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A working paper using linked hospitalisation and deaths data from Western Australia and New South Wales

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Authoritative information and statistics to promote better health and wellbeing

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Contents

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Abbreviations

AIHW	Australian Institute of Health and Welfare
ANZDATA	Australia and New Zealand Dialysis and Transplant (Registry)
CHeReL	The Centre for Health Record Linkage
CKD	chronic kidney disease
CKDEAG	Chronic Kidney Disease Expert Advisory Group
COD	cause of death
CVD	cardiovascular disease
DOHWA	Department of Health Western Australia
ESKD	end-stage kidney disease
ICD-10-AM	International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification
KRT	kidney replacement therapy
MLK	Master Linkage Key
NMD	National Mortality Database
NHMD	National Hospital Morbidity Database
NSW	New South Wales
PPN	Project Person Number
WA	Western Australia
WADLS	Western Australia Data Linkage System

Summary

End-stage kidney disease (ESKD), the most severe form of chronic kidney disease (CKD), usually requires kidney replacement therapy (KRT) for patients to survive. Monitoring the impact of ESKD is important in planning for the future health needs of the population. One way to monitor the impact in Australia is to count the number of patients who receive KRT for their ESKD by using registry data and to some extent hospital data. But it is also important to identify people with ESKD who do not receive KRT, which can be done through analyses of hospital and mortality data.

This study aimed to assess the likelihood that a patient who is hospitalised with ESKD will have ESKD recorded on their death record. This will help to establish whether mortality records in Australia reflect the actual disease pattern of people with ESKD.

Linked hospitalisation and deaths data from NSW and WA were used to assess the level of agreement between the recording of ESKD in hospitalisation and deaths data. Agreement was assessed in both directions: forwards direction: (hospital→death agreement); and backwards direction: (death→hospital agreement). Additional analyses were performed estimating the time to death for both KRT-treated and non-KRT-treated patients.

Key findings

Agreement between the hospitalisation and death records of ESKD presence was relatively poor in both directions in WA and NSW:

- In WA (between 1 July 2008 and 31 December 2010), using the most recent and current definition of ESKD status:
  - 69% of people with an ESKD hospitalisation did not have ESKD in their death record (forward direction).
  - 40% of people with ESKD recorded in deaths data did not have an ESKD diagnosis in their hospitalisation records (backward direction).
- In NSW (between 1 July 2000 and 31 December 2007) the corresponding proportions were 88% (forward direction) and 23% (backward direction) for people aged 40 and over.

The agreement between hospital and mortality records did not vary by age in the forward direction but did in the backward direction. In WA, the proportion of people who had an ESKD cause of death but no corresponding ESKD hospitalisation was much higher in older age groups.

The data also showed that non-KRT-treated cases have a much shorter time to death than KRT-treated cases (median: 8 versus 799 days). Therefore, death date appears to be a good proxy for incident date (based on first hospitalisation) for non-KRT-treated cases.

Conclusion

This study confirms that the ESKD codes used in the mortality data to estimate ESKD incidence are conservative and therefore likely to underestimate the impact of ESKD. The results suggest that there is a high proportion of patients who are hospitalised with ESKD but do not have ESKD on their death certificate. However, it is not certain that everyone treated for ESKD is treated in hospital. Further linkage to the Australia and New Zealand Dialysis and Transplant (ANZDATA) Registry would help capture data on people treated with KRT outside hospitals.

1 Introduction

Background

Chronic kidney disease (CKD) is a common chronic disease in Australia, with around 1-in-10 Australians, or 1.7 million adults, showing biomedical signs of CKD. The most visible and severe outcome of CKD is end-stage kidney disease (ESKD), which usually requires kidney replacement therapy (KRT) to survive (see Box 1.1). Not all patients with ESKD receive KRT. Prognosis, anticipated quality of life (with or without KRT), treatment burden on the patient, co-morbidities and patient preference all play a part in the decision for or against KRT (Murtagh et al. 2007).

The number of people receiving KRT treatment for ESKD has tripled over the last 2 decades and is projected to increase by at least 45% in the next decade. These increases are largely due to increases in the prevalence of diabetes, but also due to the ageing population, changes in propensity to treat, and improvements in survival for dialysis and transplant patients (AIHW 2014). Given the increasing burden of ESKD, obtaining accurate and reliable estimates of new cases of ESKD each year is critical for the ongoing monitoring and surveillance of ESKD, as well as evaluating progress in disease prevention and management, both of which will inform healthcare policy and service planning.

Box 1.1: Definitions of kidney disease

Chronic kidney disease: All kidney conditions where a person has evidence of kidney damage and/or reduced kidney function, lasting at least 3 months, regardless of the specific diagnosis of disease or condition causing the disease. Many people do not know that they have kidney disease, as up to 90% of kidney function can be lost before symptoms appear (Kidney Health Australia 2014). Fortunately, simple tests of kidney function and damage can detect the early signs of CKD.

End-stage kidney disease: The most severe form of chronic kidney disease, usually requiring kidney replacement therapy for survival. KRT has two forms—a kidney transplant or dialysis. Dialysis is an artificial way of removing waste substances from the blood and is mostly provided in hospitals or satellite dialysis units, but can also be provided in a home setting.

The AIHW routinely uses mortality and hospitalisation data to monitor ESKD in Australia. Counting cases of ESKD in these datasets relies on accurate coding of ESKD using defined codes based on the World Health Organization's (WHO) International Statistical Classification of Diseases and Related Health Problems. In reporting on the incidence and mortality of ESKD, the AIHW uses a specific set of kidney failure cause-of-death codes which are likely to be conservative, as they focus predominantly on ESKD being the underlying cause to differentiate it from less severe chronic kidney disease (see Box 1.2). However, kidney failure is more often coded as an outcome of other diseases or conditions (referred to as an 'additional cause of death') rather than the condition initiating the train of events leading to death (referred to as the 'underlying cause of death'). Compiling a full profile of a patient's hospitalisation and death records would assist in establishing whether mortality records in Australia reflect the actual disease pattern of people with ESKD.

Box 1.2: Total incidence of ESKD

Estimating the number of people that develop ESKD over a specific period (incidence) provides an important foundation for determining the ESKD-related burden in Australia. Further, policymakers can use this information to develop strategies to reduce the burden of ESKD.

Previously, the incidence of ESKD was only available for those treated with KRT in Australia, based on data from the Australian and New Zealand Dialysis and Transplant (ANZDATA) Registry, which includes data on virtually all persons who develop ESKD and undertake KRT. However, not all people with ESKD receive KRT, for various reasons, including medical reasons (such as suitability for KRT), accessibility of services, and personal choice.

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

The first results of this method were published in 2010 as a National Healthcare Agreement performance indicator (COAG Reform Council 2010). The AIHW also uses these total incidence data for ESKD monitoring work (AIHW 2011; Sparke et al. 2013).

Assumptions

The total incidence methodology has several key assumptions, including:

1. Selected death codes capture all ESKD deaths

The total incidence methodology assumes that all ESKD deaths are coded with at least one of the codes shown in Table 2.2 (see Chapter 2—Methods). However, the codes chosen to represent ESKD are likely to underestimate ESKD because they focus predominantly on ESKD being the underlying cause of death, to differentiate ESKD from less severe stages of CKD.

Other potential limitations of this method are that it relies on accurate and consistent coding of causes of death and that it cannot count those people with non-KRT-treated ESKD who have not yet died, or whose ESKD did not contribute to their death. There is also little information on the veracity of cause-of-death coding in Australia or how this may vary by jurisdiction.

2. Year of death is a proxy for incident year for untreated ESKD cases

The ESKD total incidence method also assumes year-of-death registration is a proxy for incidence year, based on the assumption that survival for those with ESKD who do not receive KRT is likely to be short.

Aim of the study

The main objective of this study is to assess the level of agreement between hospital diagnoses and causes of death for people with ESKD in order to evaluate the completeness of mortality and hospital diagnostic information, which in turn influences the accuracy of the incidence methodology described above.

This study uses linked hospitalisation and deaths data from two states that have well-established data linkage programs, NSW and WA, to assess the likelihood of a patient who is hospitalised and diagnosed with ESKD having ESKD recorded on their death record when they die.

