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End-stage kidney disease in Australia

Total incidence, 2003–2007

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Contents

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Abbreviations

ANZDATA	Australia and New Zealand Dialysis and Transplant Registry
CARI	Caring for Australians with Renal Impairment
CI	confidence interval
CKD	chronic kidney disease
COAG	Council of Australian Governments
ESKD	end-stage kidney disease
eGFR	estimated glomerular filtration rate
GFR	glomerular filtration rate
ICD-10	International Classification of Diseases, 10th Revision
KRT	kidney replacement therapy
mL	millilitre
m^2	square metre

Summary

End-stage kidney disease (ESKD) is the most severe form of chronic kidney disease (CKD), where kidney function deteriorates so much that dialysis or kidney transplantation is required to survive. This project estimates the total number of new (incident) cases of ESKD in Australia, including cases treated with dialysis or transplant and those not receiving these treatments.

The incidence of ESKD is a key indicator of the health of the Australian population, but in the past we have been limited to counting only those treated with dialysis or transplant. This report presents a new method for estimating the total incidence of ESKD.

New method for estimating the total incidence of ESKD

The number of non-KRT-treated cases is estimated using a defined set of cause of death codes in the national mortality data, with the aim of counting people who died with ESKD in the study period. This number can then be added to the already available number of dialysis and transplant cases recorded on a national register. Data linkage is used to ensure that people treated with dialysis or transplant who die during the study period are only counted once.

Key results

During the period 2003–2007, there were nearly 21,500 new cases of ESKD in Australia, amounting to about 21 cases per 100,000 people. For every new case who receives dialysis or transplant, there is about one new case that does not.

Men have higher total incidence rates than women, and Aboriginal and Torres Strait Islander people have much higher rates compared with the rest of the population. There is little variation across states and territories, the exception being the Northern Territory, which has much higher rates than the rest of the country, reflecting the higher proportion of Aboriginal and Torres Strait Islander people who live there.

Incidence rates increase with age, with a sharp increase from 70 years. The number of new cases was highest in those aged about 80 years for the whole population, but occurred much younger in Aboriginal and Torres Strait Islander people, at 50 years of age.

The proportion of all cases receiving dialysis or transplant varies greatly with age. For those aged under 65 years, close to, or more than, 90% of new cases receive these treatments. But treatment rates fall substantially in the older age groups, with only about one-tenth of those aged 80 years or over receiving dialysis or transplant. There is little variation in treatment rates by sex or Indigenous status.

1 Introduction

End-stage kidney disease (ESKD) is the most severe form of chronic kidney disease (CKD), where kidney function deteriorates so much that kidney replacement therapy (KRT) in the form of dialysis or kidney transplantation is required for the patient to survive (Kidney Health Australia 2007). At the end of 2009, there were 18,243 Australians receiving KRT for ESKD. Of these, 7,902 had a functioning kidney transplant and 10,341 were receiving dialysis treatment (McDonald et al. 2010). In general, the number of people starting KRT each year has been increasing, even after adjusting for population increases and age.

CKD refers to all conditions of the kidney, lasting at least 3 months, where a person has evidence of kidney damage and/or reduced kidney function regardless of the specific diagnosis of disease or condition causing the disease. CKD is common—one in seven Australian adults over the age of 25 years had some degree of CKD in 1999–2000 (Chadban et al. 2003). Many people do not know they have kidney disease because up to 90% of kidney function can be lost before symptoms appear. Fortunately, simple urine and blood tests can identify most cases of CKD when the disease is in its early stages, enabling treatment to prevent or slow down the progression.

CKD imposes a substantial burden in Australia, contributing to more than 13,000 deaths in 2007 and more than 1 million hospitalisations in 2007–08, almost 13% of all hospitalisations that year (AIHW 2010).

Chronic kidney disease is categorised into five stages according to the level of reduced kidney function and evidence of kidney damage (Box 1). Stages of CKD are measured by the glomerular filtration rate (GFR), which is the amount of blood the kidneys clear of waste products in 1 minute. Because GFR cannot easily be measured directly, current practice is to estimate GFR by applying a formula based on age, gender and creatinine in the blood. An individual can move up and down through the first four stages of severity, but once they reach stage 5, their kidney function does not usually improve.

The Caring for Australians with Renal Impairment guidelines (CARI 2005) recommend patients be referred to a nephrology service when their estimated GFR is below 30 mL/minute per 1.73 m^2 (stage 3), to provide enough time to prepare for KRT or supportive management and palliative care (Luxton 2010).

Transplantation is considered the preferred option for KRT by patients and health-care professionals (Mathew et al. 2005). Donated kidneys come from either a live donor—usually a relative, spouse or even a close friend—or from deceased donors (Kidney Health Australia 2007). Kidney transplantation is not a cure for ESKD; recipients live with the possibility of chronic rejection and the loss of the donor kidney. The rate of organ donation in Australia is low compared with other developed countries, so the vast majority of ESKD patients will have dialysis as their first form of treatment. In 2007, less than 3% of patients who began KRT had a transplant as their first form of treatment (McDonald et al. 2009). The more time spent on dialysis before transplantation increases mortality risk and decreases donor kidney survival rates (CARI 2007).

Deciding when to initiate KRT is not based purely on estimated GFR. Clinicians traditionally use several indicators to decide when to initiate treatment, such as the presence of uraemia (a severe build-up of wastes in the blood) and other biochemical measurements. If there is no evidence of uraemia or its complications, CARI guidelines recommend starting dialysis when GFR falls below about 6 mL/minute per 1.73 m^2 (CARI 2005).

Box 1: Stages of chronic kidney disease

Stage 1: Kidney damage (GFR at least 90 mL/minute per 1.73 m^2)

Evidence of kidney damage but without decreased GFR. Usually no symptoms.

Stage 2: Kidney damage (GFR 60–89 mL/minute per 1.73 m^2)

Evidence of kidney damage with some reduction in GFR. Most patients have no symptoms.

Stage 3: GFR 30–59 mL/minute per 1.73 m^2 (with or without evidence of kidney damage)

GFR significantly reduced. May show signs of kidney damage and often indications of dysfunction in other organs. Often without symptoms, despite a reduction in kidney function of up to 70%.

Stage 4: GFR 15–29 mL/minute per 1.73 m^2 (with or without evidence of kidney damage)

Kidney function significantly reduced. Blood levels of urea and creatinine increased, and greater evidence of dysfunction in other organs. Usually only mild symptoms.

Stage 5: Kidney failure (GFR less than 15 mL/minute per 1.73 m^2) (with or without evidence of kidney damage)

Various symptoms and laboratory defects in several organ systems, collectively referred to as uraemia. Kidney replacement therapy (dialysis or transplant) is required when kidney function is no longer sufficient to sustain life, typically at a GFR of about 7–8 mL/minute per 1.73m^2.

Source: Adapted from Obrador & Pereira (2002).

A substantial time commitment is required by patients opting for dialysis treatment. Satellite and hospital haemodialysis is usually carried out 3 times per week for 4–6 hours, while home haemodialysis can be carried out overnight (6–8 hours) and more often. Peritoneal dialysis requires that the dialysis solution be exchanged every 4–6 hours (continuous ambulatory peritoneal dialysis), or automatically overnight with a possible exchange during the day (automated peritoneal dialysis).

Dialysis treatment itself can only replace some of the functions of the kidneys, meaning substantial pharmaceutical regimes are required to partly perform the hormone and other homeostatic functions of the kidneys. Common physical complaints identified by dialysis patients include muscle, bone and joint aches, sleep disturbances, itchy/dry skin, stomach upsets, poor concentration, coughing, shortness of breath, headaches, decreased sexual function, cramps and dizziness (Cass et al. 2006). This combination of time demands and physical complaints for those on dialysis can lead to major changes in social and economic participation, and significant disruption to home life.

Prognosis, anticipated quality of life (with or without dialysis), treatment burden on the patient (if dialysis is undertaken), and patient preference all play a part in the decision for or against KRT (Murtagh et al. 2007). The most significant predictors of poor outcomes for dialysis patients are age, comorbidity, and functional capacity (Chandna et al. 1999). Managing ESKD without KRT generally involves treating the symptoms and negative social and psychological effects associated with the condition.

Relatively few studies compare the survival rates of non-KRT-treated ESKD patients with ESKD patients who receive dialysis. The research that has been done tends to focus on older (75 years and older) ESKD patients. The survival of conservatively treated ESKD patients is shorter than survival of those treated with dialysis, although the dialysis survival benefit is less for those with comorbid conditions, particularly ischaemic heart disease (Joly et al. 2003; Murtagh et al. 2007). In one study, the median survival period for ESKD patients aged over 80 years not treated with KRT was 8.9 months from entering stage 5, compared with 28.9

months for patients treated with dialysis (Joly et al. 2003). Murtagh et al. (2007) found that one- and two-year survival for patients aged over 75 years after entering stage 5 were 84% and 76% respectively for dialysis treated patients and 68% and 47% respectively for conservatively treated patients.

Estimating the incidence of ESKD provides an important foundation for determining the ESKD-related burden in Australia. Further, policy makers can use this information to develop strategies to reduce the burden of ESKD. In 2008, the Council of Australian Governments (COAG) recognised the impact that ESKD has on the health of Australians, particularly among Aboriginal and Torres Strait Islander people, and included a measure of the incidence of ESKD in the indicators for the National Healthcare Agreement (COAG Reform Council 2010).

Previously, the incidence of ESKD in Australia was only available for those treated with KRT, with the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) compiling data on virtually all persons who develop ESKD and undergo KRT. To more accurately report on this indicator, the AIHW, with advice from its CKD expert advisory committee, developed a method of estimating the total incidence of ESKD in Australia that includes persons who do not undertake KRT. This is the first time this has been done in Australia, and such work is rare elsewhere in the world. The first results of this method were published in 2010 (COAG Reform Council 2010).

There are two main purposes of this report. The first is to outline the methods used to build the new data set that includes both KRT-treated and non-KRT-treated incident cases of ESKD occurring during the period 2003–2007 (Chapter 2). The second purpose is to present the main results from the analysis of these data. Chapter 3 provides combined results of the total incidence, while Chapter 4 analyses the results with the KRT-treated and non-KRT-treated cases separated. Chapters 5 and 6 provide results for different population groups: the first for the various states and territories, and the second for Indigenous Australians compared with non-Indigenous Australians. A discussion then follows.

2 Data set construction and methods

The data set used in this analysis was constructed to report on the total incidence of ESKD for the National Healthcare Agreement indicator, first published in 2010 (COAG Reform Council 2010). A good data source for KRT-treated cases has been available from ANZDATA for many years. To count non-KRT-treated cases, mortality data were used, because individuals with ESKD not receiving KRT-treatment are unlikely to survive for long. For these cases, date of death can be used as a substitute for the incidence date.

It is important to note that this new method is an interim measure, providing an estimate of the total incidence of ESKD. As date of death is used as a substitute for incidence date, it cannot count those non-KRT-treated cases who have not died, or whose death was not registered in the year it occurred. This could result in a potential under-count for the most recent year, although these missed cases would be expected to be counted in the following year. In addition, cases where ESKD did not contribute to the death cannot be identified in the deaths data, and this method relies on accurate and consistent coding of causes of death.

Other potential limitations may be present, such as over-counting if some of the deaths identified are not actually cases of ESKD. One aspect of potential over-counting is looked at in the sensitivity analysis in the 'Discussion'. It is also possible that some people may initiate dialysis treatment, but die before being registered with ANZDATA. For these reasons, the current method provides an 'interim' approach to estimating total ESKD. It is planned that hospital admissions will be used to provide further diagnosis data, including a diagnosis date, sometime in the future, once linkage to the national hospital data is possible.

Due to the overlap between the two data sets used, it is necessary to use data linkage techniques to identify the ANZDATA cases who died during the analysis period. This ensures that each case is only counted once on the final data set. The definition of incidence used in this analysis is outlined in Box 2. Using the methods and definitions described aims to calculate exact counts of cases of ESKD. However given the limitations discussed, these counts should be seen as estimates of incidence rather than definitive. Further details are provided in the next section of this report.

Box 2: Definition of incidence of ESKD used in this study

Incidence of end-stage kidney disease (ESKD) is:

- the number of unique individuals who appeared as new cases on the ANZDATA Registry in the reference period (KRT-treated cases), plus
- the number of people who died during the reference period who were not registered with ANZDATA, and for whom ESKD was recorded as a cause of death (non-KRT-treated cases). This estimates the number of non-KRT-treated cases in the reference period, because survival for this group of people is relatively short.

ESKD in mortality data is defined as a person who died with:

- chronic renal failure (ICD-10 codes N18.0, N18.8, N18.9), hypertensive renal failure (ICD-10 codes I12.0, I13.1, I13.2) or unspecified renal failure (ICD-10 code N19) as an underlying cause of death, or
- chronic renal failure, end-stage (ICD-10 code N18.0) as an associated cause of death.

This chapter outlines the method used to construct the linked data set that combines together KRT-treated and non-KRT-treated cases. It then describes the linkage process used to ensure that cases are only counted once in the data set. The appendix to this report also contains further descriptions of the source data sets, and information on particular methods used in this report.

Data sources

Two main sources were used in the creation of this new data set. The first is the Australia and New Zealand Dialysis and Transplant Registry, known as ANZDATA, which records virtually all cases of KRT-treated ESKD in Australia and New Zealand (only Australian cases are included in this analysis).

The second is the AIHW National Mortality Database, which contains cause of death and demographic information for all deaths registered in Australia since 1964. Cause of death data—coded using the International Classification of Diseases (ICD)—can be used to identify non-KRT-treated cases, based on the assumption that survival for people with ESKD who do not receive dialysis or a transplant is short. In this analysis year of registration is used to identify deaths in a particular year. For the most part, the year of registration coincides with the year of death, with less than 5% of deaths held over from one year to the next for processing. This method allows for the most recent year of data to be used.

The other data set also used in the linkage process, the National Death Index, is a record of all deaths in Australia since 1980. It contains identifying information, and was used solely to confirm death for ANZDATA cases. Also contained in the National Death Index is a registration number that allows matching to the AIHW National Mortality Database.

More information on these data sets is contained in Appendix 2.

Extracting the data

The subset of ANZDATA used in the analysis data set is: cases receiving their first treatment in Australia between 2003 and 2007. A larger subset of ANZDATA cases was used in the linkage process to eliminate misclassification, as described in the next section.

The aim in extracting the mortality data was to include deaths for which ESKD was recorded on the death certificate. This indicates that ESKD contributed to the death. There could also be some deaths where an individual with ESKD dies from an unrelated cause (for example, an injury), in which case ESKD would not be recorded on the death certificate, but there are likely to be only a small number. As an indication, for those ANZDATA cases who were first treated and also died during 2003–2007, the proportion who died from an external cause without also having ESKD recorded as a cause of death was 2.3%.

The method of identifying people in the mortality data who died of ESKD was developed for the relevant COAG indicator in conjunction with the Chronic Kidney Disease Monitoring Advisory Committee. It is similar to another study, which also aimed to identify non-KRT-treated EKSD cases in mortality data in the United States (Stengel et al. 2003). However, this current study places more emphasis on ensuring that cases have ESKD rather than earlier stages of the disease.

The ESKD deaths extracted fall into two categories. The first is those who have 'renal failure' more broadly (that is, not necessarily end-stage) as an underlying cause of death, because if the renal failure was severe enough to be the underlying cause then it is assumed to be end-stage. The second group of deaths are those where the specific ICD code for ESKD was an associated cause of death. Note that it was not sufficient to only use the specific end-stage code for the first group described above, as many known cases of ESKD were coded with the more general renal failure codes. The specific ICD codes used are outlined in Box 2.

Data linkage

There is overlap between the two source data sets, as some of the people who commenced KRT will also have died. To identify these people present in both data sets, probabilistic data linkage (Fellegi & Sunter 1969) between ANZDATA records and the National Death Index was used to identify ANZDATA cases who had died.

The linkage was based on identifying information including date of birth, name, sex, date of death and postcode. Records of deaths between 1983 and 2007 included on the National Death Index were used in the linkage process.

