKD (Preston-Thomas et al. 2007). This relocation may be more common among Aboriginal and Torres Strait Islander patients than non-Indigenous patients. An Australia-wide study found that from 1999 to 2001, 50% of Aboriginal and Torres Strait Islander patients commencing dialysis had to relocate to access treatment. In remote regions, 78% of Aboriginal and Torres Strait Islander patients had to relocate from the community in which they lived prior to commencing treatment, compared with only 15% in urban areas (Preston-Thomas et al. 2007).

High relocation rates place a heavy toll on both the individual and the community. Relocation affects patients' quality of life, their willingness and capacity to maintain their treatment regimens and may result in financial hardship, and social and cultural isolation (Preston-Thomas et al. 2007). Conversely, others may be unable to move from major centres to rural/remote areas, or travel for work or pleasure, due to the need to stay near their place of treatment.

For Aboriginal and Torres Strait Islander patients, the need to move away from kin and community to take up KRT often results in a loss of social and cultural connectedness, loss of autonomy and control, and loss of status and authority. Key family members and cultural leaders having to relocate can profoundly affect Aboriginal and Torres Strait Islander communities (George Institute 2011). It is important to note that not all people with ESKD who move after starting treatment are doing so to live closer to their treatment.

The ANZDATA Registry collects information on postcode of residence at first treatment and at the end of the year. Although it is not possible from these data to assess if patients move before they start treatment, it is possible to assess if patients move to a different postcode after they commence treatment.

Table 4.1 shows the proportion of patients that changed remoteness categories during their first year of treatment. Data were combined for 2005–10 due to small numbers in some regions (see Table A7). It can be seen that a large proportion (57%) of patients who lived in *Very remote* areas at the start of their first treatment changed to less remote areas during their first year of treatment. The percentage of people who changed remoteness categories decreased with decreasing remoteness. Only a small proportion of people moved in the other direction – to more remote locations.

Table 4.1: ANZDATA Registry incident cases: Remoteness category of residence at first treatment and at end of incident year (proportion): 2005–2010

		Remoteness of residence at year end					
		Major cities	Inner regional	Outer regional	Remote	Very remote	Per cent moved
Remoteness of residence at first treatment	Major cities	98.5	1.1	0.4	0.1	0.0	1.5
	Inner regional	3.6	95.1	1.1	0.2	0.0	4.9
	Outer regional	4.5	4.2	90.0	0.6	0.6	10.0
	Remote	8.3	3.0	8.3	78.1	2.3	21.9
	Very remote	6.0	1.1	22.0	28.3	42.7	57.3

Notes

1. Bolded proportions indicate no change in remoteness of residence.
2. Postcodes were allocated to a remoteness category if more than 80% of that postcode fell in a region according to 2006 ASGC concordance. 1,118 cases were excluded due to their postcode at entry or end survey not being allocated to a remoteness category. Time to movement could range from 1 day to 364 days depending on when in the survey year a patient commenced treatment.

Source: AIHW analysis of ANZDATA Registry data.

Table 4.2 shows a comparison group from the Household, Income and Labour Dynamics in Australia (HILDA) Survey – a nationally representative panel survey, with coverage rules broadly in line with those that the ABS adopts in the monthly Labour Force Survey supplements (Summerfield et al. 2012) (see Appendix B).

Data from this survey show the proportion of the Australian population who change remoteness categories over a year. Over the same period 2005–2010, movement between remoteness categories after 1 year was 1% for the population who commenced the year in *Major cities*, 4% for the population that commenced the year in *Inner* and *Outer regional* areas and 9% for people who commenced the year in *Remote* and *very remote* areas.

When comparing ANZDATA Registry data to HILDA data, it is apparent that ANZDATA incident populations in *Inner regional*, *Outer regional* and particularly *Remote* and *very remote* areas move more than the general population in these areas – this is likely to be related to access to treatment.

Table 4.2: HILDA Survey: Remoteness category of usual residence and remoteness category of usual residence 1 year ago (proportion), 2005–2010 (all age groups)

		Place of usual residence at year 2					
		Major cities	Inner regional	Outer regional	Remote and very remote	Per cent moved	
Place of usual residence at year 1	Major cities	98.6	1.1	0.2	0.1	1.4	
	Inner regional	2.5	96.5	0.8	0.2	3.5	
	Outer regional	1.9	1.9	95.8	0.4	4.2	
	Remote and very remote	2.7	2.2	4.3	90.8	9.2	

Notes

1. Bolded proportions indicate no change in remoteness of residence.
2. Postcodes were allocated to a remoteness category if more than 80% of that postcode fell in a region according to 2006 ASGC concordance.

Source: AIHW analysis of the Household, Income and Labour Dynamics in Australia (HILDA) Survey (Waves 5–10).

5 Aboriginal and Torres Strait Islanders with CKD by remoteness

Key points

- Indigenous identification varies with remoteness in some of the data sources used to monitor CKD.
- Consequently, the number of hospitalisations and deaths recorded are possibly an underestimate of the true level of morbidity and mortality of Aboriginal and Torres Strait Islander people.

In 2010–11:

- Aboriginal and Torres Strait Islander people were hospitalised with a principal diagnosis of CKD (excluding regular dialysis) at a higher rate than other Australians. In *Remote and very remote* locations, Aboriginal and Torres Strait Islander people were hospitalised at 8.1 times the rate of other Australians.
- Aboriginal and Torres Strait Islander people were hospitalised with an additional diagnosis of CKD at a higher rate than other Australians. In *Remote and very remote* locations, Aboriginal and Torres Strait Islander people were hospitalised at 12.8 times the rate of other Australians.

In 2008–10:

- the rate of new cases of treated-ESKD increased with remoteness for Aboriginal and Torres Strait Islander people. The opposite was true for non-Indigenous Australians.