This study also estimates the time to death for those patients hospitalised for ESKD who do not receive kidney replacement therapy, to assess whether year-of-death registration is a good proxy for incidence year (a key assumption of the incidence methodology).

Structure of the paper

This working paper is structured as follows:

- Chapter 2 outlines the methods used to obtain and analyse the linked data.
- Chapter 3 presents results on the level of agreement in coding between hospital diagnoses and causes of death.
- Chapter 4 focuses on mortality coding, specifically ESKD cause of death codes, including a sensitivity analysis, and an assessment of unspecified kidney failure codes.
- Chapter 5 describes the estimation of time to death for people who do not receive kidney replacement therapy.
- Appendix A contains supplementary tables and figures.
- Appendix B includes further information on the linked data sets and definitions used in the analyses.
- Appendix C contains summary tables about the WA and NSW linked data sets provided to AIHW.

2 Methods

This chapter describes the linked data used in this report and the methods used for identifying ESKD cases in mortality and hospitalisation data. More detailed information on the data provided is listed in Appendix B.

2.1 Linked data sources

Western Australia

Linked hospitalisation and deaths data were obtained from Department of Health Western Australia through the Data Linkage Branch (DLB), which manages the Western Australian Data Linkage System (WADLS).

New South Wales

Linked hospitalisation and deaths data were obtained from the NSW Ministry of Health and NSW Registry of Births, Deaths and Marriages through the Centre for Health Record Linkage (CHeReL).

More details about the data linkage methods used by NSW and WA are provided in Appendix B.

2.2 Data requested

All hospitalisation and death records for people within the *population of interest* were obtained by the AIHW. The *population of interest* was defined, for a specified period, as:

- people who have at least 1 hospitalisation where the principal or additional diagnosis was cardiovascular disease (CVD), chronic kidney disease (CKD) or diabetes; plus
- people who have died due to any cause of death.

The ICD-10-AM codes used to define CVD, diabetes and CKD hospitalisations are described in Appendix B.

Linked hospitalisation and deaths data were obtained from Data Linkage Western Australia for the period 1 July 1999 to 31 December 2010, following ethical approval by the Department of Health WA Human Research Ethics Committee (project #2012/30). The data were extracted in December 2012.

The same population of interest was used to apply for hospitalisation and deaths data from CHeReL in NSW. The project was approved by the NSW Population and Health Services Research Ethics Committee (reference HREC/12/CIPHS/84).

Given that the population of interest in NSW was larger than in WA, and given AIHW budgetary constraints, the dataset obtained from NSW was restricted to people aged 40 and over. Admitted patient hospitalisation data were supplied for the period 1 July 2000 to 31 December 2010; however, the deaths data cover the period 1 July 2000 to 31 December 2007 because more recent data were not available at the time.

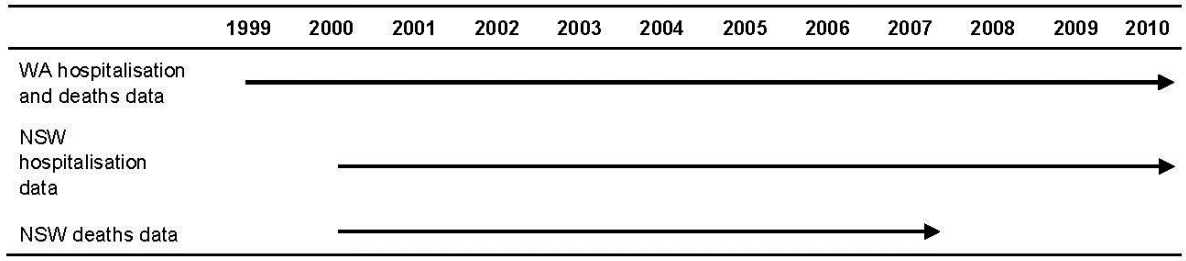


Figure 2.1: Time periods for the WA and NSW data sets

The hospitalisation data from both states consisted of hospital separation records from both public and private hospitals. From WA we obtained a total of 2,333,628 hospitalisation and death records, corresponding to 438,387 people. From NSW we obtained a 7,010,122 hospitalisation and death records, which corresponded to 1,496,319 people aged 40 and over (Table 2.1).

To assess the concordance of hospital diagnoses with cause-of-death coding for people with ESKD the study *population of interest* was defined as those with at least 1 hospitalisation record (of CVD, CKD or diabetes) and 1 death record:

- In WA there were 93,234 people with at least 1 hospitalisation record and 1 death record
- In NSW there were 233,571 people with at least 1 hospitalisation record and 1 death record

Table 2.1: Records received by AIHW in linked data sets from WA and NSW

	WA[a]		NSW[b]	
Linked data set	**People[c]**	**Episodes[e]**	**People[c]**	**Episodes[e]**
Hospitalised (no death)	330,789	1,384,950	1,172,500	5,238,299
Hospitalised and died[d]	93,234	934,314	233,571	1,681,575
Died but not hospitalised	14,364	. .	90,248	. .
Total	**438,387**	**2,333,628**	**1,496,319**	**7,010,122**

(a) WA data cover the period 1 July 1999 to 31 December 2010.

(b) NSW hospitalisation data cover the period 1 July 2000 to 31 December 2010; NSW deaths data cover the period 1 July 2000 to 31 December 2007. Data for NSW is for people aged 40 and over.

(c) The count of people consists of 1 individual counted once for all hospitalisations and/or deaths across the entire time period.

(d) The study population of interest.

(e) Includes hospitalisations and deaths. Hospitalisations are episodes of hospital care that start with the formal admission process and end with the formal separation process.

. . not applicable.

Sources: Government of Western Australia Department of Health and NSW Ministry of Health and NSW Registry of Births, Deaths and Marriages.

2.3 Definition of ESKD status

Deaths

Cause-of-death codes are either defined as the underlying cause of death (the condition that initiated the train of events leading directly to an individual's death) or the associated cause of death (causes, other than the underlying cause, that were instrumental in causing death). For each death, only 1 cause can be coded as the underlying cause; however there can be more than 1 associated cause. ESKD status was defined in the deaths data as shown in Table 2.2. These codes are based on the International Statistical Classification of Diseases and Related Health Problems (ICD) and are consistent with how ESKD deaths have been defined in the AIHW total incidence methodology.

There is one cause of death that is defined as 'Chronic renal failure—end stage' (N18.0) in mortality data. This code is included in the ESKD status definition where it is an underlying or associated cause of death. Also included in the definition are mortality codes with an underlying cause of death of 'kidney (renal) failure' more broadly (that is, not necessarily defined as end-stage). It is assumed that if kidney failure was severe enough to be the underlying cause then it is likely to be end-stage kidney disease.

Table 2.2: ESKD deaths—underlying or associated cause of death

ICD-10 codes	Definition
Underlying cause of death	
I12.0, I13.1, I13.2	Hypertensive renal disease
N18.0, N18.8, N18.9	Chronic renal failure
N19	Unspecified renal failure
Associated cause of death	
N18.0	Chronic renal failure—end-stage

Hospitalisations

ESKD status was defined in the hospitalisation data using the codes shown in Tables 2.3 and 2.4. These codes are based on the ICD-Australian Modification (ICD-AM). The hospital database contains records showing the reason why a person was admitted to hospital (identified as the principal diagnosis), and the presence of other disease conditions that required hospital treatment while they were in hospital (additional diagnosis or diagnoses).

Note that the coding system used in hospital data (ICD-10-AM) was updated a number of times in the analysis period (see Table A1). The main change was the introduction of chronic kidney disease (N18) staging in the 6th edition in 2008–09, which influences trends in hospitalisations where ESKD was an additional diagnosis, but not in the trend in ESKD as a principal diagnosis (see Figures A1 and A2).

Because of the effect of coding changes on the number of people with an additional diagnosis of ESKD, the WA data were split into pre- and post-2008–09 analyses (Chapter 3). The NSW data were not split as mortality data were only provided up to the end of 2007.

The ESKD hospitalisation codes also fall into two categories. The first category is the 'N' codes which relate to the coding of 'kidney failure', while the second category ('T' and 'Z' codes) relate to dialysis and transplant treatment for ESKD.