Following the linkage process, cause of death and demographic information were extracted from the AIHW National Mortality Database. Then the ANZDATA deaths were checked against the extracted ESKD records from the mortality data to ensure that any cases present in both data sets were only counted once.

The ANZDATA cases (24,336) used in the linkage process comprised all cases receiving treatment between 2003 and 2007 (regardless of when treatment commenced) plus any cases 'lost to follow-up'. The subset of these cases commencing treatment between 2003 and 2007 was included in the analysis data set as they are the incident cases. The remainder were not in the analysis data set, but were needed in the linkage process to ensure that any persons identified as ESKD cases in the mortality data were not incorrectly allocated to the non-KRT-treated group.

We identified 11,543 cases in the mortality data where the person died with ESKD. The overlap cases between ANZDATA and the mortality data have already been counted in the KRT-treated cases, leaving the remaining 10,421 cases as the non-KRT-treated cases.

The total number of cases in the final data set is 21,370, including 10,949 KRT-treated cases and 10,421 non-KRT-treated cases. Terminology used to describe these two groups is summarised in Box 3, along with other terms used in this report.

For the small number of linked records where demographic information differs between ANZDATA and the mortality data, the information on ANZDATA was used, as it is likely to be more accurate. This is because it is usually collected directly from the individual while they are alive, and is also subject to further verification through subsequent validation processes used for the data set. Individuals were classified as Aboriginal or Torres Strait Islander if they were recorded as such in either the ANZDATA Registry or in the mortality data.

Box 3: Terminology used in this report

KRT-treated cases: the cases of ESKD first receiving dialysis or transplant during 2003–2007. This group will include some cases who commenced KRT-treatment, but for various reasons this treatment ceased some time before death.

Non-KRT-treated cases: those identified in the mortality data as having died with ESKD but were not recorded on the ANZDATA Registry. The term 'other cases' is also used in some places. Note that it is not strictly correct to use the term 'untreated cases', as these cases would still be expected to be receiving some form of treatment (such as palliative care), just not KRT.

Total incidence: the sum of KRT-treated and non-KRT-treated cases.

Renal failure/kidney failure: used interchangeably in this report.

Underlying cause of death: the condition that initiated the train of events leading directly to an individual's death.

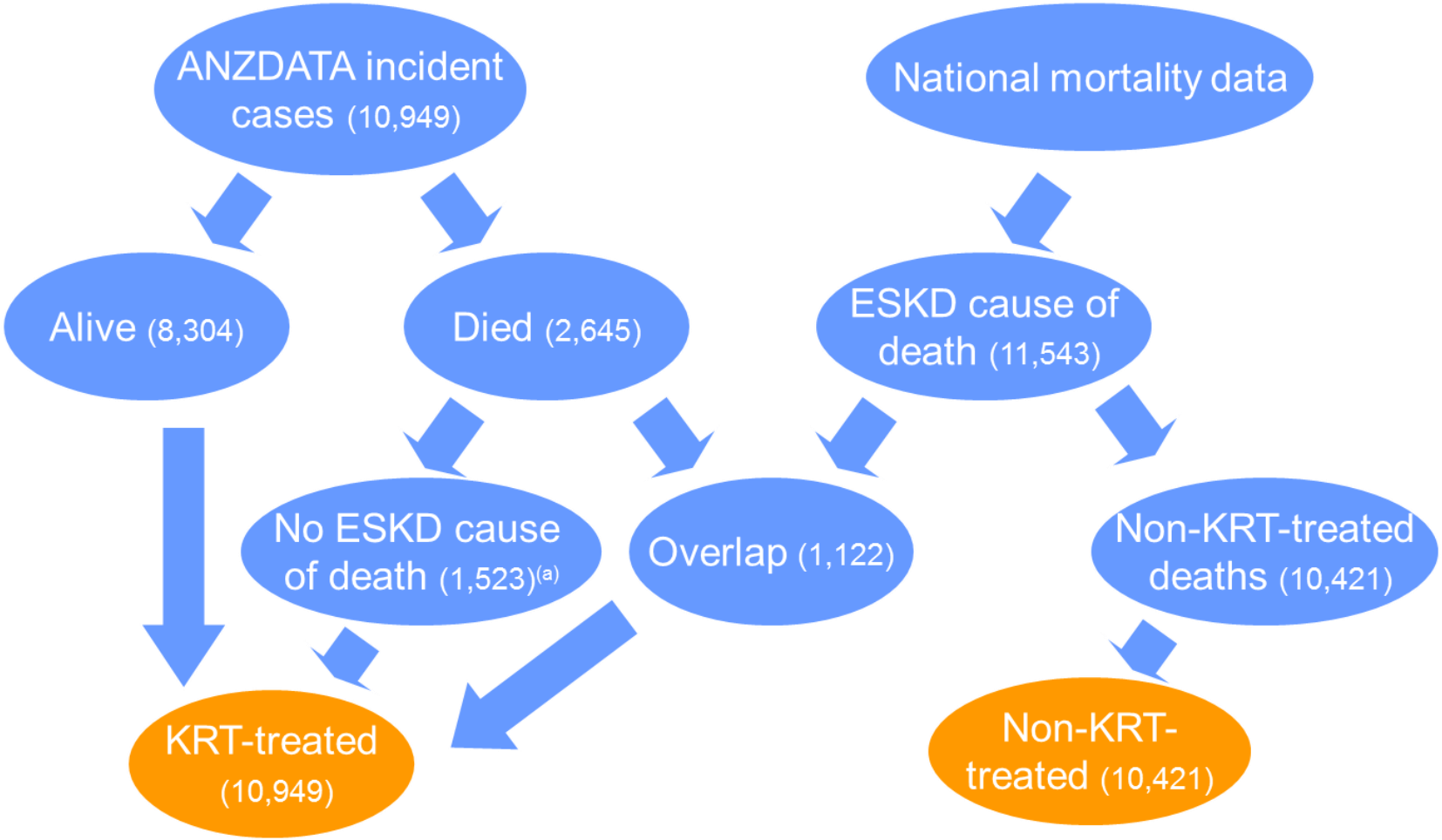
Associated cause of death: any other condition that is considered to have contributed to the death.

Mortality data: a broad term to include the two national deaths data sources that have been combined in this analysis: the National Death Index and the AIHW National Mortality Database, both of which were used in the data set construction process.

Characteristics of the linked data set

Figure 2.1 illustrates the data construction process. From the almost 11,000 incident ANZDATA cases between 2003 and 2007, 76% (8,304) were alive at the end of the analysis period. Just over 44% (1,122) of the cases who had died in this period had an ESKD ICD-10 cause of death code (matching our method), and these are the overlap cases being on both the original data sets. As mentioned above, it is legitimate that some of the ANZDATA deaths would not have an ESKD code if ESKD had not contributed to the death. However, the proportion without an ESKD code seems high, suggesting that the method used here is likely to be conservative.

Deaths among the ANZDATA cases are defined here as those cases with a valid match in the National Death Index. Note that ANZDATA recorded 2.5% more deaths than the ones identified in this report, including 80 deaths that could not be matched on the National Death Index (some of which may have died overseas or the death may not have been registered in time to be included in the data linkage process). There were also 117 deaths of ANZDATA registrants who linked with a National Death Index record but did not yet have cause of death information available. Moreover, 13 deaths found on the National Death Index had not been recorded as deaths in ANZDATA at the time of linkage.



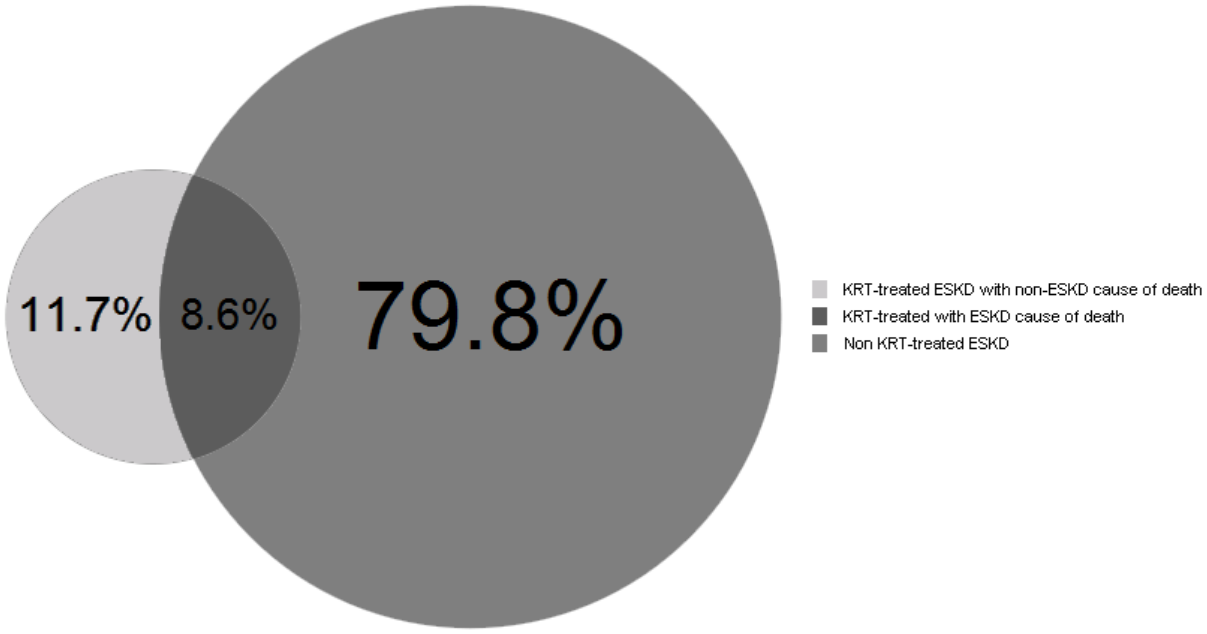
(a) Includes 117 cases for whom cause of death information was not available at the time of data linkage.

Figure 2.1: Incident cases of KRT-treated and non-KRT-treated cases, 2003–2007: data set construction flowchart

Deaths

This section looks at the deaths that occurred during the analysis period of 2003–2007 among the new cases in that period to provide a greater understanding of the data set. These deaths include those occurring among both the KRT-treated and the non-KRT-treated cases. Note that it is not possible to compare time to death or cause of death for these two groups. To be able to assess survival times, the date of onset of ESKD for the non-KRT-treated cases would be needed, along with directly comparable data for the KRT-treated group. As these two groups of deaths are not comparable, the causes of death for each group are analysed separately below.

The proportion of deaths falling into three groups is displayed in Figure 2.2. The large circle represents those who had an ESKD cause of death on the death certificate based on the definition used in this analysis. Therefore this represents the deaths that would have been identified from the mortality data, regardless of whether they were KRT-treated or other cases.



*Note: Ex*cludes 117 cases for whom cause of death information was not available at the time of data linkage.

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

Figure 2.2: Deaths of incident ESKD cases, 2003–2007

The small circle includes the KRT-treated incident ESKD cases who died during the analysis period, representing the deaths that would have been identified from the ANZDATA Registry. The overlap cases are the KRT-treated cases who died with an ESKD cause of

death. Not surprisingly, considering our method, this figure shows that the vast majority of deaths (80%) were in non-KRT-treated cases. Further, less than half (44%) of treated cases had an ESKD cause of death on the death certificate, and this is discussed in more detail below.

Non-KRT-treated cases

By definition, this group includes all of the non-KRT-treated cases, as these cases do not appear on the ANZDATA Registry and are only included in the data set when the person dies.

Cause of death

Table 2.1 shows the proportion of cases with particular underlying causes of death. The most common among this group were chronic renal failure (43% of the deaths), followed by unspecified renal failure (27%), and hypertensive renal failure (21%).

Table 2.1: Underlying cause of death for non-KRT-treated cases, 2003–2007

Underlying cause of death	ICD code/s	Number	Per cent
Chronic renal failure	N18	4,452	42.7
Unspecified renal failure	N19	2,828	27.1
Hypertensive renal failure	I12.0, I13.1, I13.2	2,179	20.9
	Deaths with an associated cause of N18.0		
Diabetic nephropathy	E10.2, E11.2, E12.2, E13.2, E14.2	32	0.3
Other diabetes	Other E10–E14 codes	185	1.8
Other chronic kidney diseases	N00–N07, N11, N12, N14, N15, N25–N28, N39.1, N39.2, B52.0, D59.3, E85.1, Q60–Q63, T82.4, T86.1	51	0.5
Cardiovascular disease	Balance of I00–I99	297	2.9
Cancer	C00–D48	150	1.4
Respiratory disease	J00–J99	62	0.6
External causes	V01–Y98	20	0.2
Other	D50–D89, F00–F99, G00–G99, L00–L99	165	1.6
Total		**10,421**	**100.0**

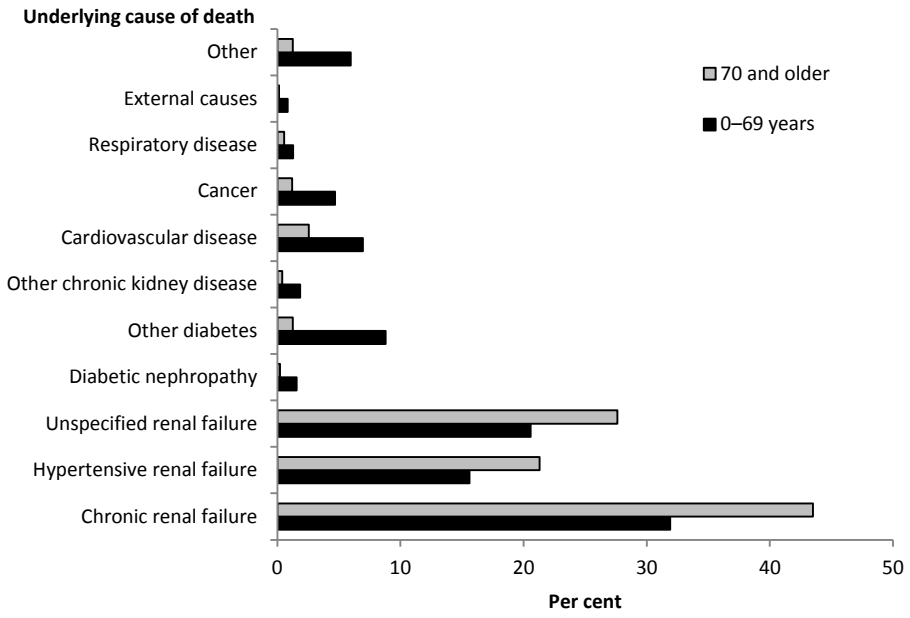
Source: Linked ANZDATA Registry, AIHW National Mortality Database and National Death Index.

Age distribution

To better understand any patterns associated with specific causes of death, it is of particular interest to look at the causes of death across age spans. The percentage distribution for the main underlying cause of death groups are shown in Figure 2.3, with more detail provided in Appendix Table A1.2.

As would be expected from our method, a very high proportion of the non-KRT-treated group have renal failure (chronic, hypertensive or unspecified) as the underlying cause of death. Some differences were seen by age, however, with a smaller proportion of those aged less than 70 years having renal failure as the underlying cause of death, and a higher

proportion having an underlying cause of death of diabetes, cardiovascular disease or cancer.



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

Figure 2.3: Underlying causes of death of non-KRT-treated cases, by age group, 2003–2007

KRT-treated cases

Cause of death

This section provides further detail on the deaths that occurred between 2003 and 2007 among incident KRT-treated cases for this period, taking into account both the underlying and associated causes of death. The middle three columns of Table 2.2 show broad groups among these deaths: those with ESKD as a cause of death, as per the definition used in this analysis; those with another CKD cause of death (but not specifically end-stage as defined in this analysis—see Appendix 2 for details), and those with no ESKD or CKD cause of death. It is important to remember that the KRT-treated group who died during the analysis period are generally the more severe cases among the KRT-treated group, surviving less than 4 years from the start of KRT. So these results should not be taken to represent the mortality pattern of all KRT-treated individuals.