Compared with other Australians, Aboriginal and Torres Strait Islander people tend to have excessive chronic disease morbidity and mortality – particularly those in remote communities – and CKD is no exception to this trend (AIHW 2011b).

This chapter highlights differences in health status between the Aboriginal and Torres Strait Islander population and the non-Indigenous population. It also explores differences in CKD and ESKD rates using three data sources: the NHMD, the NMD and the ANZDATA Registry. The quality of Indigenous identification in these data sources is important to consider when interpreting these data, and this issue is discussed.

Aboriginal and Torres Strait Islander population

Knowing how many Aboriginal and Torres Strait Islander people there are and where they live is important information for ensuring the provision of culturally appropriate health services.

The estimated number of people identified as being of Aboriginal and/or Torres Strait Islander descent at 30 June 2006 was around 517,000, representing 2.5% of the total Australian population.

Almost one-third (32%) of the estimated resident Aboriginal and Torres Strait Islander population lived in *Major cities*; 21% lived in *Inner regional* areas; 22% in *Outer regional* areas; 9% in *Remote* areas and 15% in *Very remote* areas (Table 5.1). In contrast, a much higher

proportion of the non-Indigenous population resided in *Major cities* (69%) and less than 2% in *Remote* and *Very remote* Australia (ABS 2009).

Table 5.1: Indigenous and non-Indigenous populations by remoteness, 30 June 2006

Geographical location	Indigenous			Non-Indigenous		
	Number	Proportion of total Indigenous population	Proportion of regional population	Number	Proportion of total non-Indigenous population	Proportion of regional population
Major cities	165,804	32.1	1.2	13,996,454	69.4	98.8
Inner regional	110,643	21.4	2.7	3,974,764	19.7	97.3
Outer regional	113,280	21.9	5.8	1,854,024	9.2	94.2
Remote	47,852	9.3	15.2	267,199	1.3	84.8
Very remote	79,464	15.4	48.0	86,017	0.4	52.0
Total	517,043	100.0	2.5	20,178,458	100.0	97.5

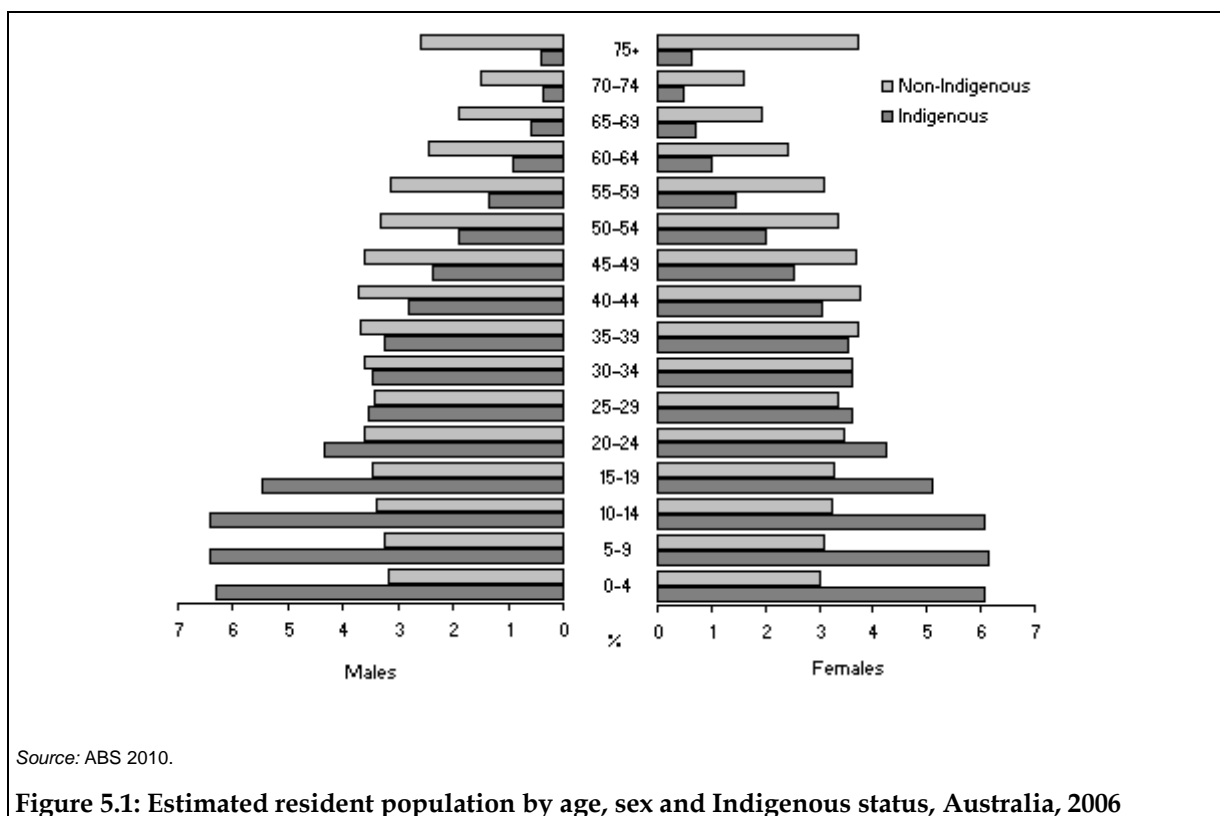
Source: ABS 2009.

As a result of the difference in population distribution, the proportion of the population that is Aboriginal and Torres Strait Islander increased with geographic remoteness – from 1% of the total population living in *Major cities* to 48% of the population living in *Very remote* areas of Australia.