Table 2.3: ESKD hospitalisations (principal or additional diagnosis) 1999–00 to 2007–08

ICD-10-AM codes	Definition
N18.0 (ICD-10-AM 1–5 editions)	Chronic renal failure —End-stage renal disease
N18.8 (ICD-10-AM 1–5 editions)	Other chronic renal failure
N18.90 (ICD-10-AM 1–5 editions)	Unspecified chronic renal failure
T82.4	Mechanical complication of vascular dialysis catheter
T86.1	Kidney transplant failure and rejection
Z49	Care involving dialysis
Z94.0	Kidney transplant status
Z99.2	Dependence on kidney dialysis

Table 2.4: ESKD hospitalisations (principal or additional diagnosis) 2008–09 onwards

ICD-10-AM codes	Definition
N18.5 (ICD-10-AM 6th edition)	Chronic kidney disease—stage 5
T82.4	Mechanical complication of vascular dialysis catheter
T86.1	Kidney transplant failure and rejection
Z49	Care involving dialysis
Z94.0	Kidney transplant status
Z99.2	Dependence on kidney dialysis

3 Agreement between ESKD coding in hospitalisation and cause-of-death data

This chapter uses linked hospitalisation and deaths data from WA and NSW to assess the level of agreement between cause-of-death coding for ESKD in mortality data, and diagnosis of ESKD in hospital data. The ESKD total incidence methodology (see Box 1.2) relies on ESKD deaths being accurately recorded in mortality data.

This chapter aims to assess the level of agreement between hospital ESKD status and cause-of-death ESKD status both 'forwards' and 'backwards':

1. hospitalisation→death agreement (forwards)
2. death→hospitalisation agreement (backwards)

The analyses were separated into pre- and post-2008–09 data (see Chapter 2).

The post-2008–09 analysis includes more detailed disaggregation and investigation into the death codes that ESKD hospitalisation cases receive and hospital coding for cases that died with an ESKD cause of death, as this is the definition currently used for the coding of ESKD hospitalisations (Tables 2.3 and 2.4 show the differences between pre- and post-2008–09 definitions).

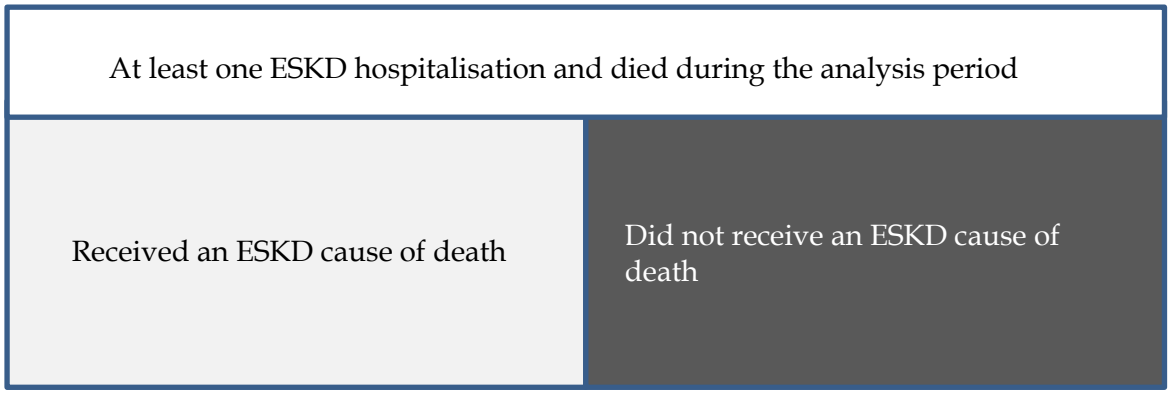
Post-2008–09 analysis is only presented for WA, as no NSW deaths data beyond 2007 were available at the time of the data request.

3.1 Forward concordance results (hospital→death agreement)

Key findings: Forward concordance (hospitalisation→death coding)

- Using the pre-2008–09 definition for ESKD hospitalisation status, in WA and NSW respectively, 86% and 88% of people with at least one hospital episode for ESKD who died during the analysis period *did not* have a corresponding ESKD cause of death.
- Using the 2008–09 onwards definition for ESKD hospitalisation status, 69% of people in WA with at least one hospital episode for ESKD who died during the analysis period *did not* have an ESKD cause of death.
- For people hospitalised with ESKD who died during the analysis period, all age groups had a similar likelihood of not having an ESKD cause of death.

The following analysis tests the accuracy of ESKD being recorded in mortality data by assessing the forward concordance between hospitalisation and deaths data—that is, the likelihood of cases that were hospitalised with ESKD and died during the analysis period (top white rectangular box) not receiving a corresponding ESKD cause of death (dark grey box) (Figure 3.1). Prior to assessing these data we hypothesised that if someone was ill enough to have ESKD in hospital and subsequently died, it is likely that the ESKD (see table 2.2 for definition) contributed to their death and therefore would be recorded on their death certificate.



Notes

1. All cases were hospitalised with ESKD and died during the analysis period.
2. Diagram not to scale.

Figure 3.1: Schematic representation of the study population of interest for the forward concordance between hospitalisation ESKD status and ESKD cause of death

Pre-2008–09 definition for ESKD hospitalisation status (WA and NSW)

Using the pre-2008–09 definition for ESKD hospitalisation status (see Table 2.3), almost 9 in 10 people hospitalised at least once for ESKD and who died did not have a corresponding ESKD cause of death—86% of people in WA (over the period 1 July 1999 to 31 December 2010) and 88% of people aged 40 years and over in NSW (1 July 2000 to 31 December 2007) (Table 3.1).

Table 3.1: People who have ever had a diagnosis of ESKD in hospital, using the pre-2008–09 definition, and a cause of death of ESKD, WA and NSW

WA[(a)]						
		ESKD cause of death				
		No		Yes		
		Number	*%*	*Number*	*%*	***Total***
ESKD hospitalisation (ever)	No	74,915	99.1	670	0.9	**75,585**
	Yes	10,825	86.0	1,769	14.0	**12,594**
	Total	**85,740**		**2,439**		**88,179**
NSW[(b)]						
		ESKD cause of death				
		No		Yes		
		Number	*%*	*Number*	*%*	***Total***
ESKD hospitalisation (ever)	No	197,508	99.3	1,298	0.7	**198,806**
	Yes	30,498	87.7	4,267	12.3	**34,765**
	Total	**228,006**		**5,565**		**233,571**

(a) WA analysis period = 1 July 1999 to 31 December 2010.

(b) NSW analysis period = 1 July 2000 to 31 December 2007, for people aged 40 and over.

Note: Deaths in NSW emergency departments are recorded as admitted patient episodes.

Sources: AIHW analysis of WA and NSW linked hospitalisation and deaths datasets.

There was little change over the analysis periods in the proportion of people with at least 1 hospital episode for ESKD who did not have an ESKD cause of death. For WA, the proportion ranged from 81% in 2009 to 90% in 2004, and for NSW from 86% in 2000 to 89% in 2005 (Table A2).

Post-2008–09 definition for ESKD hospitalisation status (WA)

Using the 2008–09 onwards definition for ESKD hospitalisation status improves the concordance between ESKD hospitalisation and ESKD cause of death—in WA 69% of people with at least 1 hospital episode for ESKD did not have an ESKD cause of death (Table 3.2).