Less than half (44%) of the deaths among the KRT-treated cases had an ESKD cause of death as defined in this analysis. However, the same proportion again had another CKD cause of death, though not specifically end-stage. The remaining 12% did not have a CKD cause of death at all. The relatively low proportion of known KRT-treated cases with an ESKD cause of death as per the definition used in this analysis suggests that this method of identifying ESKD cases in the mortality data is conservative. However, any relaxation of the counting

rules to try to pick up other cases (for example, the ones with more general CKD codes) may lead to over-counting, as at least some of these deaths are likely to not be end-stage.

Table 2.2: Causes of death for KRT-treated incident ESKD cases, 2003–2007

		With ESKD cause of death[(a)]	With other CKD cause of death[(b)]	No ESKD/CKD cause of death	
Underlying cause of death	**Number**	**Distribution (per cent)**			**Total**
Chronic renal failure	304	100.0	0.0	0.0	100.0
Hypertensive renal failure	105	100.0	0.0	0.0	100.0
Unspecified renal failure	59	100.0	0.0	0.0	100.0
Diabetic nephropathy	51	41.2	58.8	0.0	100.0
Other diabetes	383	33.7	60.3	6.0	100.0
Other chronic kidney disease	91	42.9	57.1	0.0	100.0
Other cardiovascular disease	677	25.8	58.2	16.0	100.0
Cancer	341	31.4	53.7	15.0	100.0
Respiratory disease	80	37.5	46.3	16.3	100.0
External causes	57	28.1	22.8	49.1	100.0
Other	380	36.1	42.4	21.6	100.0
Total[(c)]	**2,528**	**44.4**	**43.6**	**12.1**	**100.0**

(a) Based on the method used in this analysis, outlined in Box 1.

(b) Cases without an ESKD cause of death based on the method used in this analysis but with another CKD underlying or associated cause of death.

(c) Excludes 117 cases known to be deceased, but for whom cause of death information was not available at the time of data linkage.

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

Looking at the specific underlying cause of death in Table 2.2, by definition all the cases in the first three rows have an ESKD cause of death. The two diabetes groups have high proportions of cases having a CKD cause of death, with only 6% of the 'other diabetes' group having no CKD cause of death. The cardiovascular disease group (which is known to have a direct link to CKD) has a higher proportion of cases with no CKD code than the diabetes group. The external causes group has the lowest proportion of cases with an ESKD or CKD cause of death code. This is not surprising, as this group is likely to have the least links to CKD.

A final point to make is that when using the specific chronic renal failure, end-stage code (N18.0) alone—without the other renal failure codes as an underlying cause—only 33% of the deaths among the KRT-treated cases were counted.

Table 2.3 shows the proportion of cases in each of two groups—with and without an ESKD cause of death using the method from this analysis—with particular underlying causes of death. For the KRT-treated group with an ESKD cause of death, chronic renal failure was again the most common underlying cause of death; the next highest specific cause was for cardiovascular disease. For the second group—KRT-treated cases without an ESKD cause of death—cardiovascular disease and diabetes were the most common underlying cause of death.

Table 2.3: Underlying cause of death for KRT-treated incident ESKD cases, 2003–2007

	With ESKD cause of death		No ESKD cause of death	
Underlying cause of death	**Number**	**Per cent**	**Number**	**Per cent**
Chronic renal failure	304	27.1	—	0.0
Hypertensive renal failure	105	9.4	—	0.0
Unspecified renal failure	59	5.3	—	0.0
Diabetic nephropathy	21	1.9	30	2.1
Other diabetes	129	11.5	254	18.1
Other chronic kidney disease	39	3.5	52	3.7
Cardiovascular disease	175	15.6	502	35.7
Cancer	107	9.5	234	16.6
Respiratory disease	30	2.7	50	3.6
External causes	16	1.4	41	2.9
Other	137	12.2	243	17.3
Total	**1,122**	**100.0**	**1,406**	**100.0**

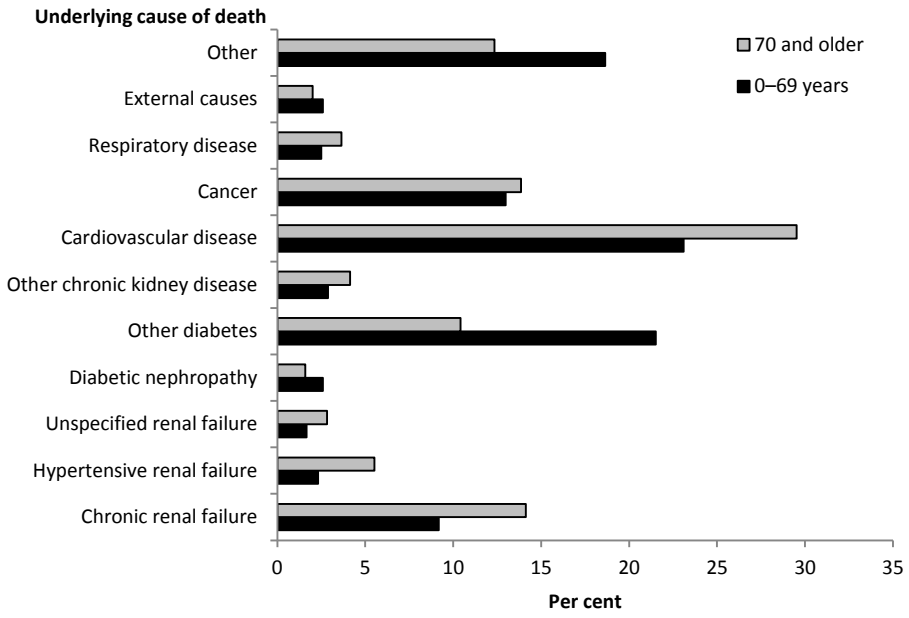
Note: Excludes 117 cases known to be deceased, but for whom cause of death information was not available at the time of data linkage.

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

Age distribution

The percentage distributions for the main underlying cause of death groups are shown in Figure 2.4, with more detail provided in Table A1.2. A large proportion of deaths in this group were due to cardiovascular disease or diabetes, with the diabetes group being particularly prominent for those aged 0–69 years, and cardiovascular disease for those aged 70 years and over. Cancer is also a common underlying cause of death in both age groups.

Further information on the actual cause of death taking into account both underlying and associated causes of death is provided in Table A1.3.



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

Figure 2.4: Underlying causes of death of KRT-treated cases, by age group, 2003–2007

3 Estimated total incidence of ESKD

This chapter provides information on the total incidence of EKSD, combining KRT-treated and non-KRT-treated cases together. This combined measure provides important information on the level of severe CKD in Australia. Later chapters separate the data into KRT-treated and non-KRT-treated cases.

There were an estimated 21,370 new cases of ESKD in Australia in the five-year period between 2003 and 2007 (Table 3.1). This is around 21 new cases per 100,000 population (crude rate). The age-standardised rate is 20 per 100,000. There were more cases among males (54% of cases) than females (46%). The age-standardised rates were 24.4 per 100,000 population for males and 16.3 per 100,000 for females.

Table 3.1: Total incidence of ESKD, by sex, 2003–2007

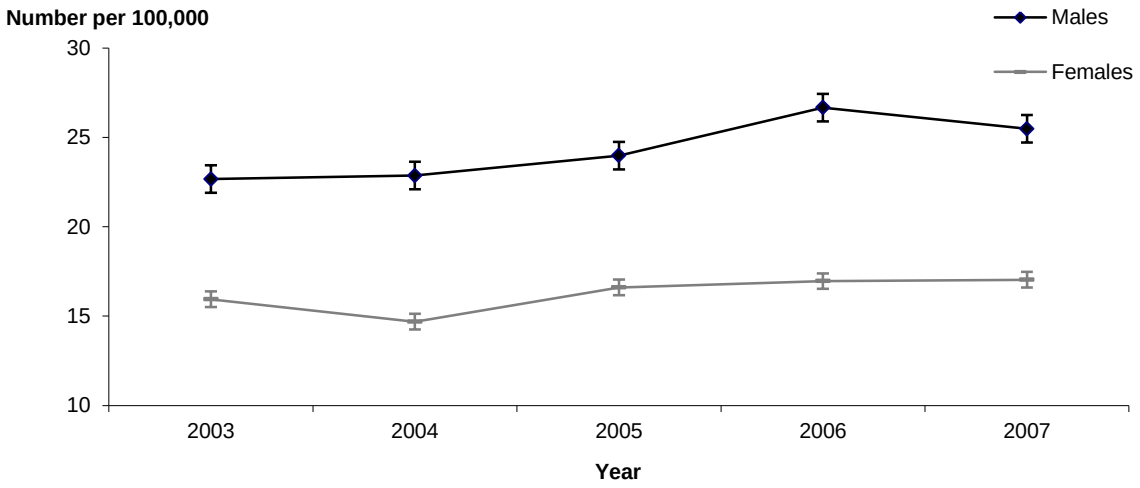
	2003	2004	2005	2006	2007	Total
			Number of cases			
Males	2,020	2,086	2,259	2,584	2,551	11,500
Females	1,841	1,738	1,999	2,103	2,189	9,870
Total	**3,861**	**3,824**	**4,258**	**4,687**	**4,740**	**21,370**
			Age-standardised rate (per 100,000 population)[(a)]			
Males	22.7	22.9	24.0	26.7	25.5	24.4
Females	15.9	14.7	16.6	17.0	17.0	16.3
Total	**18.9**	**18.3**	**19.8**	**21.3**	**20.9**	**19.9**

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

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

The number of new cases generally increased over the period in both males and females (Table 3.1). When taking into account the population size and age distribution, the rates for males increased between 2003 and 2006, but then remained steady to 2007 (Figure 3.1). For females the trend was fairly flat. There is a suggestion of a slight increase, but the confidence intervals overlapped, indicating the difference was not significant.

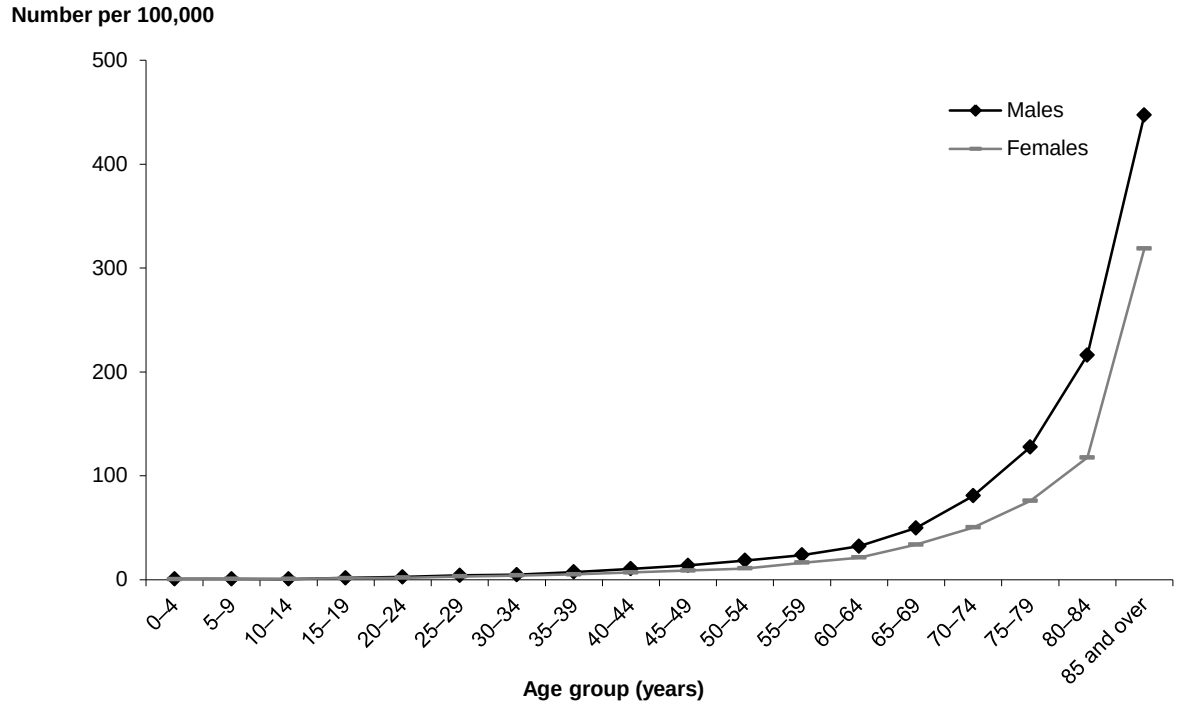
When looking at the total incidence across age groups, the rates increased very sharply with age (Figure 3.2). Over 2003–2007, 48% of new male cases and 59% of new female cases were in those aged 75 years or over. Males had higher rates than females across the whole age distribution, although the younger age groups had similar rates.



Note: Directly age-standardised to the Australian population as at 30 June 2001.

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

Figure 3.1: Total incidence of ESKD, by sex, 2003–2007



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

Figure 3.2: Total incidence of ESKD, by age, 2003–2007

4 KRT-treated and non-KRT-treated cases

This chapter breaks down the total incidence figures into KRT-treated and non-KRT-treated cases. This provides important information to help understand the characteristics of those treated with KRT compared with those who are not.

The number of KRT-treated and non-KRT-treated new cases was fairly stable between 2003 and 2004, then rose steadily until 2007 (Table 4.1). More of this increase came from the non-KRT-treated cases than the KRT-treated cases, both in relative terms (with nearly a 30% increase for non-KRT-treated cases compared with nearly a 20% increase for KRT-treated cases) and absolute terms (about 540 more non-KRT-treated cases in 2007 than in 2003, and nearly 340 more KRT-treated cases). For this period, there were 6,609 KRT-treated cases and 4,891 non-KRT-treated cases among males, and 4,340 KRT-treated and 5,530 non-KRT-treated female cases. Note that the incident age distribution varied between males and females, so these combined numbers cannot be used to gain an accurate understanding of treatment rates. This issue is dealt with in more detail below.

Table 4.1: Total incidence of ESKD, by treatment status, 2003–2007

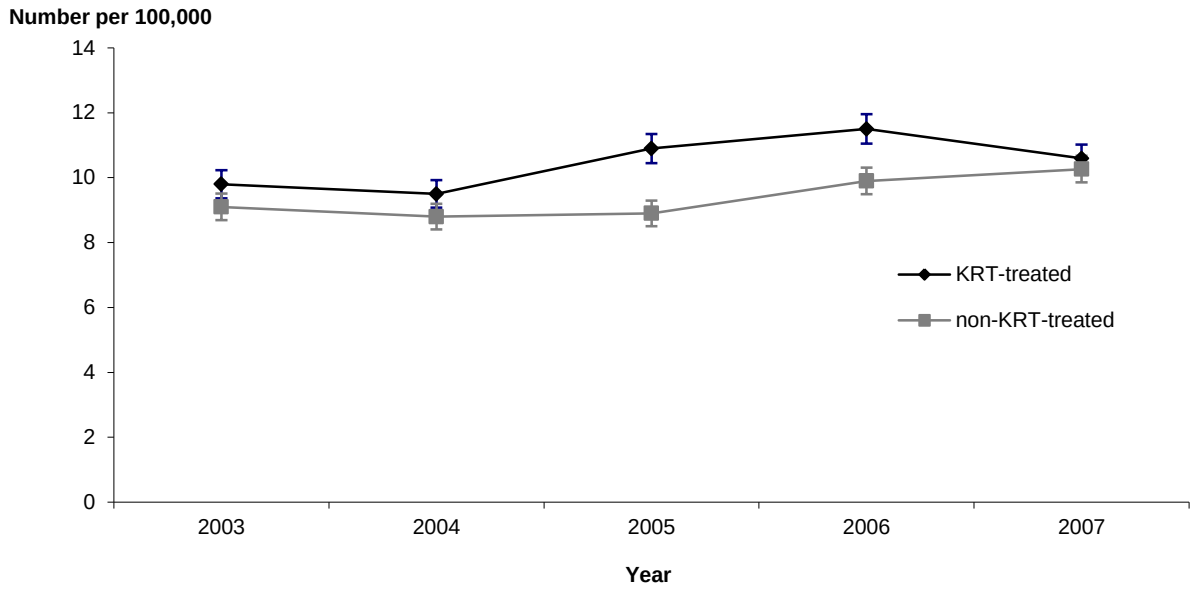
	2003	2004	2005	2006	2007	Total
			Number of cases			
KRT-treated cases	1,975	1,945	2,286	2,432	2,311	10,949
Non-KRT-treated cases	1,886	1,879	1,972	2,255	2,429	10,421
Total	**3,861**	**3,824**	**4,258**	**4,687**	**4,740**	**21,370**
			Age-standardised rate (per 100,000 population)[(a)]			
KRT-treated cases	9.8	9.5	10.9	11.5	10.6	10.5
Non-KRT-treated cases	9.1	8.8	8.9	9.9	10.3	9.4
Total	**18.9**	**18.3**	**19.8**	**21.3**	**20.9**	**19.9**

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

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

There were more KRT-treated than non-KRT-treated cases overall, but the difference was not great (Table 4.1). This is the case in most years, though in 2007 there were slightly more non-KRT-treated than KRT-treated cases.