In addition, proportionally the Aboriginal and Torres Strait Islander population is much younger than the non-Indigenous population (Figure 5.1) since:

- children aged under 15 years comprised 38% of the total Aboriginal and Torres Strait Islander population (compared with 19% in the non-Indigenous population)
- people aged 15–24 years comprised 19% of the Aboriginal and Torres Strait Islander population (compared with 14%)
- only 3% of the Aboriginal and Torres Strait Islander population were aged 65 years and over (compared with 13%).

These different age profiles reflect the higher rates of fertility among Aboriginal and Torres Strait Islander people, and because they typically die at younger ages than non-Indigenous Australians (ABS 2009).



Reporting on CKD and ESKD by Indigenous status and remoteness

There are a number of different data sources used to monitor CKD and ESKD that include information on Indigenous status. However, the accuracy of identification may vary by data collection and region, and the method of collecting these data may also vary. This report uses three main sources of data which include variables by Indigenous status and remoteness.

National hospital data

A recent study by the AIHW assessed the quality of Indigenous identification in national hospital data. An estimated 88% of Aboriginal and Torres Strait Islander patients were correctly identified in Australian public hospital admission records from April 2011 to June 2012 (AIHW 2013). The study recommends reporting aggregate national hospital data by Indigenous status for all states and territories for 2010–11 onwards. This differs from earlier advice (AIHW 2010) which recommended only using aggregate national hospital data from New South Wales, Victoria, Queensland, Western Australia, South Australia, and only public hospitals in the Northern Territory.

The same study (AIHW 2013) also showed that Indigenous identification improved with increasing remoteness, ranging from 77% in *Major cities* to 99% in *Very remote* areas. While this study is helpful for providing guidelines on what is acceptable when assessing hospital data nationally, there has been no specific audit of Indigenous identification by remoteness areas for people presenting at hospitals with CKD.

It is unknown whether Aboriginal and Torres Strait Islander clients presenting with CKD are more or less likely to have their Indigenous status correctly recorded than those presenting with other conditions (AIHW 2010). Hence the following data should be interpreted with caution.

Comparisons are made throughout the hospitalisations section of this chapter with 'other Australians', which includes hospitalisations where Indigenous status was not stated or inadequately described as well as those identifying as non-Indigenous.

In 2010–11, Aboriginal and Torres Strait Islander people were hospitalised with a principal diagnosis of CKD (excluding regular dialysis) at a higher rate than other Australians in all geographical locations (Table 5.2). The greatest difference in hospitalisation rates between Aboriginal and Torres Strait Islander people and other Australians was in *Remote and very remote* locations, where Aboriginal and Torres Strait Islander people were hospitalised at 8.1 times the rate of other Australians.

Table 5.2: Hospitalisations with a principal diagnosis of CKD (excluding regular dialysis) by Indigenous status, 2010–11

Geographical location	Indigenous			Other Australians			Rate ratio ^(c)
	Number	Rate ^(a)	Proportion ^(b)	Number	Rate ^(a)	Proportion ^(b)	
Major cities	373	332.4	1.7	21,672	151.4	98.3	2.2
Inner regional	422	701.9	5.8	6,850	156.0	94.2	4.5
Outer regional	517	738.5	16.2	2,666	133.5	83.8	5.5
Remote and very remote	920	1,062.2	66.6	462	131.8	33.4	8.1

(a) Hospitalisations per 100,000 population directly age-standardised to the 2001 Australian population.

(b) Proportion of hospitalisations for a principal diagnosis of CKD (excluding regular dialysis) in geographical location.

(c) Indigenous: Other Australian rate ratio.

Source: AIHW NHMD.

During the same period, Aboriginal and Torres Strait Islander people were more likely to be hospitalised with an additional diagnosis of CKD (excluding regular dialysis) across all remoteness categories (Table 5.3). Again, the greatest difference in hospitalisation rates was in *Remote and very remote* areas where Aboriginal and Torres Strait Islander people were hospitalised at 12.8 times the rate of other Australians.

Table 5.3: Hospitalisations with an additional diagnosis of CKD (excluding regular dialysis) by Indigenous status, 2010–11

Geographical location	Indigenous			Other Australians			Rate ratio ^(c)
	Number	Rate ^(a)	Proportion ^(b)	Number	Rate ^(a)	Proportion ^(b)	
Major cities	1,416	1,873.3	1.5	93,633	651.5	98.5	2.9
Inner regional	944	2,074.4	3.4	26,518	552.2	96.6	3.8
Outer regional	1,982	3,365.5	16.2	10,278	487.0	83.8	6.9
Remote and very remote	3,963	5,588.5	73.9	1,402	436.0	26.1	12.8

(a) Hospitalisations per 100,000 population directly age-standardised to the 2001 Australian population.

(b) Proportion of hospitalisations an additional diagnosis of CKD (excluding regular dialysis) in geographical location.

(c) Indigenous: Other Australian rate ratio.

Source: AIHW NHMD.

In 2010–11, Aboriginal and Torres Strait Islander people had higher rates of hospitalisations for dialysis treatment across all remoteness categories (Table 5.4), largely reflecting the higher prevalence of treated-ESKD among Aboriginal and Torres Strait Islander people (ANZDATA 2012).

The highest rate of dialysis hospitalisations for Aboriginal and Torres Strait Islander people was in *Outer regional* areas (closely followed by *Remote and very remote* areas), while the highest rate for other Australians was in *Major cities*.

Table 5.4: Hospitalisations for regular dialysis by Indigenous status, 2010–11

Geographical location	Indigenous			Other Australians			Rate ratio ^(c)
	Number	Rate ^(a)	Proportion ^(b)	Number	Rate ^(a)	Proportion ^(b)	
Major cities	33,166	42,802.5	4.1	775,160	5,361.2	95.9	8.0
Inner regional	15,724	28,253.3	7.7	187,339	3,942.3	92.3	7.2
Outer regional	44,430	76,598.5	39.7	67,364	3,182.5	60.3	24.1
Remote and very remote	50,389	75,313.9	91.7	4,555	1,281.5	8.3	58.8

(a) Hospitalisations per 100,000 population directly age-standardised to the 2001 Australian population.