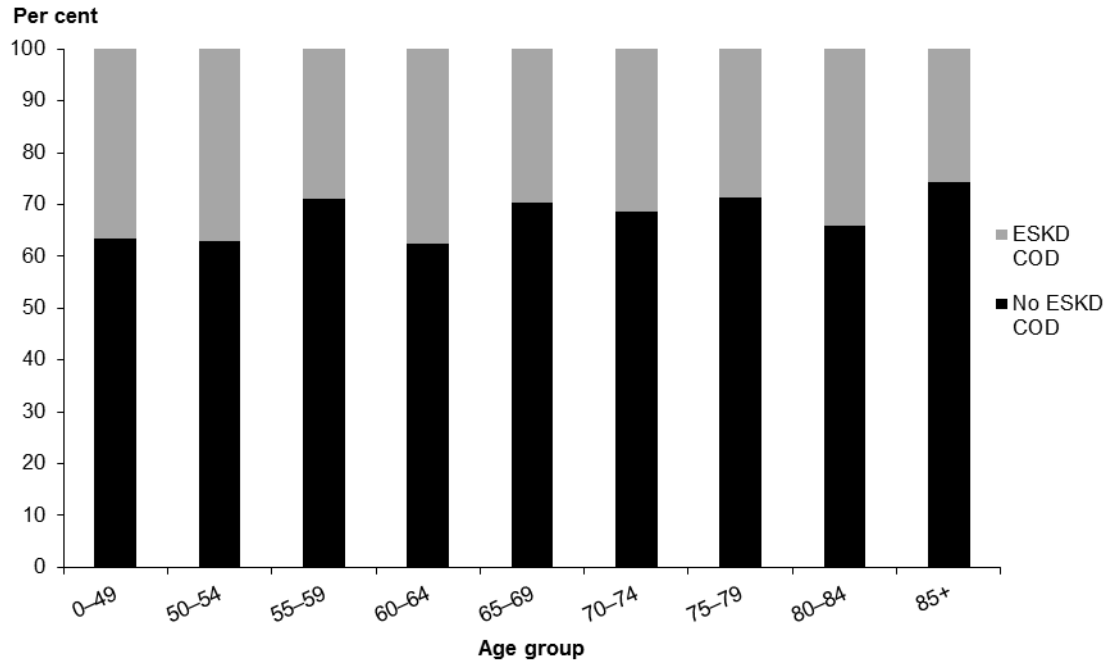
Table 3.2: People who have ever had a diagnosis of ESKD in hospital, using the 2008–09 onwards definition, and a cause of death of ESKD, WA, 1 July 2008–31 December 2010

		ESKD cause of death				
		No		Yes		
		Number	*%*	*Number*	*%*	***Total***
ESKD hospitalisation (ever)	No	15,581	98.4	251	1.6	**15,832**
	Yes	851	69.4	375	30.6	**1,226**
	Total	**16,432**		**626**		**17,058**

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

The proportion of people with at least 1 hospital episode for ESKD who did not have an ESKD cause of death ranged from 74% in 2008 to 69% in 2010 (by calendar year of death) (Table A3).

For people hospitalised with ESKD who died during the analysis period, all age groups had a similar likelihood of not having an ESKD cause of death, ranging from 63% among people aged 50 to 54 to 74% among those aged 85 years and over (Figure 3.2).



Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

Figure 3.2: People who have ever had a diagnosis of ESKD using the 2008–09 onwards definition, by ESKD cause of death (COD) status, by age group (age at death), WA, 1 July 2008–31 December 2010

The change in ESKD definition from 2008–09 onwards improves the concordance between ESKD hospitalisation and ESKD cause of death, but the proportion of people with no ESKD cause of death is still very high. These results are similar to people receiving kidney replacement therapy in the ANZDATA registry, where 56% of ANZDATA registrants who were first registered between 2003 and 2007 and died did not have an ESKD cause of death on their death certificate (AIHW 2011).

Cause-of-death information in more detail

Given that there are a substantial number of hospitalisations where ESKD is present that have no ESKD cause on their death certificate, establishing what was recorded on death certificates for these patients can help us understand their comorbidities. The analysis was restricted to the most recent definition of ESKD in hospital data, meaning only data from WA were able to be used. The most frequent underlying cause of death for people with at least 1 hospital episode for ESKD and who did not have a corresponding ESKD cause of death were unspecified chronic ischaemic heart disease (8%) and unspecified acute myocardial infarction (8%). Given that cardiovascular disease is a common comorbidity with ESKD, this is unsurprising. Diabetes, the most common cause of new cases of KRT-treated ESKD, was also a common underlying cause of death, with non-insulin-dependent diabetes and unspecified diabetes recorded in 11% of deaths (Table 3.3).

Table 3.3: Leading underlying causes of death for those people who have ever had an ESKD hospitalisation but no ESKD cause of death, WA, 1 July 2008–31 December 2010

Underlying cause of death (ICD-10)	Number	%
Chronic ischaemic heart disease, unspecified (I25.9)	71	8.3
Acute myocardial infarction, unspecified (I21.9)	67	7.9
Non-insulin-dependent diabetes mellitus, without complications (E11.9)	55	6.5
Unspecified diabetes mellitus, without complications (E14.9)	34	4.0
No code	28	3.3
Multiple myeloma (C90.0)	23	2.7
Malignant neoplasm of prostate (C61)	22	2.6
Malignant neoplasm of bronchus and lung, unspecified (C34.9)	18	2.1
Congestive heart failure (I50.0)	18	2.1
Chronic obstructive pulmonary disease, unspecified (J44.9)	14	1.6
Sepsis, unspecified (A41.9)	13	1.5

Note: 28 cases (3% of cases) did not have a cause-of-death code supplied with their death record.

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

3.2 Backward concordance results (death→hospital agreement)

Key findings: Backward concordance (death coding→hospital)

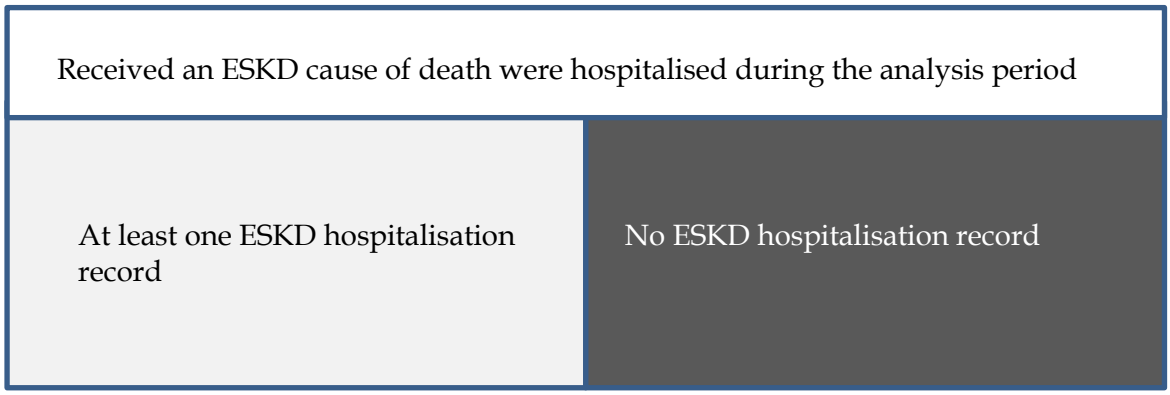
Using the pre-2008–09 definition for ESKD hospitalisation status:

- 28% and 23% of people with an ESKD cause of death and who were hospitalised *did not* have a hospital episode with a diagnosis of ESKD in WA and NSW, respectively.

Using the 2008–09 onwards definition, in WA:

- 40% of people with an ESKD cause of death and who were hospitalised *did not* have at least one hospital episode with a diagnosis of ESKD
- the likelihood of a person with an ESKD cause of death *not* having a previous hospitalisation with an ESKD diagnosis increased with increasing age.

The purpose of this section is to determine the number of cases that were hospitalised during the analysis period and received an ESKD cause of death (white box) but did not have a hospital episode with a diagnosis of ESKD (dark grey box) (see Figure 3.3).



Note: Figure not to scale.

Figure 3.3: Schematic representation of the study population of interest for the backward concordance (death→hospital agreement) between hospitalisation ESKD status and ESKD cause of death in linked data

Pre-2008–09 definition for ESKD hospitalisation status (WA and NSW)

Around 1 in 4 people with an ESKD cause of death and who were hospitalised did not have a hospital episode with a diagnosis of ESKD—28% of people in WA (over the period 1 July 1999 to 31 December 2010) and 23% of people aged 40 and over in NSW (over the period 1 July 2000 to 31 December 2007) (Table 3.4).

Table 3.4: People who have ever had a diagnosis of ESKD in hospital, using the pre 2008–09 definition, and a cause of death of ESKD, WA and NSW

WA[(a)]

		ESKD hospitalisation (ever)				
		No		Yes		
		Number	*%*	*Number*	*%*	***Total***
ESKD cause of death	No	74,915	87.4	10,825	12.6	**85,740**
	Yes	670	27.5	1,769	72.5	**2,439**
	Total	**75,585**		**12,594**		**88,179**

NSW[(b)]

		ESKD hospitalisation (ever)				
		No		Yes		
		Number	*%*	*Number*	*%*	***Total***
ESKD cause of death	No	197,508	86.6	30,498	13.4	**228,006**
	Yes	1,298	23.3	4,267	76.7	**5,565**
	Total	**198,806**		**34,765**		**233,571**

(a) WA analysis period = 1 July 1999 to 31 December 2010.