Age-standardised rates for the period were similar for KRT-treated and non-KRT-treated cases, and the rates were not significantly different. This indicates that the broad pattern, after adjusting for age, was that there was about one non-KRT-treated case for every KRT-treated case. Looking at the individual years, the rates were slightly higher for KRT-treated than non-KRT-treated cases in most years, but notably in 2007 the rates were very similar (Figure 4.1).

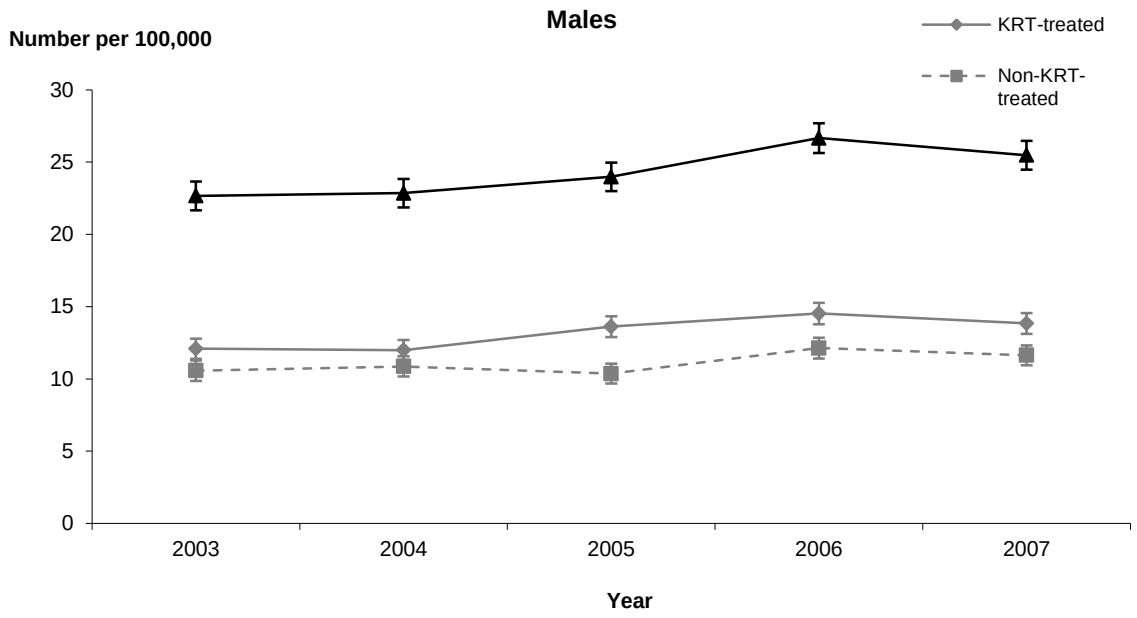


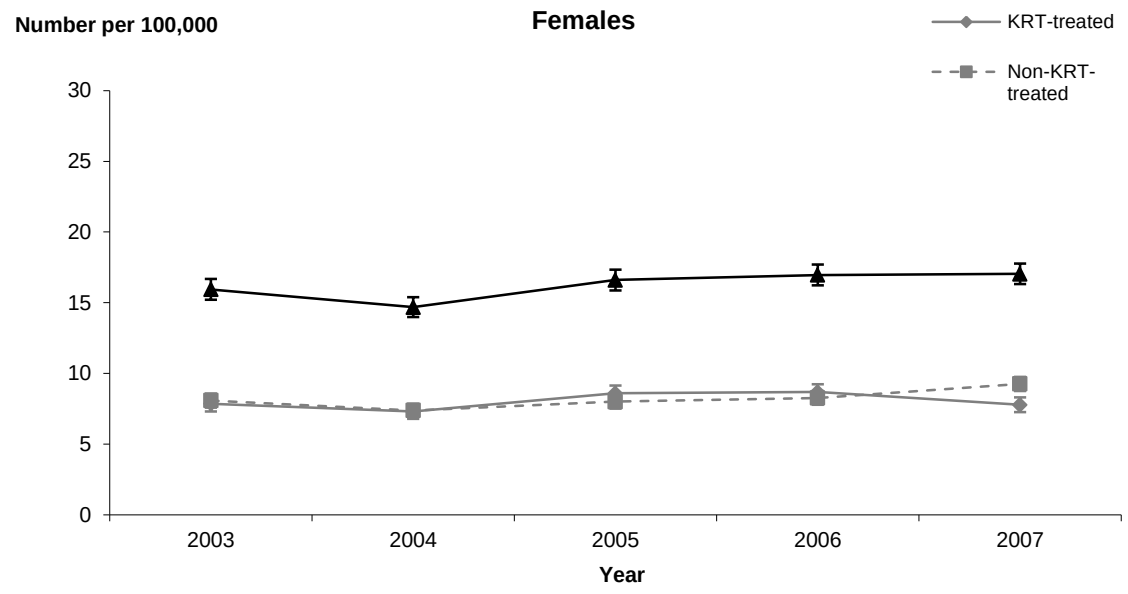
Note: Directly age-standardised to the Australian population as at 30 June 2001.

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

Figure 4.1: Total incidence of ESKD, by treatment status, 2003–2007

There are some differences in these patterns between males and females. Figure 4.2 shows that the rates for KRT-treated compared with non-KRT-treated cases differed for males, but not for females, except in 2007. This suggests that overall, age-adjusted treatment rates were slightly higher for males than females.



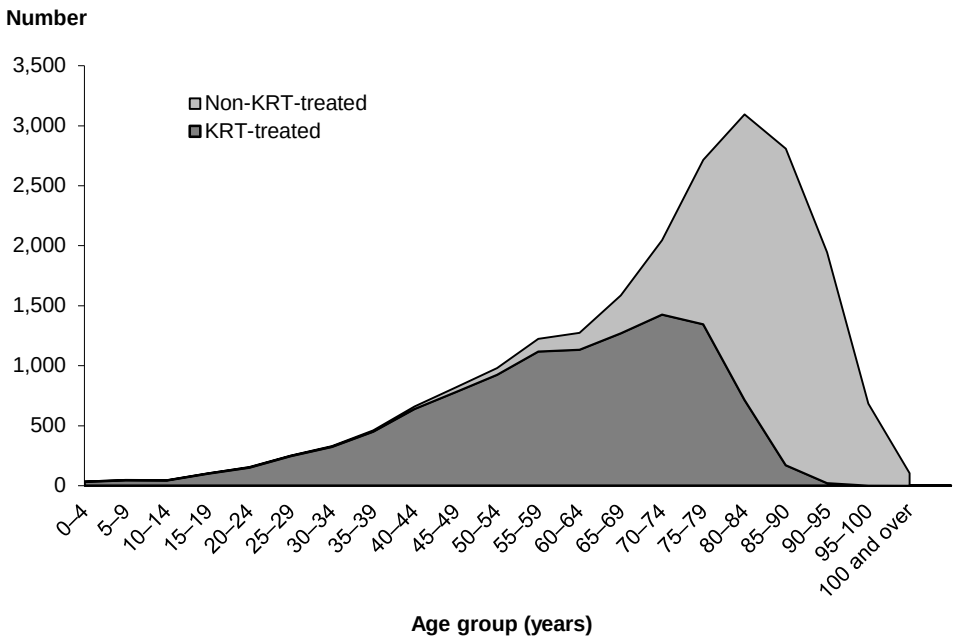


Note: Directly age-standardised to the Australian population as at 30 June 2001.

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

Figure 4.2: Total incidence of ESKD, by sex and treatment status, 2003–2007

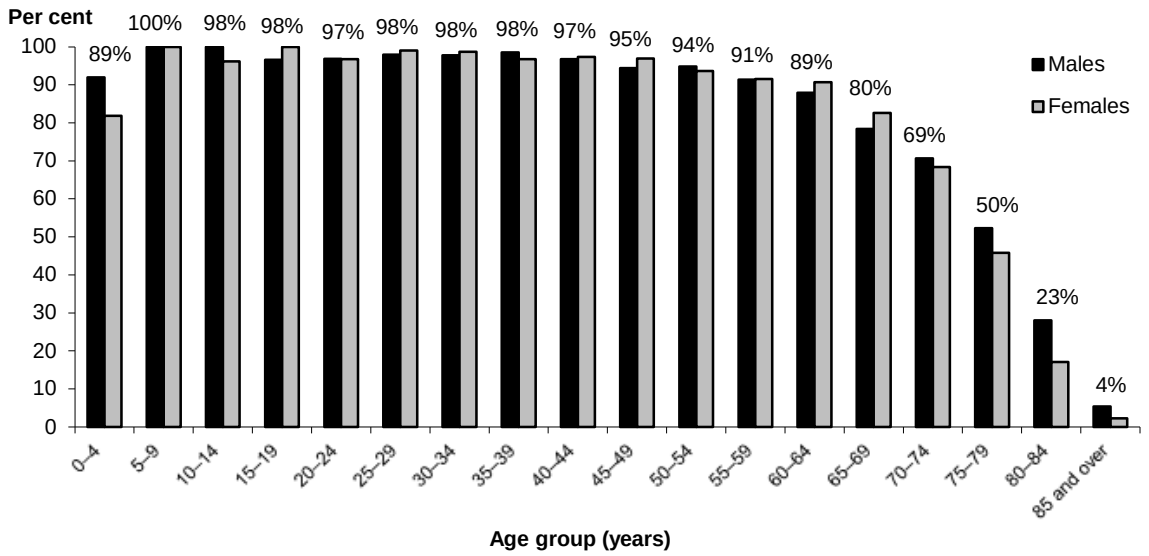
If the almost 1:1 ratio for KRT-treated to non-KRT-treated cases seems high, it is important to recognise that the vast majority of the non-KRT-treated cases were among the oldest age groups (Figure 4.3; Table A1.1). For the period 2003–2007, more than 80% of the non-KRT-treated cases were in people aged 70 years or over.



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

Figure 4.3: Number of KRT-treated and non-KRT-treated cases, by age group at ESKD onset, 2003–2007

The actual treatment rates (proportion of all cases who receive KRT-treatment) differed by age group (Figure 4.4). The dominating pattern was the sharp drop in treatment rates among the oldest age groups. There was little difference in the treatment rates for males and females in most age groups, although treatment rates were higher for males in the oldest age groups.



Note: Numbers above bars relate to the proportion of people who are KRT-treated in that age group.

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

Figure 4.4: Proportion of all cases who are KRT-treated, by age group at ESKD onset and sex, 2003–2007

5 State and territory results

This chapter provides analysis by state and territory. The majority of results are presented by the state or territory where patients received their first treatment for KRT-treated cases, and state or territory of death registration for non-KRT-treated cases. This matches the method used in the COAG indicator. There are also some results presented by state or territory of residence. Comparison of these two approaches is discussed below.

Total incidence

The total number of new cases of ESKD between 2003 and 2007 ranged from 6,800 in New South Wales to 360 in the Australian Capital Territory, based on state or territory of first treatment or death registration (Table 5.1). There were more males than females in all jurisdictions except the Northern Territory.

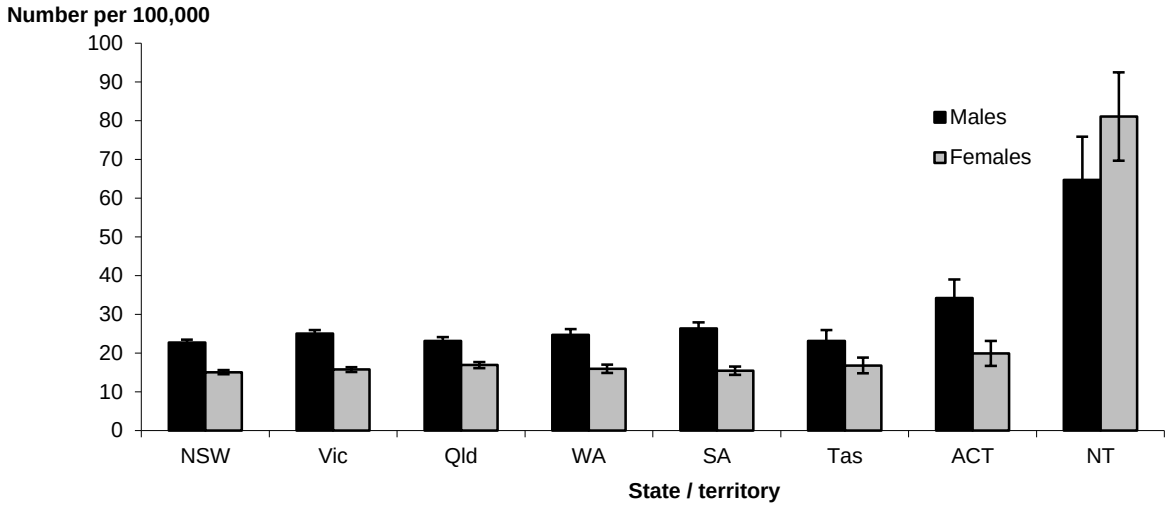
Table 5.1: Total incidence of ESKD, by sex and state and territory of treatment/registration, 2003–2007

	Number of cases			Age-standardised rate (per 100,000 population)[(a)]		
State/territory	Males	Females	Total	Males	Females	Total
NSW	3,646	3,153	6,799	22.8	15.1	18.5
Vic	2,947	2,488	5,435	25.0	15.8	19.9
Qld	2,065	1,843	3,908	23.2	16.9	19.8
WA	1,082	860	1,942	24.7	16.0	19.9
SA	1,058	838	1,896	26.4	15.5	20.2
Tas	279	274	553	23.2	16.8	19.7
ACT	208	150	358	34.2	20.0	26.2
NT	215	264	479	64.7	81.1	71.8
Total	**11,500**	**9,870**	**21,370**	**24.4**	**16.3**	**19.9**

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

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

Total incidence rates were very similar across most states and territories. The key exception was in the Northern Territory, which had much higher rates, reflecting the higher proportion of Aboriginal and Torres Strait Islander people (who are known to have higher rates of ESKD) making up that population (Table 5.1; Figure 5.1). The Australian Capital Territory also had somewhat higher rates among males. This is likely due to a number of cases from surrounding New South Wales being treated in the Australian Capital Territory. These cases are included in the numerator of the rate, but the denominator only counts the population of the Australian Capital Territory, resulting in inflated rates. Male rates were higher than female rates in all cases except the Northern Territory, where there was no statistically significant difference between the rates for males and females.



Note: Directly age-standardised to the Australian population as at 30 June 2001.

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

Figure 5.1: Total incidence of ESKD, by state and territory of treatment/registration, 2003–2007

The issue of state or territory of treatment versus state or territory of residence is important when comparing estimates across jurisdictions. Data presented in Table 5.1 and Figure 5.1 based on state or territory of treatment/registration match the specifications for the COAG indicator, which aims to make comparisons based on where people are treated. Another option would be to produce estimates based on where people live. This would give more of an epidemiological perspective, and the populations for the numerator and denominator would match.

Table 5.2 shows how estimates vary when using state or territory of residence to group individuals rather than state or territory of treatment/registration. The main resulting change in the number of cases is for the Australian Capital Territory, which has 46% less cases when using state of residence (mostly due to those cases living outside the Australian Capital Territory who are treated there). Not surprisingly, New South Wales had the other main change in numbers, gaining the cases treated in the Australian Capital Territory. But New South Wales also gained more than 50 cases treated in each of Queensland and Victoria.