(b) Proportion of hospitalisations for regular dialysis in geographical location.

(c) Indigenous: Other Australian rate ratio.

Source: AIHW NHMD.

National mortality data

It is known that there is under-identification of Aboriginal and Torres Strait Islander people in mortality data and that Indigenous identification varies with geographical location (ABS 2012a).

An ABS study in 2006, which linked Indigenous death records to census data, found that coverage of Indigenous deaths in death registration data is about 85% nationally, ranging from 76% in New South Wales to 99% in the Northern Territory. However, the estimates in this study were subject to limitations, including that 26% of Indigenous deaths did not link to census data (ABS 2008a, 2008b). The study did not estimate coverage rates by remoteness.

Recently, the AIHW undertook a linkage project of several national data sets (NHMD, aged care, perinatal, and mortality data) to assess identification (AIHW 2012c). An ‘ever-Indigenous’ approach was used in determining Indigenous status from the various data sets. The approach classifies the individual as Indigenous if indicated by any of the data sets. The death registration data set (2001–2006) used for this project contained 10,547 deaths listed as Indigenous. The linkage of the additional data sets to the death registration data identified 1,081, or 10%, more deaths than the 10,547 originally recorded on the death registration data as ‘Indigenous’.

Similarly, the AIHW has linked ANZDATA Registry incidence data to national mortality data and taken a similar approach for records linked between 2004 and 2007. These combined data are also used to estimate the total incidence of ESKD (see Chapter 2 Total incidence section). The analysis was limited to jurisdictions where Indigenous identification in mortality data is considered of sufficient quality for national reporting – New South Wales (NSW), Queensland (Qld), South Australia (SA), Western Australia (WA) and Northern Territory (NT) (ABS 2012b).

Between 2004 and 2007, 425 cases were recorded as Indigenous in both ANZDATA incidence data and mortality data. A further 5.7% Indigenous cases (26 cases) were identified in the ANZDATA Registry that were not identified as Indigenous in mortality data. A similar proportion of linked cases (6.2%, 28 cases) were identified as Indigenous in mortality data but not the ANZDATA Registry (Table 5.5). When this is assessed by remoteness based on geographic variables from the mortality data, both data sources potentially misclassify a substantial proportion of Indigenous cases from *Major cities* in particular.

Table 5.5: Potential misclassification (%) of Indigenous status in ANZDATA incidence data and mortality data, 2004–2007

Geographical location	Potential misclassification mortality data (%) ^(a)	Potential misclassification in ANZDATA (%) ^(b)
Major cities	9.5	26.8
Inner regional	7.9	6.6
Outer regional	8.0	4.6
Remote	5.0	0.4
Very remote	0.2	0.9
Total	5.7	6.2

(a) Potential misclassification in mortality data = number of linked cases recorded as Indigenous in ANZDATA incidence data only/ the number of linked cases recorded as Indigenous in both mortality data and ANZDATA incidence data and in mortality data only.

(b) Potential misclassification in ANZDATA incidence data = number of linked cases recorded as Indigenous in mortality data only/ the number of linked cases recorded as Indigenous in both mortality data and ANZDATA incidence data and in ANZDATA only.

Note: Analysis limited to NSW, QLD, WA, SA, and NT.

Source: Combined data from the ANZDATA Registry, AIHW National Mortality Database and the National Death Index.

ANZDATA Registry

The annual ANZDATA report, peer-reviewed articles and past AIHW publications have reported ANZDATA Registry data by Indigenous status and remoteness. As Indigenous identification in the ANZDATA Registry is based on self-identification in hospital data, it is generally considered comparable to hospital data in the level of identification.

It has also been argued that because patients registered in the ANZDATA Registry have regular contact with services until death, and a new form is filled out annually, identification in the registry may be better than general hospital records (Cass et al. 2001). However, as noted above, a greater level of under-identification in *Major cities* has been found compared to other regions in the subset of data presented in Table 5.5. The extent to which this applies to other cases on the ANZDATA Registry is unknown.

In 2008–2010, the rate of new cases of treated-ESKD increased with remoteness for Aboriginal and Torres Strait Islander people while the opposite was true for non-Indigenous Australians (Table 5.6). This trend for non-Indigenous Australians is in line with results from other recent studies (Gray et al. 2011). Some of this difference may be due to the better identification of Aboriginal and Torres Strait Islander people in *Remote* and *Very remote* areas.

Table 5.6: New cases of treated-ESKD by geographical location of first treatment and Indigenous status, 2008–2010

Geographical location	Indigenous			Non-Indigenous		
	Number	Rate ^(a)	Proportion ^(b)	Number	Rate ^(a)	Proportion ^(b)
Major cities	111	44.7	2.4	4,577	10.6	97.6
Inner regional	56	31.5	4.1	1,323	9.4	95.9
Outer regional	157	83.1	21.4	578	9.1	78.6
Remote and very remote	320	139.5	80.2	79	7.5	19.8

(a) Treated-ESKD patients per 100,000 population, directly age-standardised to the 2001 Australian population.

(b) Proportion of new cases of treated-ESKD in geographical location.

Note: Male and female counts may not add up to total numbers (persons) due to rounding associated with allocating postcodes of residence to ASGC categories.

Source: AIHW analysis of ANZDATA Registry data.