(b) NSW analysis period = 1 July 2000 to 31 December 2007 for people aged 40 and over.

Sources: AIHW analysis of WA and NSW linked hospitalisation and deaths datasets.

In WA, the proportion of people with an ESKD cause of death, but no hospital record with an ESKD diagnosis, fluctuated over time, ranging from 23% in 2000 to 41% in 2010 (Table A4). For NSW, the corresponding proportions did not vary substantially over time, ranging from 26% in 2000, to 21% in 2007 (Table A4).

Post-2008–09 onwards definition for ESKD hospitalisation status (WA)

Using the 2008–09 onwards definition for ESKD hospitalisation status, 40% of people with an ESKD cause of death and who were hospitalised did not have a hospital episode with a diagnosis of ESKD (over the period 2008 to 2010) (Table 3.5). This proportion ranges over time, from 43% in 2008 to 38% in 2010 (Table A5).

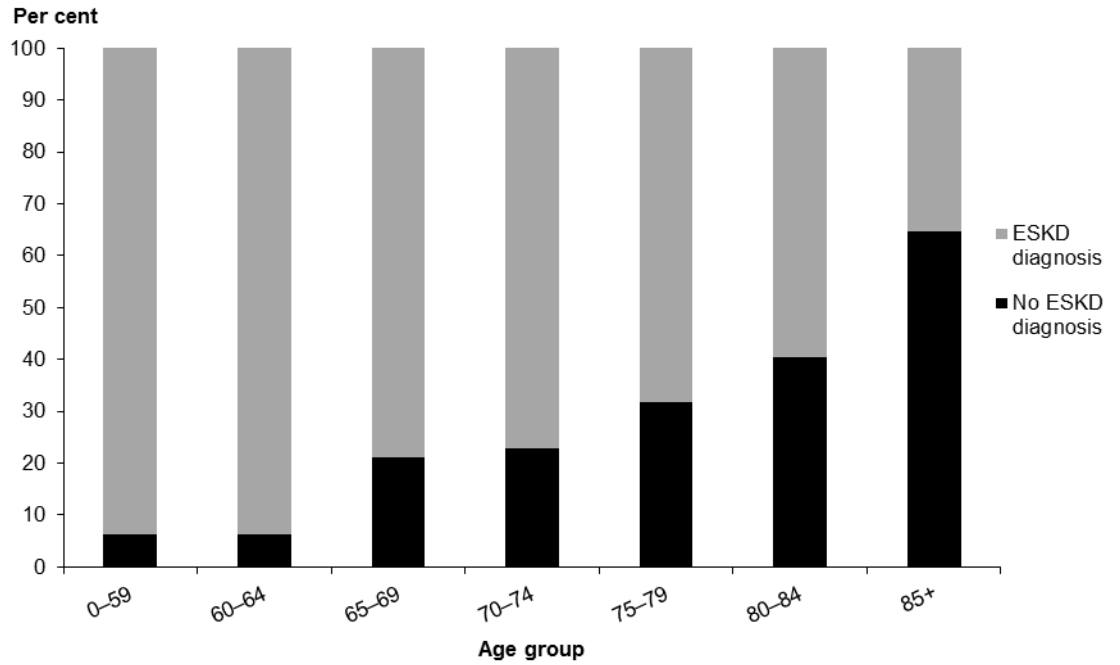
Table 3.5: People who had an ESKD cause of death and at least 1 hospital episode with ESKD (using the 2008–09 onwards definition), WA, 1 July 2008–31 December 2010

		ESKD hospitalisation (ever)				
		No		Yes		
		Number	*%*	*Number*	*%*	***Total***
ESKD cause of death	No	15,581	94.8	851	5.2	**16,432**
	Yes	251	40.1	375	59.9	**626**
	Total	**15,832**		**1,226**		**17,058**

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

In WA, the likelihood of a person with an ESKD cause of death not having a previous hospitalisation with an ESKD diagnosis increased with age, from 6% among 0–59 year olds to 65% among those aged 85 years and over. Those aged 85 and over were more likely to not

have had a previous hospitalisation with an ESKD diagnosis than to have had a diagnosis (Figure 3.4).



Note: No deaths with an ESKD cause of death were recorded for people aged 55–59 for those that were hospitalised at least once and died.

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

Figure 3.4: People with an ESKD cause of death by ESKD hospital diagnosis status, by age group (age at death), WA, 1 July 2008–31 December 2010

Principal diagnoses for people with an ESKD cause of death but no ESKD hospitalisation

For those people who had an ESKD cause of death recorded but no hospitalisation with an ESKD diagnosis, the most frequent principal diagnosis was congestive heart failure (10%) followed by care involving rehabilitation (7%). Unspecified acute kidney failure was recorded as the principal diagnosis in 2% of the hospitalisations (Table 3.6).

Table 3.6: Leading principal diagnoses for those people with an ESKD cause of death without an ESKD hospitalisation (2008–09 onwards definition) during the analysis period, WA, 1 July 2008–31 December 2010

Principal diagnosis (ICD-10-AM)	Number	%
Congestive heart failure (I50.0)	189	10.1
Care involving use of rehabilitation procedure, unspecified (Z50.9)	130	6.9
Atrial fibrillation and flutter (I48)	52	2.8
Left ventricular failure (I50.1)	42	2.2
Pneumonia, unspecified (J18.9)	39	2.1
Acute kidney failure, unspecified (N17.9)	37	2.0
Unstable angina (I20.0)	35	1.9
Urinary tract infection, site not specified (N39.0)	33	1.8
Acute subendocardial myocardial infarction (NSTEMI) (I21.4)	31	1.7
Holiday relief care (Z75.5)	31	1.7
Cellulitis of lower limb (L03.11)	27	1.4

Note: The same person may show up more than once in this table as people can have multiple hospitalisations.

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

3.3 Interpretation of the concordance results

The concordance between ESKD hospitalisation and ESKD cause of death in the backward direction is better than in the forward direction. However, the change in ESKD definition in hospital from 2008–09 onwards appears to have worsened the backward concordance, and improved the forward concordance results. The likelihood of cases that were hospitalised with ESKD not receiving an ESKD cause of death did not vary substantially by age (forward concordance—Figure 3.2). However, the proportion of people who had an ESKD cause of death but no corresponding ESKD hospitalisation was much higher in older age groups (backward concordance—Figure 3.4).

These age-related results raises the possibility that, if it is assumed that hospitalisation data record virtually all ESKD cases, there is a high proportion of deaths in older age groups that may be misclassified as having ESKD. This could lead to an overestimation in the incidence of untreated ESKD among these age groups, relative to younger age groups. However, it is also possible that the hospitalisation data do not record all ESKD cases, and to fully assess this it would be necessary to determine whether these cases are receiving health care outside of the hospital setting. Such analysis could involve linking to the ANZDATA registry to identify KRT-treated cases.

The overall poor forward concordance results presented in this chapter are broadly in line with the results from an earlier AIHW study on total incidence of ESKD in Australia (AIHW 2011) which showed that, for the individuals in that study who started KRT treatment between 2003 and 2007 and died during that period, only 44% had ESKD (as defined in Table 2.1) recorded on their death certificate. A further 44% of the KRT-treated cases had other CKD codes recorded on their death certificates, with the remaining 12% of KRT-treated ESKD cases having no record of CKD contributing to their death. If the same trend applies to the non-KRT-treated cases, there would be many more cases than we currently count (Sparke et al. 2013). This suggests that the codes used to identify ESKD cases in mortality data are likely to be conservative.

4 Mortality coding

Key findings of sensitivity analysis

- The overall poor forward concordance results for the WA and NSW data suggests that the standard codes used to identify ESKD cases in mortality data are likely to be conservative.
- The standard (conservative) ESKD mortality codes result in fewer actual ESKD cases being identified (poor sensitivity) in hospital data and proportionally fewer non-ESKD cases captured (good specificity).
- When non-conservative (broad) mortality coding is used, the opposite trend occurs—good sensitivity but poor specificity.