The Australian Capital Territory age-standardised rate fell significantly when using the state or territory of residence rather than the state or territory of treatment/registration, moving it from the second highest to the lowest. The New South Wales rate increased only slightly (the confidence intervals still overlap), and the remainder were stable.

Table 5.2: Total incidence of ESKD by state/territory of treatment/registration and residence, 2003–2007

	Number of cases		Age-standardised rate (per 100,000 population)	
	State/territory of treatment/ registration	State/territory of residence	State/territory of treatment/ registration (CI)	State/territory of residence (CI)
NSW	6,799	7,035	18.5 (18.1–19.0)	19.2 (18.7–19.6)
Vic	5,435	5,387	19.9 (19.3–20.4)	19.7 (19.2–20.2)
Qld	3,908	3,850	19.8 (19.2–20.4)	19.5 (18.9–20.1)
WA	1,942	1,942	19.9 (19.0–20.8)	19.9 (19.0–20.8)
SA	1,896	1,872	20.2 (19.3–21.1)	19.9 (19.0–20.8)
Tas	553	560	19.7 (18.0–21.3)	20.0 (18.3–21.6)
ACT	358	245	26.2 (23.5–29.0)	18.2 (15.9–20.5)
NT	479	478	71.8 (64.0–79.6)	71.8 (64.0–79.6)
Total	**21,370**	**21,369**	**19.9 (19.6–20.1)**	**19.9 (19.6–20.1)**

Note: One case deleted from state of residence column due to missing information.

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

For the rest of this chapter, the COAG definition for state/territory based on place of treatment or death registration has been used. However, the Australian Capital Territory has been grouped with New South Wales, due to small numbers in the Australian Capital Territory, which limited analysis for some of the breakdowns. This also removes the main complication with the state or territory of treatment/registration due to the Australian Capital Territory treating some New South Wales residents. In addition, estimates for the Northern Territory have not been separately provided in the following analysis, due to large relative standard errors for the various estimates.

KRT-treated cases and non-KRT-treated cases

Table 5.3 breaks down the total incidence into those treated with KRT and other cases, by state or territory of treatment/registration. There were similar numbers of KRT-treated and non-KRT-treated cases in each of the jurisdictions. The main exceptions were Tasmania and South Australia, which had more non-KRT-treated cases, though the Tasmanian results could be affected by the relatively small number of cases in that state.

A better comparison can be made based on age-adjusted rates (Table 5.3; Figure 5.2). For three jurisdictions, the KRT-treated rates were significantly higher than for non-KRT-treated cases, most notably for Queensland and Western Australia. The only jurisdiction with a significantly higher non-KRT-treated rate than KRT-treated rate was Tasmania.

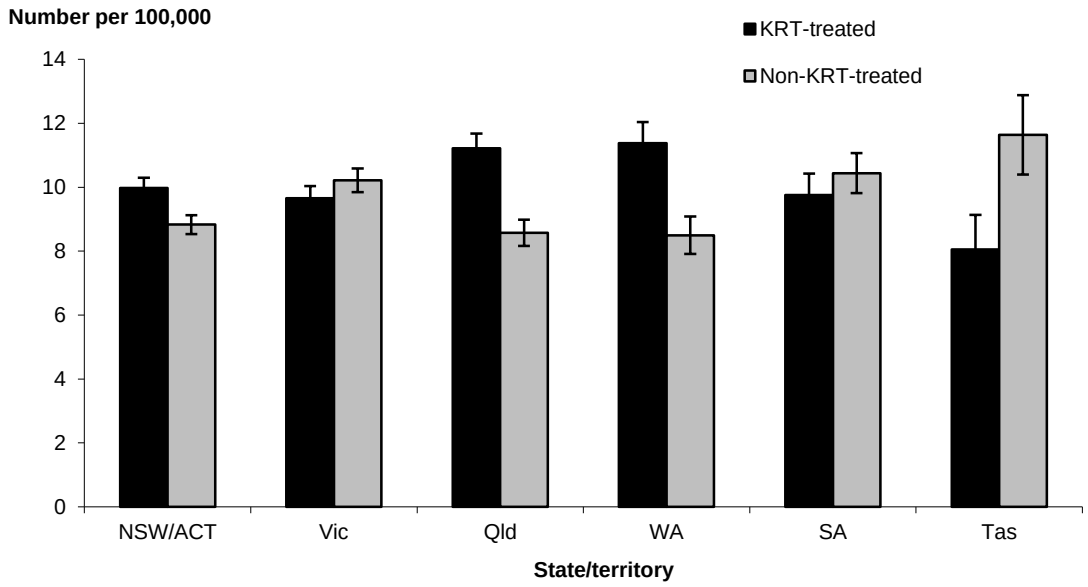
Table 5.3: Total incidence of ESKD, by treatment status and state/territory of treatment/registration, 2003–2007

	Number of cases			Age-standardised rate (per 100,000 population)[(a)]		
	KRT-treated	Non-KRT-treated	Total	KRT-treated	Non-KRT-treated	Total
NSW/ACT	3,660	3,497	7,157	10.0	8.8	18.8
Vic	2,523	2,912	5,435	9.7	10.2	19.9
Qld	2,227	1,681	3,908	11.2	8.6	19.8
WA	1,132	810	1,942	11.4	8.5	19.9
SA	826	1,070	1,896	9.8	10.4	20.2
Tas	214	339	553	8.1	11.6	19.7
Total[(b)]	**10,949**	**10,421**	**21,370**	**10.5**	**9.4**	**19.9**

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

(b) The Northern Territory was included in the total, but could not be separately listed due to large relative standard errors of the estimates.

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



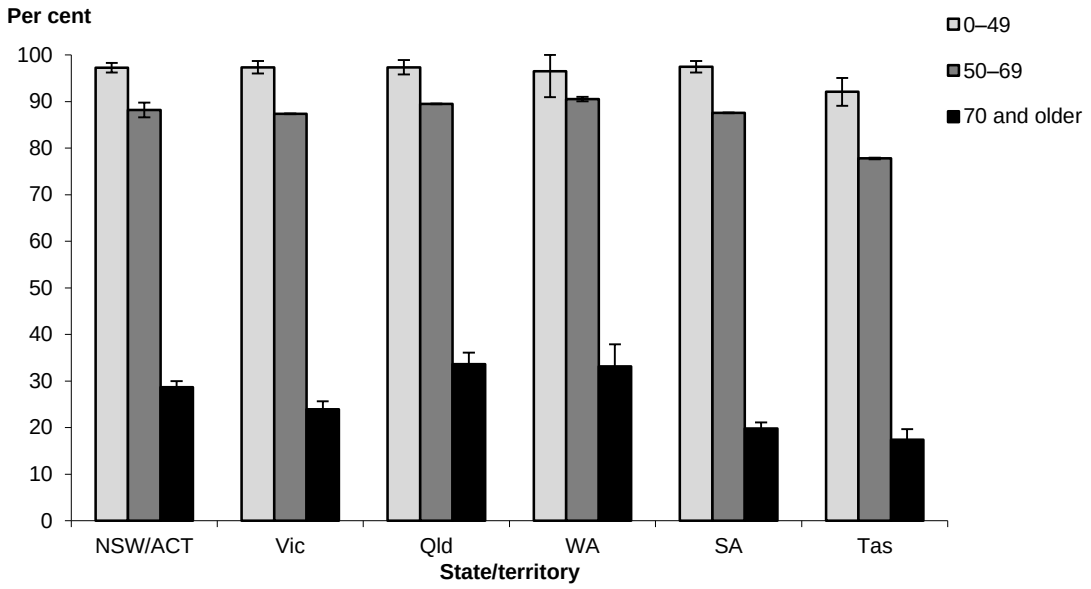
Notes

1. Directly age-standardised to the Australian population as at 30 June 2001.
2. The Northern Territory could not be displayed due to large relative standard errors of the estimates.

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

Figure 5.2: Total incidence of ESKD, by treatment status and state/territory, 2003–2007

Treatment rates by broad age groups across the jurisdictions are shown in Figure 5.3. The general pattern across age groups holds for all states and territories, with treatment rates above 90% for those aged 0–49 years, about 80% or higher for those aged 50–69 years, and dropping off dramatically for the oldest group to about 30% or lower. For the two younger age groups, the rates were similar across the jurisdictions, but with slightly lower rates for those aged 50–69 years in Tasmania. There was more variation in those aged 70 years or more.



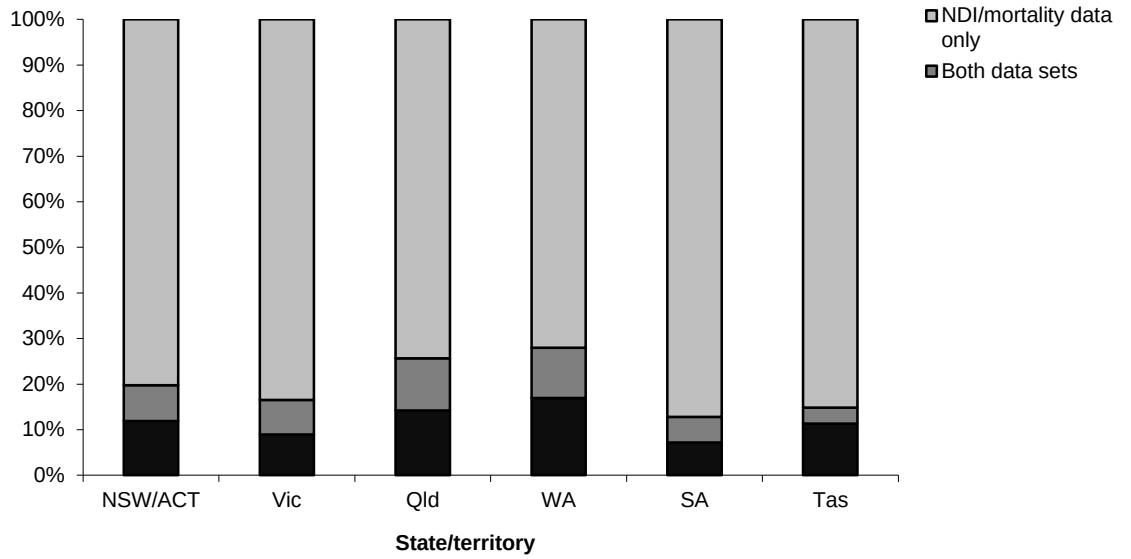
Note: The Northern Territory could not be displayed due to large relative standard errors of the estimates.

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

Figure 5.3: Proportion of cases treated with KRT, by age group and state/territory, 2003–2007

Deaths

This section compares the deaths that occurred during 2003–2007 among these incident cases. Figure 5.4 shows that most deaths were among the non-KRT-treated cases, as expected. Queensland and Western Australia had slightly lower proportions, reflecting their higher treatment rates as discussed above. In line with the national results in Table 2.2, less than half of the deaths among the KRT-treated cases had an ESKD cause of death. The lowest proportion was in Tasmania.



Note: The Northern Territory could not be separately displayed due to large relative standard errors of the estimates.

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

Figure 5.4: Proportion of deaths, by data source and state/territory, 2003–2007

Table 5.4 looks at the deaths only among the KRT-treated cases to see what information was recorded on the corresponding death certificates. This shows that the proportion with an ESKD cause of death ranged from 48% in Victoria down to 41% in Western Australia and Tasmania. Deaths with another CKD code ranged from 59% in Tasmania to 40% in Queensland. Most states had between 10% and 14% of these cases with no CKD/ESKD cause of death. However, in Tasmania, all KRT-treated cases that died during the period did have a CKD/ESKD cause of death.

Table 5.4: More detail on cause of death among KRT-treated cases, by state/territory, 2003–2007

		With ESKD cause of death[(b)]	With other CKD cause of death[(c)]	No CKD/ESKD cause of death	Total
	Number[(a)]	Per cent			
NSW/ACT	827	41.5	45.6	12.9	100.0
Vic	557	47.8	42.0	10.2	100.0
Qld	564	46.1	39.9	14.0	100.0
WA	305	40.7	47.9	11.5	100.0
SA	154	44.8	40.9	14.3	100.0
Tas	34	41.2	58.8	0.0	100.0
Total	**2,528**	**44.4**	**43.6**	**12.1**	**100.0**

(a) Excludes 117 cases known to be deceased, but for whom cause of death information was not available at the time of data linkage.

(b) Based on the method used in this analysis, outlined in Box 1.

(c) Cases without an ESKD cause of death based on the method used in this analysis, but with another chronic kidney disease underlying or associated cause of death.

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

6 Aboriginal and Torres Strait Islander people

This chapter provides results for Indigenous Australians compared with non-Indigenous Australians. Indigenous identification in deaths data is considered of sufficient quality for national reporting for New South Wales, Queensland, Western Australia, South Australia and the Northern Territory only. For further information refer to 'Reporting of Indigenous data' in Appendix 2. The exclusion of the other three jurisdictions means that the totals in this chapter do not match those in earlier chapters.

Total incidence

In 2003–2007, there were nearly 1,200 new cases of ESKD in Aboriginal and Torres Strait Islander people in the jurisdictions used in this chapter, compared with about 13,800 among the non-Indigenous population (Table 6.1). Only 0.4% of records did not have Indigenous status recorded. Among Indigenous Australians more females than males developed ESKD during the study period, the opposite to non-Indigenous Australians.

Table 6.1: Total incidence of ESKD, by sex and Indigenous status, 2003–2007

	Indigenous	Non-Indigenous	Not-stated
	Number of cases		
Males	542	7,491	33
Females	651	6,273	34
Total	**1,193**	**13,764**	**67**
	Age-standardised rate (per 100,000 population)[(a)]		
Males	114.6	22.7	—
Females	115.3	14.7	—
Total	**114.2**	**18.3**	**—**

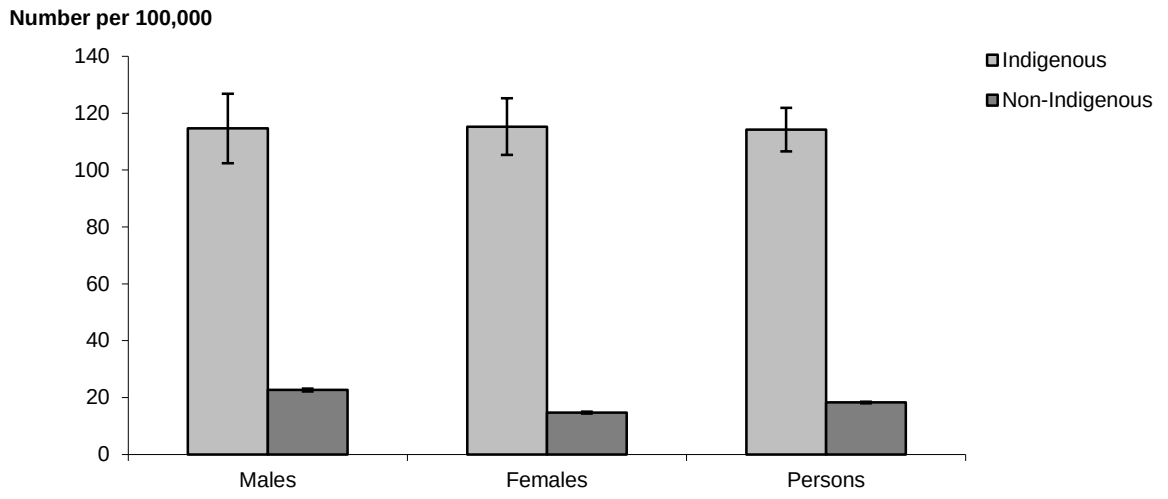
(a) Directly age-standardised to the Australian population as at 30 June 2001.

Notes

1. Only New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are included.
2. — nil or rounded to zero.

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

When taking into account the size and age-structure of the populations, the rate for Indigenous Australians was more than 6 times as high as that for non-Indigenous Australians (Table 6.1; Figure 6.1). Male and female age-standardised rates were not significantly different in the Indigenous population, which differs from the non-Indigenous population, where male rates were higher than female rates (Figure 6.1).