Appendix A: Supplementary tables

Box A1: Stages of chronic kidney disease

Stage 1: Kidney damage with normal kidney function (eGFR \geq 90 mL/min/1.73 m²)

Usually no symptoms but high blood pressure is more frequent than for patients without CKD.

Stage 2: Kidney damage with mild loss in kidney function (eGFR 60–89 mL/min/1.73 m²)

Most patients have no symptoms but high blood pressure is frequent.

Stage 3a and b: Mild–moderate loss of kidney function (eGFR 45–59 mL/min/1.73 m²) (3a), or moderate–severe loss of kidney function (eGFR 30–44 mL/min/1.73 m²) (3b)

Possibly no symptoms, or may experience an increased need to urinate during the night (nocturia), a mild feeling of being ill and loss of appetite. Common complications include high blood pressure, mineral and bone disorders, anaemia, sleep apnoea, restless legs, cardiovascular disease, malnutrition and depression.

Stage 4: Severe loss of kidney function (eGFR 15–29 mL/min/1.73 m²)

Symptoms are as for Stage 3, plus nausea, itching skin, restless legs and shortness of breath. Common complications of this stage are also as for Stage 3, along with electrolyte disturbances such as raised blood levels of phosphate and potassium and increased acidity of the blood.

Stage 5: End-stage kidney disease (eGFR $<$ 15 mL/min/1.73 m² or on dialysis)

Symptoms are as for Stage 4. Additional common complications include inflammation of the tissue layers surrounding the heart, bleeding in the gastrointestinal tract, altered brain function and structure, and disturbances or structural or functional changes in the peripheral nervous system.

Source: Adapted from Kidney Health Australia (2007, 2012).

Table A1: Hospitalisations with a principal diagnosis of CKD (excluding regular dialysis), 2010–11

Geographical location	Male		Female		Persons	
	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)
Major cities	10,534	142	11,511	145	22,045	142
Inner regional	3,505	145	3,767	157	7,272	149
Outer regional	1,487	133	1,696	158	3,183	144
Remote and very remote	550	210	832	365	1,382	606

(a) Hospitalisations per 100,000 population directly age-standardised to the 2001 Australian population.

Note: Numbers exclude hospitalisations where geographic location of residence could not be assigned due to missing data, non-Australian residency etc.

Source: AIHW NHMD.

Table A2: Hospitalisations with an additional diagnosis of CKD (excluding regular dialysis), 2010–11

Geographical location	Male		Female		Persons	
	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)
Major cities	53,655	752	41,394	458	95,049	585
Inner regional	15,695	631	11,767	413	27,462	512
Outer regional	7,073	629	5,187	440	12,260	528
Remote and very remote	2,572	1,064	2,793	1,285	5,365	1,160

(a) Hospitalisations per 100,000 population directly age-standardised to the 2001 Australian population.

Note: Numbers exclude hospitalisations where geographic location of residence could not be assigned due to missing data, non-Australian residency etc.

Source: AIHW NHMD.

Table A3: Deaths per 100,000 population where CKD was the underlying cause, 2010

Geographical location	Male		Female		Persons	
	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)
Major cities	867	12.5	1,056	9.6	1,923	10.8
Inner regional	299	12.6	373	10.7	672	11.6
Outer regional	123	12.1	166	12.2	289	12.2
Remote and very remote	42	19.0	57	29.0	99	23.9

(a) Deaths per 100,000 population directly age-standardised to the 2001 Australian population.

Notes

1. Directly age-standardised to the Australian population as at 30 June 2001.
2. Deaths for 2010 are based on a preliminary version of cause of death data, and are subject to further revision.
3. These data have not been adjusted for the additional deaths arising from outstanding registrations of deaths in Queensland in 2010. For more detail please refer to Technical note 3 in *Causes of death, Australia, 2010* (ABS 2012b).

Source: AIHW NMD.

Table A4: Deaths per 100,000 population where CKD was an associated cause, 2010

Geographical location	Male		Female		Persons	
	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)
Major cities	4,026	58.0	3,366	31.5	7,392	42.3
Inner regional	1,342	55.4	1,135	33.7	2,478	43.2
Outer regional	613	58.2	525	39.1	1,138	47.7
Remote and very remote	155	79.2	132	67.1	287	72.4

(a) Deaths per 100,000 population directly age-standardised to the 2001 Australian population.

Notes

1. Directly age-standardised to the Australian population as at 30 June 2001.
2. Deaths for 2010 are based on a preliminary version of cause of death data, and are subject to further revision.
3. These data have not been adjusted for the additional deaths arising from outstanding registrations of deaths in Queensland in 2010. For more detail please refer to Technical note 3 in *Causes of death, Australia, 2010* (ABS 2012b).
4. Male and female counts may not add up to total numbers (persons) due to rounding associated with allocating deaths to ASGC categories.

Source: AIHW NMD.

Table A5: Total incidence of ESKD, by sex and geographical location, 2005–2007

	Major cities	Inner regional	Outer regional	Remote	Very remote
Number of cases					
Males	4,847	1,507	759	144	129
Females	3,978	1,299	690	147	169
Total	8,825	2,806	1,449	290	299
Age-standardised rate (per 100,000 population)^(a)					
Males	25.3	23.5	26.1	36.6	65.5
Females	15.6	15.9	20.6	36.2	99.5
Total	19.9	19.4	23.2	35.7	81.1

(a) Directly age-standardised to the Australian population as at 30 June 2001.

Note: Male and female counts may not add up to total numbers (persons) due to rounding associated with allocating cases to ASGC categories.

Source: Linked ANZDATA Registry, AIHW National Mortality Database and National Death Index.