The results presented in Chapter 3 indicate that at least two-thirds of people hospitalised for ESKD who had died did not have a corresponding ESKD cause of death. Previous AIHW analysis linking ANZDATA to mortality data, using the same set of mortality codes, also showed that around half of people who started KRT treatment had deaths other than ESKD recorded on their death certificates. These findings suggest that the codes used to identify ESKD cases in mortality data are likely to be conservative—they therefore underestimate the contribution of ESKD to mortality. However, changing the death codes to reflect a less conservative method of identifying ESKD cases in mortality data has the potential to overestimate the number of ESKD cases.

This chapter aims to assess the effect of changing the death codes used to identify ESKD cases in mortality data, by undertaking a sensitivity analysis on the concordance between hospitalisation ESKD status and ESKD cause of death. WA linked data were used for this analysis and the 2008–09 onwards definition was used to identify ESKD hospitalisations because cause of death up until 2010 was available from WA at the time of the data request.

Two groupings of ESKD cause-of-death definitions were used in the sensitivity analysis:

- *Standard*: As described in the Methods section, Table 2.1.
- *Broad*: All codes used in the standard definition, but as both underlying and associated causes of death (broad definition).

The sensitivity analysis was also split by age, as the likelihood of a person with an ESKD cause of death not having a previous hospitalisation with an ESKD diagnosis increases substantially with age (Figure 4.2).

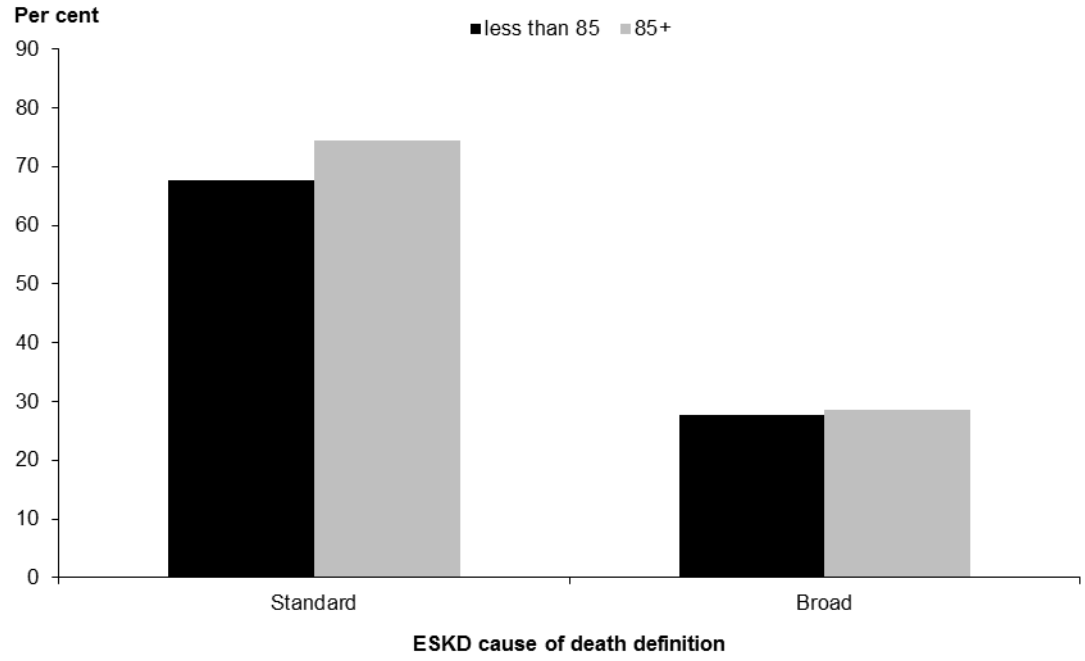
The interpretation of the sensitivity analysis is complicated by the fact that it is not certain that all ESKD cases in the study population receive an ESKD hospitalisation code.

The interpretation that follows assumes that ESKD cases receive an ESKD code in the hospital data; however, these results should be used with caution.

4.1 Sensitivity analysis

Forward concordance

Using the broad definition improves the concordance between ESKD hospitalisation and ESKD cause of death. The proportion of people with at least 1 ESKD hospitalisation who *did not* receive an ESKD cause of death decreases substantially from 69% when the standard definition is used to 28% when the broad definition is used (Table A6). There was little difference in the proportions for those aged over 85 compared to those under 85 when the broad definition is used (Figure 4.1, Table A6).

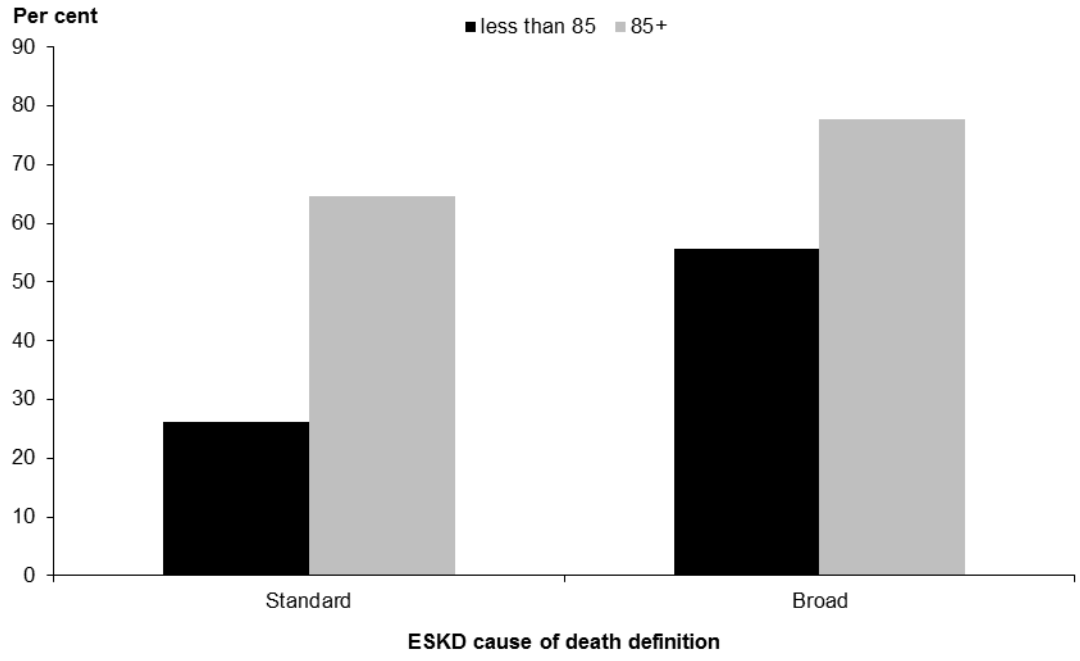


Source: AIHW analysis of the WA linked hospitalisation and deaths data set.

Figure 4.1: People who have ever had an ESKD hospital diagnosis but no ESKD cause of death using different ESKD cause of death definitions, by age group, WA, 1 July 2008–31 December 2010

Backward concordance

The proportion of people who had an ESKD cause of death but no ESKD hospital diagnosis increased with the broad definition—from 40% based on the standard definition to 65% when the broad definition is used (Table A6). For both broad and standard definitions the proportion of people with an ESKD cause of death but no ESKD hospital diagnosis was higher for those aged 85 and over than those aged less than 85—this was particularly so based on the standard definition (Figure 4.2, Table A6).