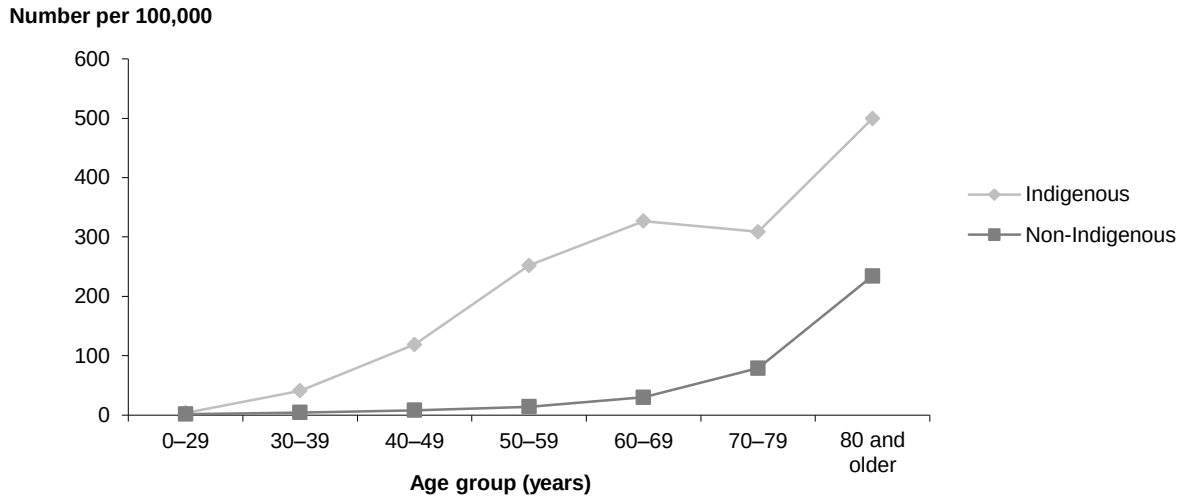
Notes

1. Only New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are included.
2. Directly age-standardised to the Australian population as at 30 June 2001.

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

Figure 6.1: Total incidence of ESKD, by sex and Indigenous status, 2003–2007

Incidence rates largely increased with age for both Indigenous and non-Indigenous Australians (Figure 6.2). Age-specific rates for Indigenous Australians were found to be between 2 and 18 times as high as for non-Indigenous Australians, with the largest relative difference in those aged 50–59 years. In absolute terms, the largest difference was in those aged 60–69 years, with nearly 300 more incident cases per 100,000 population among Aboriginal and Torres Strait Islander people.



Note: Only New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are included.

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

Figure 6.2: Total incidence of ESKD, by age and Indigenous status, 2003–2007

KRT-treated and non-KRT-treated cases

Between 2003 and 2007, 84% of the Indigenous cases in New South Wales, Queensland, Western Australia, South Australia and the Northern Territory received KRT (Table 6.2). Among non-Indigenous Australians, the number of KRT-treated and non-KRT-treated cases was similar (Table 6.2). The split between KRT-treated and non-KRT-treated cases in the Indigenous population compared with the non-Indigenous population are somewhat surprising at first glance: 84% of Indigenous cases were KRT-treated compared with only 51% of non-Indigenous cases. However, these crude proportions do not take into account the age at which these cases occur. It is important to look at age-specific information to properly understand treatment rates (see below).

Table 6.2: Total incidence of ESKD, by treatment status and Indigenous status, 2003–2007

	Indigenous	Non-Indigenous	Not stated
	Number of cases		
KRT-treated	997	6,968	—
Non-KRT-treated	196	6,796	67
Total	**1,193**	**13,764**	**67**
	Age-standardised rate (per 100,000 population)[(a)]		
KRT-treated	82.5	9.5	—
Non-KRT-treated	31.7	8.8	—
Total	**114.2**	**18.3**	**—**

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

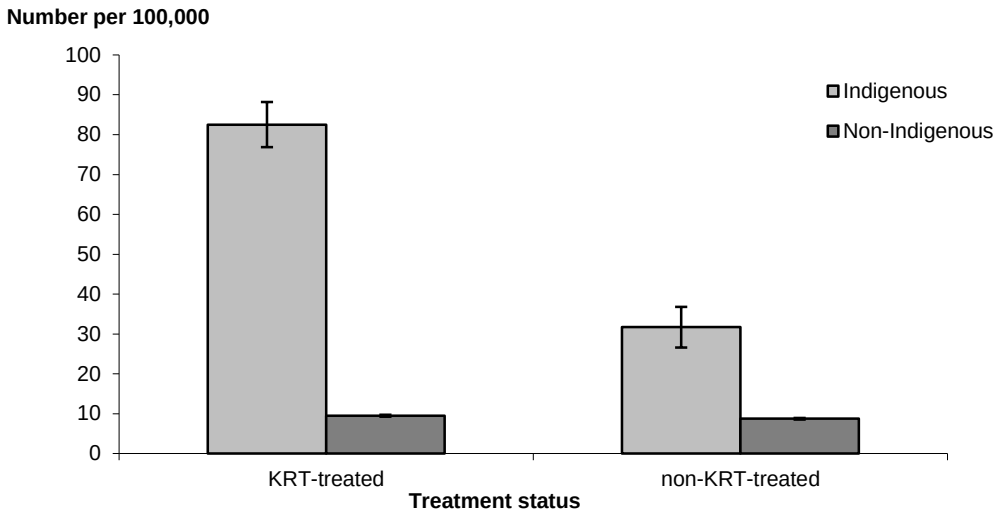
Notes

1. Only New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are included.
2. — nil or rounded to zero.

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

The age-standardised rates show that both the KRT-treated and the non-KRT-treated rates are much higher in the Indigenous population than in the non-Indigenous population (Table 6.2; Figure 6.3). Note that these figures cannot be used to calculate treatment rates, which are analysed below.

The number of non-KRT-treated cases among Aboriginal and Torres Strait Islander people increased with age particularly from 50–54 years, with more than 87% of the non-KRT-treated cases aged 50 years and over (Figure 6.4). This is considerably younger than for non-Indigenous Australians, for which 80% of the non-KRT-treated cases were in people aged 70 years or over (Figure 4.3). There is also a much smaller group of non-KRT-treated cases among the Indigenous population compared with the non-Indigenous population. This appears to be because there are fewer cases among the older age groups in the Indigenous population.

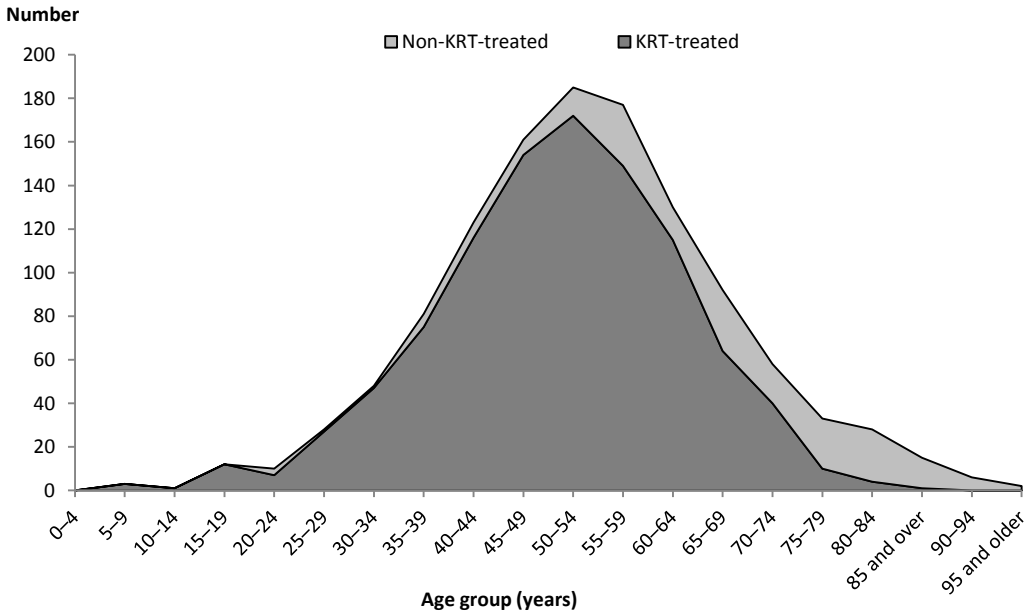


Notes

1. Only New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are included.
2. Directly age-standardised to the Australian population as at 30 June 2001.

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

Figure 6.3: Total incidence of ESKD, by treatment status and Indigenous status, 2003–2007



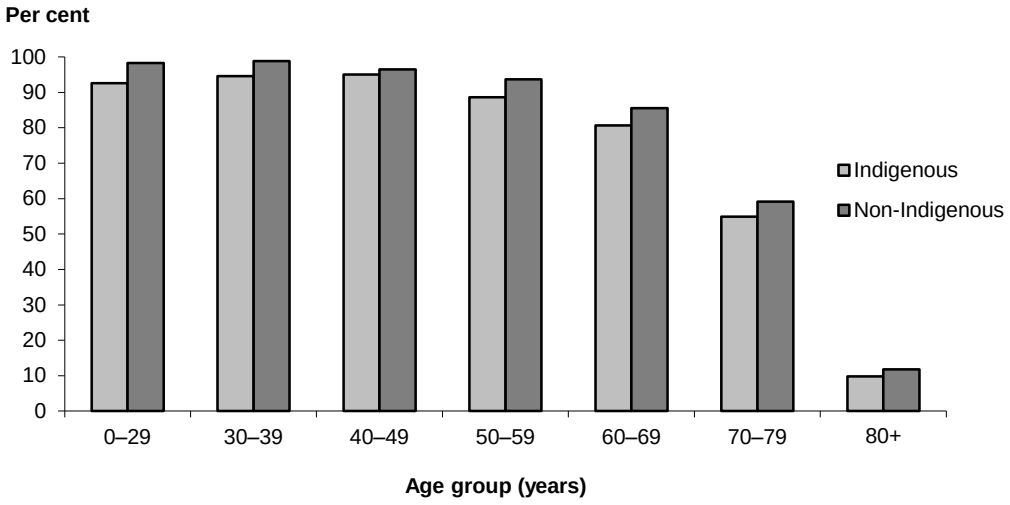
Notes: Only New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are included.

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

Figure 6.4: Number of KRT-treated and non-KRT-treated cases among Aboriginal and Torres Strait Islander people, by age group, 2003–2007

To compare treatment rates, it is important to look at them across age groups, as they vary substantially by age for both Indigenous and non-Indigenous Australians. Surprisingly, given the numbers in the Table 6.1, the treatment rates by age group did not vary greatly between Indigenous and non-Indigenous Australians due to the very different age distributions of cases (Figure 6.5). In fact, the treatment rates were actually higher for non-Indigenous Australians in all age groups. For Indigenous Australians, nearly 70% of total cases (KRT-treated and non-KRT-treated) occurred before the age of 60 years. For non-Indigenous Australians, this figure was just over 20% (Figures 4.3 and 6.4). Coupled with the fact that treatment rates vary greatly by age, this makes interpretation of figures that are not age-adjusted very misleading.

The age-standardised ratio of treatment rates between Indigenous and non-Indigenous Australians was 0.96, indicating that Indigenous Australians had slightly lower treatment rates.



Note: Only New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are included.

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

Figure 6.5: Proportion of cases treated with KRT, by age group and Indigenous status, 2003–2007

Deaths

There are large differences in the distribution of deaths between Indigenous and non-Indigenous Australians with ESKD who were incident and died between 2003 and 2007. For non-Indigenous Australians, 80% of deaths occurred in the non-KRT-treated group (Table 6.3). However, the vast majority (94%) of non-KRT-treated cases among non-Indigenous Australians were aged 70 years or over. In contrast, almost half the deaths of Indigenous Australians were in the non-KRT-treated group.

Table 6.3: Proportion of deaths, by treatment status and Indigenous status, 2003–2007

	Indigenous	Non-Indigenous	Not stated
KRT-treated with non-ESKD cause of death	27.7	11.3	0.0
KRT-treated with ESKD cause of death	25.1	8.6	0.0
Non KRT-treated	47.2	80.1	100.0

Notes:

1. Only New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are included.
2. Excludes 55 cases known to be deceased, but for whom cause of death information was not available at the time of data linkage.

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

The recording of cause of death on death certificates for KRT-treated deaths was similar between Indigenous and non-Indigenous Australians (Table 6.4). There was a slightly higher proportion of Indigenous deaths with an ESKD cause of death (48%) than for non-Indigenous deaths (43%). A similar proportion of these Indigenous and non-Indigenous deaths had another CKD cause of death (41% and 44%). Overall, the proportion with no CKD/ESKD cause of death was very similar in the two groups (12% and 13%).

Table 6.4: More detail on cause of death among KRT-treated cases, by Indigenous status, 2003–2007

		With ESKD cause of death[(a)]	With other CKD cause of death[(b)]	No CKD/ESKD cause of death	Total
	Number	Per cent			
Indigenous	219	47.5	40.6	11.9	100.0
Non-Indigenous	1,687	43.3	43.9	12.7	100.0
Total	**1,906**	**43.8**	**43.5**	**12.6**	**100.0**

(a) Based on the method used in this analysis, outlined in Box 1.

(b) Cases without an ESKD cause of death based on the method used in this analysis, but with another chronic kidney disease underlying or associated cause of death.

Notes

1. Only New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are included.
2. There were no cases where Indigenous status was 'not stated'.
3. Excludes 55 cases known to be deceased, but for whom cause of death information was not available at the time of data linkage.

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

7 Discussion

Key findings

This report presents the first detailed analysis of a new data set that includes both KRT-treated and non-KRT-treated cases of ESKD in Australia. The key question that can be answered from this new data set is 'What is the total incidence of ESKD in Australia?'. Previously, it was possible to count the number of new KRT-treated cases, but only the addition of national mortality data makes it possible to also count non-KRT-treated cases. As well as the total number of new cases in Australia, this report also looks at differences by age, by sex, by Indigenous status, and across the states and territories. It also splits these results by treatment status, depending on whether individuals are treated with KRT or not.

As the analysis is based on a newly established data set, the methods used to build it have been described in detail in Chapter 2. In summary, information from two data sources has been combined: KRT-treated cases are contained in ANZDATA, and deaths from ESKD are extracted from the AIHW National Mortality Database. The mortality data allow the non-KRT-treated cases to be included by using a specific set of causes of death. To remove 'duplicates' between these two data sets—which occur when someone who is KRT-treated dies with ESKD as a cause of death (as defined in this study)—data linkage was used.

The scope of the analysis data set used in this report is all new (incident) cases of ESKD occurring during 2003–2007, determined as cases newly starting KRT treatment during this time, plus any others who died of ESKD in the same period. This results in 21,370 incident cases of ESKD occurring during 2003–2007. Further details on the construction and characteristics of the data set are included in Chapter 2.

During 2003–2007, there were, on average, 20 new cases of ESKD each year per 100,000 population. The incidence rate was higher for males than females: 24 compared with 16 per 100,000 population. The rate increased substantially with age, and more than half of all new cases were in people aged 75 years and over.

There were a similar number of non-KRT-treated cases as KRT-treated cases. However, the vast majority of the non-KRT-treated cases were in people aged 70 years or over. This means that a very high proportion of cases in the younger age groups are KRT-treated: in all age groups between 5 and 60 years, more than 90% of cases were KRT-treated. This percentage fell sharply in older age, decreasing to less than 30% of new cases occurring in those aged over 80 years receiving KRT.

The total incidence of ESKD is much higher among Indigenous Australians compared with non-Indigenous Australians—about 6 times as high. A slightly lower proportion of new cases of ESKD among Indigenous Australians in all age groups were treated with KRT than was the case for non-Indigenous Australians. However, the difference was not great.

Most states and territories had similar total incidence rates. The main exception to this was in the Northern Territory, where the rate was about 3.5 times as high as the overall Australian rate. This is likely to be driven by the much higher rates among Indigenous Australians, which make up a higher proportion of that jurisdiction's population compared with other states and territories.