Table A6: Hospitalisations for regular dialysis by geographical location of residence, 2010–11

Geographical location	Male		Female		Persons	
	Number	Rate ^(a)	Number	Rate ^(a)	Number	Rate ^(a)
Major cities	495,244	6,821	313,082	3,790	808,326	5,164
Inner regional	122,581	4,960	80,482	3,045	203,063	3,937
Outer regional	61,676	5,304	50,118	4,384	111,794	4,823
Remote and very remote	23,828	8,975	31,116	13,851	54,944	11,144

(a) Hospitalisations per 100,000 population directly age-standardised to the 2001 Australian population.

Note: Numbers exclude hospitalisations where geographic location of residence could not be assigned due to missing data, non-Australian residency etc.

Source: AIHW NHMD.

Table A7: ANZDATA Registry incident cases: Remoteness category of residence at first treatment and at end of incident year (number), 2005–2010

		Remoteness of residence at year end				
		Major cities	Inner regional	Outer regional	Remote	Very remote
Remoteness of residence at first treatment	Major cities	9,138	99	33	10	0
	Inner regional	88	2,326	26	5	0
	Outer regional	57	53	1,128	7	8
	Remote	25	9	25	236	7
	Very remote	22	4	81	104	157

Notes

1. Bolded numbers indicate no change in remoteness of residence.
2. Postcodes were allocated to a remoteness category if more than 80% of that postcode fell in a region according to 2006 ASGC concordance. 1,118 cases were excluded due to their postcode at entry or end survey not being allocated to a remoteness category. Time to movement could range from 1 day to 364 days depending on when in the survey year a patient commenced treatment.

Source: AIHW analysis of ANZDATA Registry data.

Appendix B: Methods

Age-specific rates

Age-specific rates are calculated by dividing the number of cases occurring in each specified age group by the corresponding population in the same age group, expressed as a rate (for example, number per 100,000 persons). Information on the populations used in this report is provided in the section on populations below.

Age-standardised rates

Age-standardisation is a technique used to eliminate the effect of differences in population age structures when comparing rates for different periods of time, geographical areas, and/or population groups. Definitions are included in the *National health data dictionary* (Health Data Standards AIHW: Health Data Standards Committee 2006).

There are two methods of age-standardisation, direct and indirect. The method used in this report is direct age-standardisation.

Direct age-standardisation

Direct age-standardisation applies the age-specific rates to a standard population in order to determine the rate that would have occurred in the standard population. This allows direct comparison of different rates applied to the same standard population. When selecting the standard population to use in age-standardisation, it is necessary to consider the population at risk. For the vast majority of rates which are age-standardised, such as the hospitalisation rates presented in this report, the total population is at risk. For these types of rates, the Australian population as at 30 June 2001 has been used as the standard.

The method used for the calculation of age-standardised rates consists of three steps:

- Step 1: Calculate the age-specific rate for each age group.
- Step 2: Calculate the expected number of cases in each age group by multiplying the age-specific rate by the corresponding standard population to get the expected number of cases.
- Step 3: Find the sum of the expected number of cases in each age group, divide by the total of the standard population and multiply by 100,000. This gives the age-standardised rate.

In general, the age-standardised rates presented in this report have been calculated using 5-year age groups to over 75. Rates calculated using small numbers (less than five events in the numerator) can be unstable, show considerable fluctuation from year to year, and exhibit wide confidence intervals. In some cases, it has been necessary to combine younger age groups (0–29) to prevent this from occurring.

Populations used in this report

Population data are used throughout this report to calculate rates. The population data used are estimated resident populations (ERPs) derived from the ABS Census of Population and Housing. ERPs adjust census data to add people that the census missed and people overseas on census night, and to remove overseas visitors. In between census years, the ERPs are updated using indicators of population change such as deaths, births and net migration. The ERPs used in this report are based on the 2006 Census.

Where a rate is calculated for a calendar year (for example, with the ANZDATA Registry incidence data), the population used is the ERP as reported at 30 June of that year. Where a rate is calculated for a financial year, as with hospitalisation data, the population used is as at 31 December. For example, to calculate the hospitalisation rate of the 2008–09 financial year, the ERP at 31 December 2008 would be used.

Throughout this report, rates are age-standardised. In these cases, the standard population used to calculate the age-standardised rate is the Australian ERP as at 30 June 2001.

Geographical structures used in report

The data were analysed in this report using the ASGC. The ASGC is a hierarchical classification system of geographical areas and consists of a number of interrelated structures. It provides a common framework of statistical geography and enables the production of statistics which are comparable.

The main structure used to analyse data in this report are Statistical Local Areas (SLAs). The SLA is a general purpose spatial unit. In aggregate, SLAs cover Australia without gaps or overlaps. In non-census years, the SLA is the smallest unit defined in the ASGC. In census years, a SLA consists of one or more whole collection districts, which are made up of mesh blocks (the smallest level of geography in census years).

Reporting data by remoteness

Comparisons of region in this report use the six ASGC remoteness areas, based on their distance from major population centres and services. The six remoteness areas are:

- *Major cities*
- *Inner regional*
- *Outer regional*
- *Remote*
- *Very remote*
- *Migratory.*

Data from *Migratory* areas are not analysed in this report. The boundaries of the different remoteness areas are re-drawn after each census to account for changes to available services and population change. The remoteness areas used in this report are based on the 2006 Census.

Allocating cases to ASGC categories

For remoteness allocations, different geographic variables are used to allocate persons to remoteness categories. For those records sourced from the ANZDATA Registry data, postcode at entry (incidence) and current postcode (prevalence) are used as a proxy for

postal area to agree with 2006 SLAs and then to remoteness categories. For records based on NMD and NHMD data, SLA of usual residence is used to concord to 2006 SLAs (where necessary) and then to remoteness categories. Refer to the NMD and NHMD data quality statements for more information on geographical variables in these data sources (see links below).