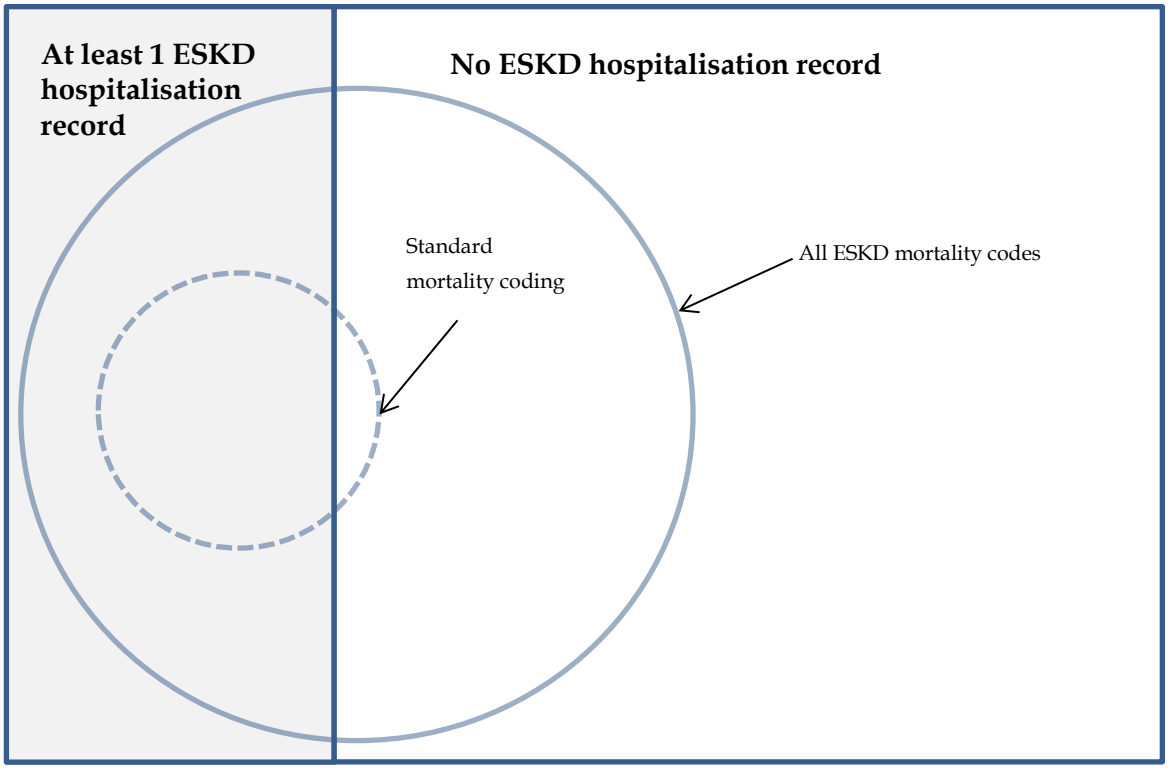
Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

Figure 4.2: People who have an ESKD cause of death but no ESKD hospital diagnosis, using different ESKD cause of death definitions, by age group, WA, 1 July 2008–31 December 2010

Interpretation of sensitivity analysis

The use of differing mortality codes results in a trade-off between sensitivity and specificity. Sensitivity refers to the proportion of actual ESKD cases (identified in hospital data) that are recorded as having ESKD in mortality data (reflected in the forward concordance results—Figure 4.1). Specificity refers to the proportion of cases that do not have ESKD (according to hospital data) that are coded as not having ESKD in mortality data (reflected in the backward concordance results—Figure 4.2).

The tradeoff between sensitivity and specificity for the standard and broad mortality definitions is illustrated in Figure 4.3.



Notes

1. All cases included in this figure were for people who were hospitalised and died during the analysis period.
2. The shaded area represents all people who died during the analysis period and were hospitalised with ESKD.
3. The white area represents all people who died during the analysis period but were not hospitalised with ESKD.
4. Cases within the solid circle represent people who received any mortality code from Table 2.1, either as an underlying or associated cause of death (broad definition).
5. Cases within the dashed circle represent cases that received a cause-of-death code from the standard coding list (conservative coding).

Figure 4.3: Schematic representation of the trade-off between sensitivity and specificity of identifying ESKD using standard or broad ESKD mortality codes.

When all ESKD mortality codes (solid circle) are used, a larger number of hospital cases are identified. This results in more actual ESKD cases being identified in hospital data (good sensitivity) but also higher identification of non-ESKD cases in hospital data (poor specificity). The opposite trend occurs when the standard (conservative) mortality codes are used—fewer actual ESKD cases are identified (poor sensitivity) in hospital data but proportionally fewer non-ESKD cases are also captured in hospital data (good specificity).

The results in Figure 4.1 and 4.2 appear to indicate that the backward concordance—people who have ESKD cause of death but no ESKD hospital diagnosis—is poorer for older people (those aged 85 and over) for both the standard and broad mortality definitions. There is little difference for the forward concordance.

This analysis leaves an open question as to which definition would be best to use. The answer would likely depend on the research question. Linking to ANZDATA would better help us understand how sensitive and specific these definitions are. Further, the poorer backward concordance in those aged over 85 suggests that further work would be required by age to assess these codes. It may be worth considering using different codes for estimating

incidence in different age groups or only estimating incidence using mortality data in people under a certain age.

4.2 Unspecified kidney failure (N19) mortality analysis

Key findings

- The ICD-10 code for unspecified kidney failure (N19) in mortality data has been included in the definition of ESKD (Table 2.1) under the assumption that most people who die of kidney failure are likely to have had the chronic condition.
- In WA, 39% of people who died with N19 as an underlying cause of death were assessed in this analysis to have the chronic condition, while another 27% *did not* have a CKD diagnosis in any of their hospitalisation records prior to death.
- In NSW, 30% of people with an N19 underlying cause of death were assessed in this analysis to have the chronic condition, while another 30% *did not* have a CKD diagnosis in any of their hospitalisations prior to death.

In performing the previous analysis we have assumed that all ESKD deaths are coded with at least one of the codes shown in Table 2.1 (see Chapter 2 – Methods). Unspecified kidney failure (ICD-10 code N19) as an underlying cause of death has been included in the definition of ESKD under the assumption that most people who die of kidney failure are likely to have had the chronic condition. However, this assumption has not been validated.

This section assesses hospital codes and the pattern of admissions over time for cases with a death code of unspecified kidney failure to test whether this code captures chronic cases of kidney failure, or acute cases. People with an N19 underlying cause of death were classified into one of the following categories:

- *Probably acute*: only 1 CKD hospitalisation with an Acute Kidney Failure code (N17) within 1 month of death and where the CKD length of stay in hospital is less than 3 months;
- *Possibly acute*: only 1 CKD hospitalisation within 1 month of death and where the CKD length of stay in hospital is less than 3 months (and not 'probably acute');
- *Chronic*: 2 or more CKD hospitalisations over more than 3 months or CKD length of stay in hospital is greater than 3 months;
- *Unknown*: 1 or more CKD hospitalisations within less than 3 months before death (and none earlier) and CKD length of stay in hospital is less than 3 months;
- *No CKD*: no CKD diagnoses in any of their hospitalisations.

Hospitalisations with an unspecified kidney failure death

Around 1 in 4 people who were hospitalised at least once and died with ESKD had an underlying cause of death recorded as 'unspecified kidney failure'—27% of people in WA (1 July 1999 to 31 December 2010) and 23% of people aged 40 years and over in NSW (1 July 2000 to 31 December 2007) (Table 4.1).

Table 4.1: People with an underlying cause of death recorded as 'unspecified kidney failure', by category, WA[(a)] and NSW[(b)]

Category	Number of people		%	
	WA	**NSW**	**WA**	**NSW**
Probably acute	49	100	8.9	8.2
Possibly acute	74	183	13.5	15.0
Unknown	49	158	8.9	12.9
Chronic	211	363	38.5	29.7
No CKD diagnosis	145	371	26.5	30.3
Other[(c)]	20	48	3.6	3.9
Total	**548**	**1,223**	**100.0**	**100.0**

(a) WA data period = 1 July 1999 to 31 December 2010.

(b) NSW data period = 1 July 2000 to 31 December 2007 for people aged 40 years and over.

(c) People in the 'Other' category did not fit the criteria of the other 5 named categories as they only had 1 CKD hospital episode more than 3 months prior to their death and with a length of survival of less than 3 months.

Sources: AIHW analysis of WA and NSW linked hospitalisation and deaths datasets.

Based on the classifications defined above, 39% of people in WA with an underlying cause of death of unspecified kidney failure were classified as having the chronic condition based on their previous hospitalisations; 27% did not have a diagnosis of CKD in any of their hospitalisations. In NSW the corresponding proportions were 30% and 30%, respectively.

In the WA data, people with *No CKD diagnosis* in any of their hospital records were more likely to be older, with the majority aged 85 and over. (Figure A3). It should be noted that the greatest number of cases falling under 5 different classifications occurred in older age groups (Figure A3), reflecting the higher number of deaths in these age groups.