New methods in this analysis

The method used in the report of counting both non-KRT-treated as well as KRT-treated cases of ESKD has greatly improved incidence estimates. However, it is important to note that this method of estimating the incidence of non-KRT-treated ESKD is new, and some caution is required in interpreting these results. Counting the non-KRT-treated cases from the mortality data relies on the ESKD being accurately recorded in national mortality data and in a manner that differentiates it from CKD more broadly. Further, the cases can only be counted in the mortality data once the person has died. There will be a period after the onset of the ESKD and before death in which these cases cannot be counted. This particular aspect is expected to just delay the counting of these cases, rather than result in missing cases.

Another potential limitation discussed in Chapter 2 is that the current method uses a substitute incident date for the non-KRT-treated cases—the date of death. It would be better to have the actual incidence date to ensure cases are allocated to the most accurate incidence year. This extra information would also allow comparisons of survival between KRT-treated and non-KRT-treated cases. Because of these various uncertainties for the non-KRT-treated cases, the COAG indicator for which these data are used is currently considered an interim indicator.

It is unknown whether the current method of counting non-KRT-treated cases overestimates or underestimates the true number. There are several reasons why it may be an under-count. The first and most important is that not all people dying with ESKD may have it recorded on the death certificate. This is shown to be the case in this report for the KRT-treated cases examined here—those who were newly treated during 2003–2007 and also died during that period—with only 44% having ESKD recorded on their death certificate. The second reason is that we are not currently able to count the non-KRT-treated cases who have not yet died.

It is also possible that this estimate is too high, as it may include some non-KRT-treated cases who were end-stage, but not to the degree that would require dialysis or transplantation. However, this would only likely be applicable for the relatively small proportion of all cases included in this report because they had an associated cause of death of chronic renal failure, end-stage (N18.0) and were not treated with KRT. The remaining non-KRT-treated cases were included because they had chronic renal failure as an underlying cause of death. It is reasonable to assume that if the disease was the underlying cause of death then it was severe enough to have required dialysis or transplant for survival.

Sensitivity analysis

In light of the above, a sensitivity analysis was done to determine the effect of including the non-KRT-treated cases with an associated cause of death of chronic renal failure, end-stage.

Appendix 1 contains recalculations of the main results with these 962 cases excluded. The first point to note is that these cases only accounted for 9% of all the non-KRT-treated cases, 12% of male cases and 7% of female cases (Table A1.5). Excluding all of these cases resulted in the total incidence of ESKD falling only slightly, from 19.9 to 19.0 per 100,000 population (age-standardised). The non-KRT-treated rate fell from 9.4 to 8.5 per 100,000 population (Table A1.6). The excluded cases were in almost all age groups, but the main ones affected were aged 65–90 years, accounting for more than three-quarters of the excluded cases (Figure A1.1). Excluding these cases also reduced the number of cases by more than 20% in most age groups below 75 years. This resulted in small increases in the treatment rates across these age groups (seen by comparing Figure A1.2 with Figure 4.4). However, in nearly all

cases the increase was less than 3.5 percentage points. The two age groups with the largest increases were those aged 65–69 years and 70–74 years, which increased by 5.2 and 4.8 percentage points, respectively. The final point to note is that excluding these cases resulted in similar changes in the number of Indigenous and non-Indigenous cases (Table A1.7).

The result of this sensitivity analysis is that the removal of all the non-KRT-treated cases with an associated cause of death of chronic renal failure, end-stage does not substantially alter the estimates of the total incidence of ESKD contained in this report.

Future improvements to methods

There are plans to further develop the data for the total incidence measure. It is hoped linking the current data set with hospital data will be possible in the future. This would have two main benefits. Firstly, it would find non-KRT-treated cases where the person is still alive. And secondly, it would also provide valuable information about how the coding in the hospitals and deaths databases compare, potentially providing extra information that could be used to improve the accuracy of the incidence estimates. Unfortunately, linkage to the national hospital data is not currently possible.

Another avenue that may help refine the current measure would to be to conduct a validation of the death certificate data. The key aims would be to check that the death certificate does include ESKD when it contributed to the death by validating against information in the clinical records, and to check that the coding of the death certificate information is correct. It would also be useful to determine what proportion of people dying with ESKD will not have it recorded on their death certificate because it did not contribute to the death. These cases will not be able to be identified in the deaths data, even with perfectly accurate information.

There have been some previous studies comparing cause of death of ESKD patients on death certificates against another source of deaths data, such as one in Australia (Li et al. 2003) and one in the United States (Perneger et al. 1993). These both showed large variation in the agreement between the two data sets being compared, depending on the cause of death. The Australian study compared the cause of death in the ANZDATA Registry with that in the national deaths data. It found agreement ranged from poor (genitourinary diseases) to good (cancer), but as the ANZDATA Registry cause of death data is not based on ICD-10 coding, comparability is limited. The agreement measures in these studies depend on the accuracy of the data in both data sets, rather than being a comparison to a 'gold standard'. Neither of these studies compared the death certificate data with clinical records, which would be the aim of the potential validation described above.

Important new information on total incidence

Even with these caveats, this new information adds a great deal of new knowledge about the patterns of severe CKD in Australia. It shows that the total incidence rates are about double what was previously known when information on KRT-treated cases was all that was available. It also shows a great deal of variation across different population groups in these incidence rates.

There is very limited information from other countries on the total incidence of ESKD, and it appears that this is the first time the total incidence of ESKD has been estimated for a whole country. Several studies from the United States have used a similar method of data linkage to

determine the number of people with ESKD who do not receive KRT (Klag et al. 1996; Powe et al. 2003; Stengel et al. 2003). However, each of these were looking at the incidence for people within a particular cohort—such as the National Health and Nutrition Examination Survey—rather than directly calculating the total incidence for a whole population such as a country.

Another important difference is that the three studies mentioned above used a wider range of ICD codes to identify deaths corresponding to the wider group of CKD rather than ESKD. This means it is more likely that these studies included some less severe cases who were not end-stage. In contrast, the aim of this current study is to include only the ESKD cases—a more conservative approach.

It is clear that this analysis has produced important new information, but it is essential that the results are not interpreted inappropriately. In particular, while this analysis provides incidence estimates of both KRT-treated and non-KRT-treated cases, it is not possible to infer from the available data the reasons some cases are treated with KRT and others are not. These reasons are likely to be a mix of many factors, including medical reasons (such as suitability for KRT), accessibility of services, and personal choices. Kidney replacement therapy is a complex treatment, and individual patients must make complicated choices about its pros and cons in their particular circumstance.

Future analysis

There are many avenues for more, very valuable, analysis that could be done with this new data set. These include looking at trends over time more closely. With only 5 years of data included to date, it is difficult to draw firm conclusions on the trends over time—this will be possible when more years can be added to the data. There is much potential to do further analysis of variations across population groups, including by remoteness and socioeconomic status, and more in-depth analysis of patterns in the Indigenous population. There is also much interest in variations in treatment rates, and whether it is possible to compare the characteristics of those treated with KRT with the characteristics of those who are not.

Conclusion

The construction of the new data set described in this report, which includes both KRT-treated and non-KRT-treated cases, has added greatly to our information on ESKD. The analysis presented in this report provides valuable information on the total incidence of ESKD, the split between KRT-treated and non-KRT-treated cases, and differing patterns by age and sex, between the Indigenous and non-Indigenous population, and across the Australian states and territories. This new method of counting the total incidence of ESKD will continue to be developed and further looked at in the future.

Appendix 1

Additional tables and figures

Table A1.1: Number of KRT-treated and non-KRT-treated cases, by age group at ESKD onset, 2003–2007

Age group (years)	KRT-treated	Non-KRT-treated	Total
0–14	122	5	127
15–24	252	7	259
25–34	571	10	581
35–39	451	10	461
40–44	640	20	660
45–49	781	38	819
50–54	925	55	980
55–59	1,119	105	1,224
60–64	1,134	140	1,274
65–69	1,271	315	1,586
70–74	1,427	619	2,046
75–79	1,346	1,370	2,716
80–84	716	2,379	3,095
85–90	171	2,638	2,809
90+	23	2,710	2,733
Total	**10,949**	**10,421**	**21,370**

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

Table A1.2: Age distribution of causes of death, underlying only, by age group at death, 2003–2007

Underlying cause of death	ICD-10 code/s	0–54	55–69	70–79	80+	Total	0–54	55–69	70–79	80+	Total
Non-KRT-Treated				**Number**					**Per cent**		
Chronic renal failure	N18	50	175	839	3,388	4,452	34.5	31.3	42.2	43.8	42.7
Hypertensive renal failure	I12.0, I13.1, I13.2	19	91	364	1,705	2,179	13.1	16.3	18.3	22.1	20.9
Unspecified renal failure	N19	27	118	483	2,200	2,828	18.6	21.1	24.3	28.5	27.1
Diabetic nephropathy	E10.2, E11.2, E12.2, E13.2, E14.2	n.p.	10	n.p.	12	32	n.p.	1.8	n.p.	0.2	0.3
Other diabetes	Other E10–E14 codes	10	52	65	58	185	6.9	9.3	3.3	0.8	1.8
Other chronic kidney diseases	N00–N07, N11–12, N14–15, N25–N28, N39.1–2, B52.0, D59.3, E85.1, Q60–Q63, T82.4, T86.1	5	8	15	23	51	3.4	1.4	0.8	0.3	0.5
Cardiovascular disease	Balance of I00–I99	10	39	77	171	297	6.9	7.0	3.9	2.2	2.9
Cancer	C00–D48	3	30	52	65	150	2.1	5.4	2.6	0.8	1.4
Respiratory diseases	J00–J99	n.p.	n.p.	24	29	62	n.p.	n.p.	1.2	0.4	0.6
Digestive diseases	K00–K93	3	4	20	14	41	2.1	0.7	1.0	0.2	0.4
Infectious diseases	A00–B99	n.p.	11	n.p.	11	32	n.p.	2.0	n.p.	0.1	0.3
Other endocrine diseases	Balance of E00–E89	n.p.	n.p.	11	10	25	n.p.	n.p.	0.6	0.1	0.2
Musculoskeletal system	M00–M99	n.p.	3	n.p.	8	16	n.p.	0.5	n.p.	0.1	0.2
Other genitourinary diseases	Balance of N00–N99	n.p.	n.p.	6	16	23	n.p.	n.p.	0.3	0.2	0.2
External causes	V01–Y98	3	3	7	7	20	2.1	0.5	0.4	0.1	0.2
Other	D50–D89, F00–F99, G00–G99, L00–L99, balance of Q00–Q99, R00–R99	5	7	6	10	28	3.4	1.3	0.3	0.1	0.3
Total		**145**	**560**	**1,989**	**7,727**	**10,421**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(continued)

Table A1.2 (continued): Age distribution of causes of death, underlying only, by age group at death, 2003–2007

Underlying cause of death	ICD-10 code/s	0–54	55–69	70–79	80+	Total	0–54	55–69	70–79	80+	Total
KRT-treated				**Number**					**Per cent**		
Chronic renal failure	N18	27	71	111	94	304	8.4	9.4	12.0	18.0	12.0
Hypertensive renal failure	I12.0, I13.1, I13.2	7	18	41	39	105	2.2	2.4	4.4	7.5	4.2
Unspecified kidney failure	N19	n.p.	18	n.p.	12	59	n.p.	2.4	n.p.	2.3	2.3
Diabetic nephropathy	E10.2, E11.2, E12.2, E13.2, E14.2	9	20	14	8	51	2.8	2.6	1.5	1.5	2.0
Other diabetes	Other E10–E14 codes	81	151	118	33	383	25.1	20.0	12.7	6.3	15.2
Other chronic kidney diseases	N00–N07, N11–12, N14–15, N25–N28, N39.1–2, B52.0, D59.3, E85.1, Q60–Q63, T82.4, T86.1	5	26	39	21	91	1.5	3.4	4.2	4.0	3.6
Cardiovascular disease	Balance of I00–I99	61	189	254	173	677	18.9	25.0	27.4	33.1	26.8
Cancer	C00–D48	36	104	153	48	341	11.1	13.8	16.5	9.2	13.5
Respiratory disease	J00–J99	11	16	28	25	80	3.4	2.1	3.0	4.8	3.2
Digestive diseases	K00–K93	19	31	47	16	113	5.9	4.1	5.1	3.1	4.5
Infectious diseases	A00–B99	12	27	15	20	74	3.7	3.6	1.6	3.8	2.9
Other endocrine diseases	Balance of E00–E89	10	17	13	6	46	3.1	2.3	1.4	1.1	1.8
Musculoskeletal system	M00–M99	19	15	21	6	61	5.9	2.0	2.3	1.1	2.4
Other genitourinary diseases	Balance of N00–N99	n.p.	7	n.p.	7	17	n.p.	0.9	n.p.	1.3	0.7
External causes	V01–Y98	12	15	22	8	57	3.7	2.0	2.4	1.5	2.3
Other	D50–D89, F00–F99, G00–G99, L00–L99, Balance of Q00–Q99, R00–R99	11	30	22	6	69	3.4	4.0	2.4	1.1	2.7
Total		**323**	**755**	**927**	**522**	**2,528**[(a)]	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Total includes one case for whom age at death was not available.

Notes:

1. n.p.—Not published due to small cell sizes.

2. Where smaller subsets of a diagnosis group have been analysed separately (such as with diabetic nephropathy, a subset of diabetes), these have been excluded from the analysis of the larger group.

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

Table A1.3: Age distribution of causes of death (underlying and associated), by age group at death, 2003–2007

Cause of death	ICD-10 code/s	0–54	55–69	70–79	80+	Total	0–54	55–69	70–79	80+	Total
Non-KRT-Treated				**Number**					**Per cent**		
Cardiovascular diseases	Balance of I00-I99	72	363	1,340	4,990	6,765	49.7	64.8	67.4	64.6	64.9
Chronic renal failure	N18	100	364	1,232	4,226	5,922	69.0	65.0	61.9	54.7	56.8
Unspecified renal failure	N19	29	125	522	2,518	3,194	20.0	22.3	26.2	32.6	30.6
Respiratory disease	J00–J99	44	176	580	2,174	2,974	30.3	31.4	29.2	28.1	28.5
Other genitourinary diseases	Balance of N00–N89	20	66	433	1,669	2,188	13.8	11.8	21.8	21.6	21.0
Hypertensive renal failure	I120, I131, I132	19	92	364	1,707	2,182	13.1	16.4	18.3	22.1	20.9
Symptoms, signs	R00–R99	21	81	247	1,056	1,405	14.5	14.5	12.4	13.7	13.5
Other diabetes	Other E10–E14 codes	29	170	359	608	1,166	20.0	30.4	18.0	7.9	11.2
Other endocrine diseases	Balance of E00–E89	31	69	217	624	941	21.4	12.3	10.9	8.1	9.0
Infectious diseases	A00–B99	35	94	230	557	916	24.1	16.8	11.6	7.2	8.8
Digestive diseases	K00–K93	32	86	200	573	891	22.1	15.4	10.1	7.4	8.6
Cancer	C00–D48	8	70	200	518	796	5.5	12.5	10.1	6.7	7.6
Musculoskeletal system	M00–M99	12	26	90	404	532	8.3	4.6	4.5	5.2	5.1
External causes	V01–Y98	15	35	95	274	419	10.3	6.3	4.8	3.5	4.0
Other chronic kidney diseases	N00–N07, N11–12, N14–15, N25–N28, N39.1–2, B52.0, D59.3, E85.1, Q60–Q63, T82.4, T86.1	10	14	29	68	121	6.9	2.5	1.5	0.9	1.2
Diabetic nephropathy	E10.2, E11.2, E12.2, E13.2, E14.2	n.p.	n.p.	15	21	51	n.p.	n.p.	0.8	0.3	0.5
Congenital abnormalities	Balance of Q00–Q99	8	0	0	4	12	5.5	0.0	0.0	0.1	0.1
Total		**145**	**560**	**1,989**	**7,727**	**10,421**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(continued)

Table A1.3 (continued): Age distribution of causes of death (underlying and associated), by age group at death, 2003–2007