AIHW National Mortality Database

The AIHW NMD contains *cause of death* information for all deaths that occurred in Australia and were registered in Australia from 1965 onwards. The data are provided by the Registries of Births, Deaths and Marriages and the National Coroners Information System and the ABS codes these data. The data are maintained at the AIHW in the NMD.

In this report, deaths for 2010 are based on preliminary data and are subject to further revision. Data are assembled based on the year of registration of death. While for the most part, year of death and registration coincide, there is some lag in death registrations such that approximately 5% of deaths are not registered until the next or a later year than when the death occurred.

Cause of death information in the NMD for the years included in this report is classified according to the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10). ICD-10 codes used to identify deaths for CKD are summarised in Table A8.

The data in this report were extracted from the AIHW NMD in July 2012 and small changes may have occurred since this time.

The data quality statements underpinning the AIHW National Mortality Database can be found in the following ABS publications:

ABS Quality declaration summary for *Causes of death, Australia, 2010* (ABS 2012b, ABS cat. no. 3303.0)

<<http://www.abs.gov.au/Ausstats/abs@.nsf/0/D4A300EE1E04AA43CA2576E800156A24?OpenDocument>> and

ABS Quality declaration summary for *Deaths, Australia, 2011* (ABS 2012a, ABS cat. no. 3302.0)

<<http://www.abs.gov.au/Ausstats/abs@.nsf/0/9FD0E6AAA0BB3388CA25750B000E3CF5?OpenDocument>>.

Table A8: ICD-10^(a) codes used to define diagnosis groups for CKD

Group of chronic kidney disease	ICD-10 codes
Regular dialysis	
Haemodialysis	Z49.1*
Peritoneal dialysis	Z49.2*
Other	
Diabetic nephropathy	E10.2, E11.2, E12.2, E13.2, E14.2
Hypertensive kidney disease	I12, I13, I15.0, I15.1
Glomerular diseases	N00–N07, N08*
Kidney tubulo-interstitial diseases	N11, N12, N14, N15, N16*
Chronic kidney disease	N18
Unspecified kidney failure	N19
Other disorders of kidney and ureter	N25–N28, N39, E85.1 [^] , D59.3 [^] , B52.0 [^]
Congenital malformations	Q60–Q63
Complications related to dialysis and kidney transplant	T82.4, T86.1
Preparatory care for dialysis	Z49.0*
Kidney transplant and dialysis status	Z94.0*, Z99.2*

(a) ICD-10 codes are used to code mortality data. ICD-10-AM codes are used to code hospital morbidity data.

[^] These codes were used for identification in mortality data only.

* These codes were used for identification in hospital morbidity data only.

AIHW National Hospital Morbidity Database

The NHMD contains demographic, diagnostic, procedural and duration of stay information on episodes of care for patients admitted to hospital. The database records information on patients who undergo a formal hospital admission process, complete an episode of admitted patient care, and 'separate' (discharge) from the hospital (AIHW 2012b). A record is included for each separation (hospitalisation), not for each patient, so patients who were hospitalised more than once in a given year have more than one record in the NHMD.

State and territory health authorities supply data for this annual collection which the AIHW compiles and maintains. The database is episode-based and it is not possible to count patients individually.

Diagnoses and procedures in the NHMD for 2010–11 included in this report are classified according to the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM), 7th edition. ICD-10-AM codes used to define diagnosis groups for CKD are summarised in Table A6.

The data quality statement for the AIHW NHMD can be found at on the AIHW's MetadataOnline Registry (METeOR) – National Hospital Morbidity Database Data Quality Statement: 2010–11 <<http://meteor.aihw.gov.au/content/index.phtml/itemId/511338>>.

Hospitalisations for regular dialysis

A regular dialysis hospitalisation is defined in this publication as a hospitalisation with a principal diagnosis of ICD-10-AM code Z49.1 (haemodialysis) or Z49.2 (peritoneal dialysis).

For a hospitalisation to record a principal diagnosis of ICD-10-AM codes Z49.1 or Z49.2, the intent for admission must be same day and the patient discharged on the same or next day of admission. In cases where the intent of a regular dialysis admission was same day, but it was extended due to some other condition or complication of treatment, the condition responsible for extending the patient's length of stay is coded as the principal diagnosis, and regular dialysis (Z49.1 or Z49.2) is coded as an additional diagnosis. Where a kidney dialysis episode of care was multi-day and the intent for admission was not same day, the condition necessitating the admission was coded as the principal diagnosis. In these circumstances, kidney dialysis was indicated by the procedure code (NCCH 2010).

Although 23,000 occasions of non-admitted patient occasions of dialysis service were provided in public acute hospitals during 2010–11, these are not recorded in the NHMD (AIHW 2012b).

Indigenous identification in national hospital data

In a recent study by the AIHW which assessed quality of Indigenous identification in national hospital data, an estimated 88% of Aboriginal and Torres Strait Islander patients were correctly identified in Australian public hospital admission records from April 2011 to June 2012 (AIHW 2013). The study recommends reporting aggregate national hospital data by Indigenous status for all States and Territories for 2010–11 onwards. This report follows that recommendation.

The data in this report were extracted from the AIHW NHMD in July 2012 and small changes may have occurred since this time.

Australia and New Zealand Dialysis and Transplant Registry

In Australia and New Zealand, all people receiving KRT where the intention to treat is long term – that is, kidney function is not expected to recover – are registered with the ANZDATA Registry. The registry compiles data on incidence and prevalence of treated-ESKD, complications, comorbidities and patient deaths. All relevant hospitals and related dialysis units participate. While patients may opt out of having part or all of their data recorded, this rarely happens.

The interpretation and reporting of ANZDATA Registry information in this report has been undertaken by the AIHW, and does not represent ANZDATA Registry policy or interpretation.

Information about the data quality of ANZDATA can be found in the *The 34th Annual ANZDATA Report 2011* (ANZDATA 2012) <http://www.anzdata.org.au/v1/report_2012.html>.

Australian Diabetes, Obesity and Lifestyle Study

The AusDiab study, conducted by the International Diabetes Institute in 1999–2000, was designed to provide national estimates of the prevalence of diagnosed and undiagnosed diabetes.

It also provided national measurements of eGFR, albuminuria, proteinuria, haematuria, blood pressure, blood lipids, blood glucose, body fat, height and weight, and waist and hip circumference, as well as self-reported information on cardiovascular disease, anti-hypertensive and lipid lowering medication use, diet, smoking, alcohol consumption, physical activity, and general health and wellbeing.

The study collected information in urban and non-urban areas in all states and the Northern Territory from more than 11,000 people aged 25 years and over who underwent a physical examination. This represents a response rate of 37% (Dunstan et al. 2002). Through linkage to the National Death Index, associations between indicators of CKD and mortality were also obtained.

The target population of non-institutionalised adults aged 25 years and over residing in private dwellings in each of the six states and the Northern Territory were included in the survey if they had resided at the address for a minimum of 6 months prior to the survey. Visitors to private dwellings were not included (Dunstan et al. 2002).

A stratified cluster sampling method was used, involving seven strata (six states and the Northern Territory) and clusters based on census Collector Districts (CDs—the smallest geographic unit defined by the Australian Bureau of Statistics at each census, with an average of 225 dwellings each). Within each state, six CDs were randomly selected with a selection probability proportional to the population size (population aged over 25 years). Due to the logistic and economic constraints of the survey, and to avoid the bias of including an unrepresentative number of high prevalence groups, the following exclusion criteria were adopted:

- CDs containing fewer than 100 persons aged 25 years and over
- CDs that formed part of a SLA that was classified as 100% rural according to 1996 Census data
- CDs that contained more than 10% Indigenous population (Dunstan et al. 2002).

Information about the data quality of the AusDiab study can be found in *The Australian Diabetes, Obesity and Lifestyle Study (AusDiab) – methods and response rates* (Dunstan et al. 2002).

The Household, Income and Labour Dynamics in Australia Survey

This paper uses unit record data from the HILDA Survey. The HILDA project was initiated and funded by the Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) and is managed by the Melbourne Institute of Applied Economic and Social Research (Melbourne Institute). The findings and views reported in this paper, however, are those of the author and should not be attributed to either FaHCSIA or the Melbourne Institute.

The HILDA Survey is a household-based panel study which began in 2001 and has the following key features:

- It collects information about economic and subjective wellbeing, labour market dynamics and family dynamics.
- Special questionnaire modules are included each wave.
- The Wave 1 panel consisted of 7,682 households and 19,914 individuals. In Wave 11, this was topped up with an additional 2,153 households and 5,477 individuals.
- Interviews are conducted annually with all adult members of each household.
- The panel members are followed over time.

Information about the data quality of HILDA Survey data can be found in *HILDA User Manual – Release 11* (Summerfield et al. 2012)

<http://www.melbourneinstitute.com/downloads/hilda/User%20Manual/HILDA%20User%20Manual%20Release_11.0.pdf>.

Glossary

Albuminuria	The presence of albumin (a type of protein) in the urine. Two positive tests for albumin in the urine over several weeks indicate persistent albuminuria, a first sign of diabetic kidney disease.
Associated cause of death	Causes, other than the underlying cause, that were instrumental in causing death. They encompass conditions that intervened or significantly contributed to death.
Chronic kidney disease (CKD)	Refers to all kidney conditions where a person has evidence of kidney damage and/or reduced kidney function, lasting at least 3 months, regardless of the specific diagnosis of disease or condition causing the disease.
Dialysis	An artificial method of removing waste substances from the blood and regulating levels of circulating chemicals – functions usually performed by the kidneys.
End-stage kidney disease (ESKD)	The most severe form of chronic kidney disease, also known as Stage 5 chronic kidney disease (CKD) or kidney failure.
Estimated glomerular filtration rate (eGFR)	A measure of kidney function which shows how well the kidneys are cleaning the blood. GFR is usually estimated (eGFR) from the results of the creatinine blood test.
Haemodialysis	A form of dialysis where a machine is connected to a person's bloodstream to filter the blood externally.
Incidence	The number of new cases (of an illness, disease or event) occurring during a given period.
Kidney replacement therapy (KRT)	Includes having a functional kidney transplant or receiving regular dialysis.
Nephron	The functional and structural units of the kidney responsible for the purification and filtration of the blood.

Peritoneal dialysis	A form of dialysis where a solution is pumped into the abdominal cavity where the body's own peritoneum membrane acts as a dialysis filter to remove waste products and water.
Prevalence	The number or proportion (of cases, instances) present in a population at a given time.
Proteinuria	The presence of excess proteins (commonly albumin) in the urine likely to reflect a decline in kidney function.
Satellite dialysis	Dialysis performed in centres that are usually located away from their parent hospital so as to decrease the travel burden sometimes associated with accessing certain dialysis services.
Underlying cause of death	The disease or injury that initiated the train of events leading directly to death, or the circumstances of accident or violence that produced the fatal injury.

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Chronic kidney disease is a common and serious problem in Australia and its management can be resource intensive, particularly for the most severe form of the disease: end-stage kidney disease.

Rates of chronic kidney disease vary by geographic location. This report shows:

- people from Remote and very remote areas were 2.2 times more likely to die from chronic kidney disease than people from Major cities.
- people from Very remote areas were at least 4 times more likely to start kidney replacement therapy (dialysis or kidney transplant) than people from non-remote areas.