Underlying cause of death	ICD-10 code/s	0–54	55–69	70–79	80+	Total	0–54	55–69	70–79	80+	Total
KRT-treated				**Number**					**Per cent**		
Cardiovascular diseases	Balance of I00–I99	186	495	663	355	1,699	57.6	65.6	71.5	68.0	67.2
Chronic renal failure	N18	184	442	561	320	1,508	57.0	58.5	60.5	61.3	59.7
Unspecified renal failure	N19	40	116	152	68	376	12.4	15.4	16.4	13.0	14.9
Respiratory diseases	J00–J99	42	132	187	120	482	13.0	17.5	20.2	23.0	19.1
Other genitourinary diseases	Balance of N00–N89	13	40	47	35	135	4.0	5.3	5.1	6.7	5.3
Hypertensive renal failure	I120, I131, I132	31	81	127	95	334	9.6	10.7	13.7	18.2	13.2
Symptoms, signs	R00–R99	31	82	82	56	252	9.6	10.9	8.8	10.7	10.0
Other diabetes	Other E10–E14 codes	142	285	238	83	748	44.0	37.7	25.7	15.9	29.6
Other endocrine diseases	Balance of E00–E89	43	101	95	42	281	13.3	13.4	10.2	8.0	11.1
Infectious diseases	A00–B99	78	154	159	78	470	24.1	20.4	17.2	14.9	18.6
Digestive diseases	K00–K93	52	112	137	69	370	16.1	14.8	14.8	13.2	14.6
Cancer	C00–D48	44	135	217	90	486	13.6	17.9	23.4	17.2	19.2
Musculoskeletal system	M00–M99	33	49	50	24	156	10.2	6.5	5.4	4.6	6.2
External causes	V01–Y98	49	112	118	61	340	15.2	14.8	12.7	11.7	13.4
Other chronic kidney diseases	N00–N07, N11–12, N14–15, N25–N28, N39.1–2, B52.0, D59.3, E85.1, Q60–Q63, T82.4, T86.1	19	60	64	34	177	5.9	7.9	6.9	6.5	7.0
Diabetic nephropathy	E10.2, E11.2, E12.2, E13.2, E14.2	12	32	22	10	76	3.7	4.2	2.4	1.9	3.0
Congenital abnormalities	Balance of Q00–Q99	n.p.	3	n.p.	n.p.	7	n.p.	0.4	n.p.	n.p.	0.3
Total		**323**	**755**	**927**	**522**	**2,528**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

Notes:

1. n.p.—Not published due to small cell sizes.
2. Where smaller subsets of a diagnosis group have been analysed separately (such as with diabetic nephropathy, a subset of diabetes), these have been excluded from the analysis of the larger group.
3. Columns will not add to total as multiple causes of death can be recorded. Total for KRT-treated deaths includes one case for whom age at death was not available.

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

Table A1.4: Number of KRT-treated and non-KRT-treated cases among Aboriginal and Torres Strait Islander people, by age group at ESKD onset, 2003–2007

Age group (years)	KRT-treated	Non-KRT-treated	Total
0–34	97	5	102
35–39	75	6	81
40–44	116	7	123
45–49	154	7	161
50–54	172	13	185
55–59	149	28	177
60–64	115	15	130
65–69	64	28	92
70–74	40	18	58
75–79	10	23	33
80+	5	46	51
Total	**997**	**196**	**1,193**

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

Sensitivity analysis

This section contains recalculations of the main results presented in this report with the non-KRT cases who died with an associated cause of death of chronic renal failure, end-stage (ICD-10 code N18.0) removed.

Table A1.5: Total incidence of ESKD, by sex, 2003–2007

	Without associated N18.0	With associated N18.0
	Number of cases	
Males	10,922	11,500
Females	9,486	9,870
Total	**20,408**	**21,370**
	Age-standardised rate (per 100,000 population)[(a)]	
Males	23.1	24.4
Females	15.6	16.3
Total	**19.0**	**19.9**

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

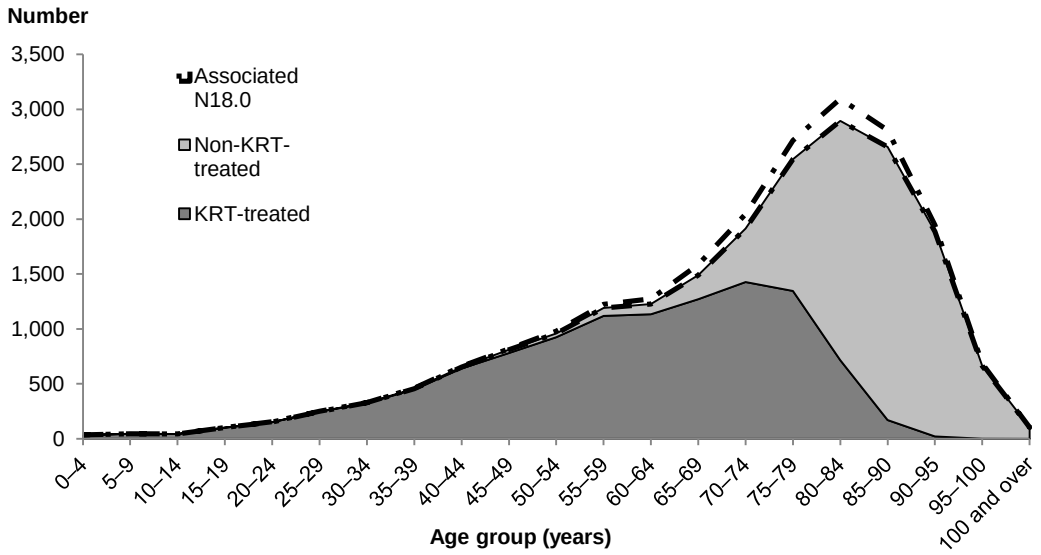
Source: Linked ANZDATA Registry, AIHW National Mortality Database and National Death Index.

Table A1.6: Total incidence of ESKD by treatment status, 2003–2007

	Without associated N18.0	With associated N18.0
	Number of cases	
KRT-treated cases	10,949	10,949
Non-KRT-treated cases	9,459	10,421
Total	**20,408**	**21,370**
	Age-standardised rate (per 100,000 population)[(a)]	
KRT-treated cases	10.5	10.5
Non-KRT-treated cases	8.5	9.4
Total	**19.0**	**19.9**

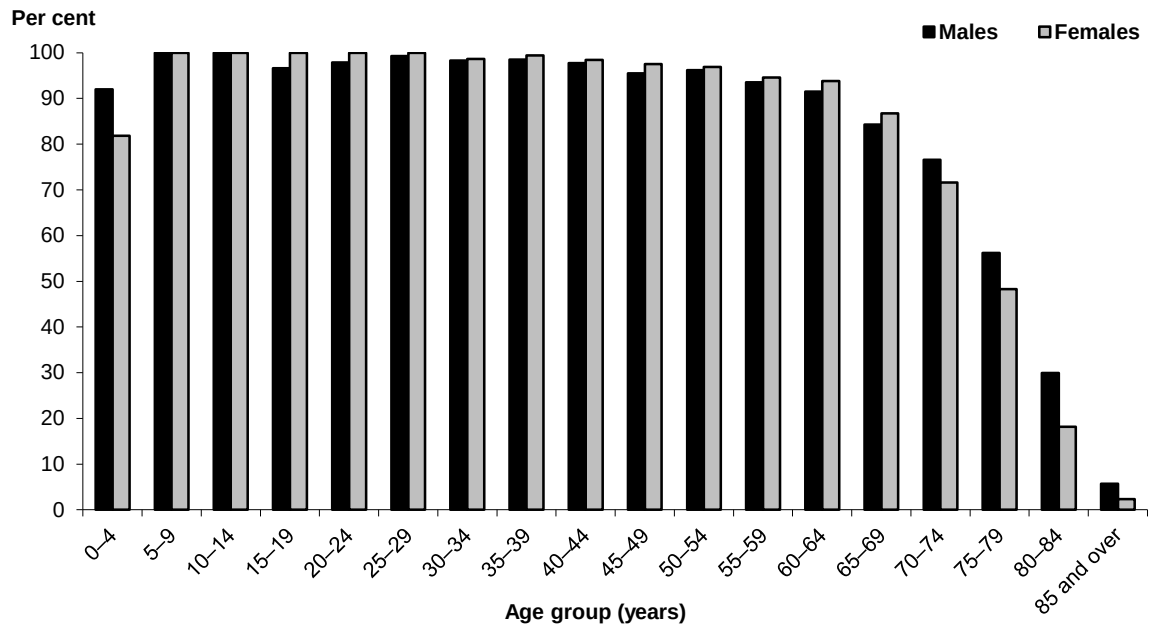
(a) Directly age-standardised to the Australian population as at 30 June 2001.

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



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

Figure A1.1: Number of KRT-treated and non-KRT-treated cases, by age group, associated N18.0 separated, 2003–2007



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

Figure A1.2: Proportion of all cases who are KRT-treated, by age group and sex, without associated N18.0, 2003–2007

Table A1.7: Total incidence of ESKD, by sex and Indigenous status, 2003–2007

	Without associated N180			With associated N180		
	Indigenous	Non-Indigenous	Not stated	Indigenous	Non-Indigenous	Not stated
			Number of cases			
Males	520	7,156	32	542	7,491	33
Females	616	6,073	33	651	6,273	34
Total	**1,136**	**13,229**	**65**	**1,193**	**13,764**	**67**
			Age-standardised rate (per 100,000 population)[(a)]			
Males	107.4	21.6	—	114.6	22.7	—
Females	108.3	14.3	—	115.3	14.7	—
Total	**107.3**	**17.6**	**—**	**114.2**	**18.3**	**—**

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

Notes

1. Only New South Wales, Queensland, Western Australia, South Australia and the Northern Territory are included.
2. — nil or rounded to zero.

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

Appendix 2

Data sources

Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry

In Australia, people who develop ESKD and undergo KRT—dialysis or kidney transplantation—are registered with the ANZDATA Registry. It compiles data on incidence and prevalence of KRT-treated ESKD, complications, comorbidities and patient deaths. All relevant hospitals and related satellite units in Australia participate. The ANZDATA Registry does not use the International Classification of Diseases (ICD) to code cause of death.

AIHW National Mortality Database

The AIHW National Mortality Database is a national collection of de-identified information for all deaths in Australia maintained by the AIHW. Information on the characteristics and causes of death of the deceased is provided by a medical practitioner certifying the death on the Medical Certificate Cause of Death, or by a coroner. The data are collected by the Registrars of Births, Deaths and Marriages in each state/territory. The Australian Bureau of Statistics collates these data, and code them according to the rules set down in the International Classification of Diseases (ICD). The underlying cause of death is the condition that initiated the train of events leading directly to death; an associated cause is any other condition that is considered to have contributed to the death.

Table A2.1: ICD-10 codes used to define diagnosis groups for mortality causes of death

Condition	Code/s
Used to define CKD-related deaths in mortality data	
Chronic renal failure	N18
Hypertensive renal failure	I12.0, I13.1, I13.2
Unspecified renal failure	N19
Diabetic nephropathy	E10.2, E11.2, E12.2, E13.2, E14.2
Other chronic kidney disease	N00–N07, N11–12, N14–15, N25–N28, N39.1, N39.2, B52.0, D59.3, E85.1, Q60–Q63, T82.4, T86.1
Used to define other deaths in mortality data	
Diabetes	E10–E14 codes
Cardiovascular disease	I00–I99
Cancer	C00–D48
Respiratory diseases	J00–J99
Digestive diseases	K00–K93
infectious diseases	A00–B99
Endocrine diseases	E00–E89
Musculoskeletal system	M00–M99
Other genitourinary diseases	N00–N99
Congenital abnormalities	Q00–Q99
External causes	V01–Y98
Symptoms, signs and other ill-defined conditions	R00–R99

Note: Where smaller subsets of a diagnosis group have been analysed separately in this report (such as with diabetic nephropathy, a subset of diabetes), these have been excluded from the analysis of the larger group.

Reporting of Indigenous data

The Australian Bureau of Statistics has assessed the quality of Indigenous deaths in death registration data by states and territories in the Census Data Enhancement Mortality Quality Study. This study involved linking Census records with death registration records to look at differences in reporting of Indigenous status across the two data sets. This assessment indicates that the Indigenous identification rate is 87% or higher for New South Wales, Queensland, Western Australia and the Northern Territory, and about 65% for the remaining jurisdictions. Historically, Indigenous identification in South Australia, Western Australia and the Northern Territory has been of sufficient quality to include in analyses from 1991 onwards. Queensland was included in the analysis from 1998, and in 2010 a decision was made to include data from New South Wales from 2001 onwards. The proportion of the Indigenous population covered by these jurisdictions is 89%, and these are used to provide indicative national information.

National Death Index

The National Death Index is a database developed and maintained by the AIHW. The database is a listing of all deaths that have occurred in Australia since 1980. It can be combined with the AIHW National Mortality Database to include demographic and cause of death information. Unlike the ANZDATA Registry, underlying and associated cause of death are coded in the mortality data using the ICD.

Methods

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, different geographic areas and/or different population groups. Definitions are included in the *National health data dictionary* (AIHW 2006).

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

Direct age-standardisation applies the age-specific rates to a 'standard population' 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 that are age-standardised, such as the incidence rates presented in this report, the population at risk is the total population. For these types of rates, the Australian population as at 30 June 2001 has been used as the standard. Treatment rates are different, however, with the denominator being a subset of the whole population—people who have ESKD. For these calculations, the total number of new cases of ESKD over the reference period was used as the standard population.

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: Sum 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.

The age-standardised rates presented in this report have been calculated using the age groups 0–29 years then 10-year age groups to 80 years and over.

Significance testing

The rate measured for a population in a given year based on a complete count can be considered as a sample of one of a large number of possible measurements, all of which cluster in a normal distribution (bell curve) around the 'true' (unknown) rate of the population. Calculating a confidence interval for a rate based on a complete count recognises that an observed rate is not a precise estimate of the underlying rate.

Typically, rates based on large numbers provide stable estimates from one year to the next. Conversely, rates based on small numbers might fluctuate dramatically from year to year, or differ considerably from one region to another, even when there is no meaningful difference. Meaningful analysis of differences in rates between regions or over time requires that the random variation in rates be quantified; this is especially important when rates or percentages have small numerators, as is the case with some analyses contained in this report.

There are several methods for calculating confidence intervals for these type of data. For this report the method described in Box A2.1 was chosen. Another commonly used method for these types of data (Dobson et al. 1991) results in almost identical confidence intervals at the national level. The confidence intervals are used to provide an approximate indication of the differences between rates. Where the confidence intervals of two rates do not overlap, the corresponding rates are statistically different from each other; that is, there is at least 95% confidence that the difference in a rate is greater than that which could be explained by chance.

In this report, where a comment has been made stating there is a difference between groups, the 95% confidence intervals do not overlap.

Box A2.1: Formulae for calculating standard errors and 95% confidence intervals

There are several methods for calculating standard errors and confidence intervals for administrative data. For this report the following method has been used:

For directly standardised rates:

Standard error of the age-standardised rate has been estimated as:

$$SE(ASR) = \sqrt{\left[\sum \left(N_i^2 p_i / n_i\right) / \left(\sum N\right)^2\right]}$$

95% confidence intervals:

for p' (age-standardised rate or ratio) as $p' \pm (1.96 \times SE(ASR))$

Where:

$_i$ = age group

N = number of subjects in standard population

R = number of events in standard population

P = standard population event rate (R/N)

p = special population event rate (r/n)

n = number of subjects in special population

r = number of events in special population

Populations used in this report

Population data are used throughout this report to calculate rates. The population data used are estimated resident populations derived from the Australian Bureau of Statistics Census

of Population and Housing. Estimated resident populations adjust Census data to add people missed by the Census and people overseas on census night, and to remove overseas visitors. Between census years, the estimated resident populations are updated using indicators of population change such as deaths, births and net migration. The estimated resident populations used in this report are based on the 2006 Census. Australia's Indigenous population is also calculated from the Census, and uses estimated resident populations as described above.

Where a rate is calculated for a calendar year—for example, with incidence and death data—the population used is the estimated resident populations as reported at 30 June of that year.

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

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