Of the 145 people in WA with an underlying cause of death of unspecified kidney failure and no CKD diagnosis listed on their hospital records (Table 4.1), 18% had a diabetes diagnosis, while 99% had a CVD diagnosis (as either a principal or additional diagnosis).

Principal diagnoses

Table 4.2 shows the top 10 principal diagnoses during hospitalisation for people with unspecified kidney failure as an underlying cause of death but no CKD diagnoses during any of their hospitalisations. Note these are hospital episodes, therefore 1 person can have more than 1 hospital episode during the analysis period. Data are for WA only because cause-of-death data up until 2010 were available from WA at the time of the data request.

The most common hospitalisations were care involving use of an unspecified rehabilitation procedure (7%), and congestive heart failure (5%).

Table 4.2: Leading principal diagnoses for hospitalisations with 'unspecified kidney failure' (N19) as the underlying cause of death, but no CKD hospital diagnoses, WA, 1 July 1999–31 December 2010

Principal diagnosis (ICD-10-AM)	Number	%
Care involving use of rehabilitation procedure, unspecified (Z50.9)	43	7.2
Congestive heart failure (I50.0)	30	5.0
Unstable angina (I20.0)	19	3.2
Pharmacotherapy session for neoplasm (Z51.1)	19	3.2
Atrial fibrillation and flutter (I48)	18	3.0
Angina pectoris, unspecified (I20.9)	16	2.7
Acute subendocardial myocardial infarction (NSTEMI) (I21.4)	13	2.2
Chronic obstructive pulmonary disease with acute exacerbation, unspecified (J44.1)	13	2.2
Urinary tract infection, site not specified (N39.0)	13	2.2
Acute kidney failure, unspecified (N17.9)	11	1.8
Left ventricular failure (I50.1)	10	1.7
Syncope and collapse (blackout and fainting) (R55)	10	1.7
Person awaiting admission to residential aged care service (Z75.11)	10	1.7
Pneumonia, unspecified (J18.9)	9	1.5
Transient cerebral ischaemic attack, unspecified (G45.9)	7	1.2
Fracture of subcapital section of femur (S72.03)	7	1.2
Fracture of intertrochanteric section of femur (S72.11)	7	1.2
Total number of hospitalisation records	**596**	

Note: The same person may show up more than once in this table as people can have multiple hospitalisations.

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

5 Time-to-death analysis

Key findings

- Hospital data show that compared to KRT-treated cases, non-KRT-treated cases have a shorter mean time to death (166 days versus 1,057 days) and a shorter median time to death (8 versus 799 days).
- Death date appears to be a good proxy for incident date (based on first hospitalisation) for those cases that do not receive KRT.

The total ESKD incidence methodology developed by AIHW (AIHW 2011) counts people receiving kidney replacement therapy (KRT) for their ESKD and people who do not. Data linkage (between ANZDATA and national mortality data) is used to estimate the number of new cases of ESKD not treated with KRT and to ensure that people treated with dialysis or transplant who die during the study period are only counted once. One of the key assumptions of the total incidence methodology is that year of death registration is a proxy for incidence year for those cases that do not receive KRT for their ESKD. This is based on the assumption that survival for people with ESKD who are not receiving KRT is likely to be short (Joly et al. 2003).

The purpose of this chapter is to validate this assumption using linked hospital and deaths data. Data from WA only were used because cause-of-death data up until 2010 were available from WA at the time of the data request. Using the date of first admission to hospital for ESKD and estimating the time to death for those who do not receive KRT, it will be possible to better inform this assumption. However, the analysis presented in this chapter does not account for any period between the actual onset of ESKD and the first hospitalisation for it.

Box 5.1 shows the criteria used to identify people with non-KRT-treated ESKD in hospital.

Box 5.1: Definition of non-KRT-treated ESKD in hospital

A case with a principal or additional diagnosis of:

N18.0 (ICD-10-AM 1st–5th editions): Chronic renal failure—end-stage renal disease

or

N18.5 (ICD-10-AM 6th edition): Chronic kidney disease—stage 5

But not a principal or additional diagnosis of:

T82.4: Mechanical complication of vascular dialysis catheter

T86.1: Kidney transplant failure and rejection

Z49: Care involving dialysis

Z94.0: Kidney transplant status

Z99.2: Dependence on kidney dialysis

5.1 Time-to-death of people with non-KRT-treated ESKD in hospital

Of the 1,359 people who had an initial episode of non-KRT-treated ESKD and did not have at least 1 hospitalisation for KRT treatment recorded prior to their death:

- Only 24% had an ESKD cause of death.
- The mean time to death was 166 days, and the median was 8 days.
- The mean age at initial non-KRT-treated hospitalisation was 78 years, and the median was 80 years.

By comparison, of the 1,859 people who had an initial episode of KRT-treated ESKD:

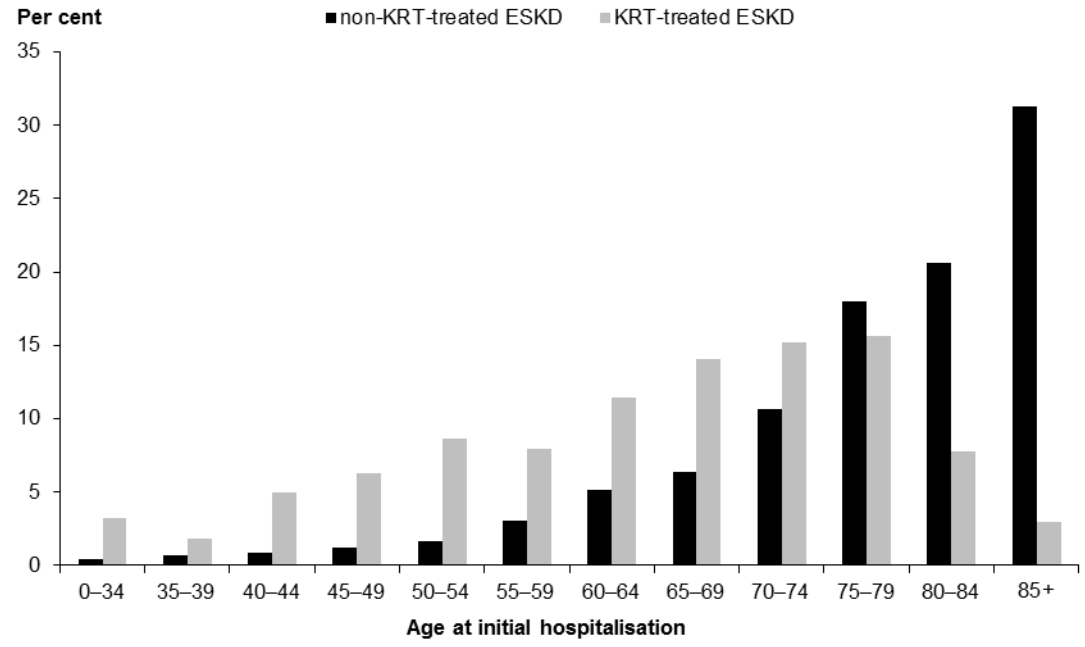
- 41% had an ESKD cause of death.
- The mean time to death was 1,057 days and the median was 799 days.
- The mean age at initial KRT-treated hospitalisation was 64 years, and the median was 67 years.

Table 5.1: Time to death (days) and age of people with non-KRT-treated or KRT-treated ESKD at initial ESKD hospitalisation, WA, 1 July 1999 to 31 December 2010

			Time to death (days)				Age (years)			
	Number	Proportion with an ESKD cause of death (%)	Mean	Median	Min	Max	Mean	Median	Min	Max
Non-KRT-treated	1,359	24	166	8	0	3,303	78	80	0	101
KRT-treated	1,859	41	1,057	799	0	4,053	64	67	4	94

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

Overall, people with KRT-treated ESKD were younger than those with non-KRT-treated ESKD—up to 70–74 years of age there was a higher proportion of ESKD cases that received KRT treatment. However, this proportions drops off rapidly for cases for people 80 years and over (Figure 5.1). Reasons for non-KRT-treatment in older people include prognosis, anticipated quality of life (with or without KRT) medical comorbidity, treatment burden on the patient and total functional capacity (Chadna et al. 1999; Murtagh et al. 2007; Tamura 2009). These findings align with the AIHW's previous total incidence of ESKD work (AIHW 2011).



Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

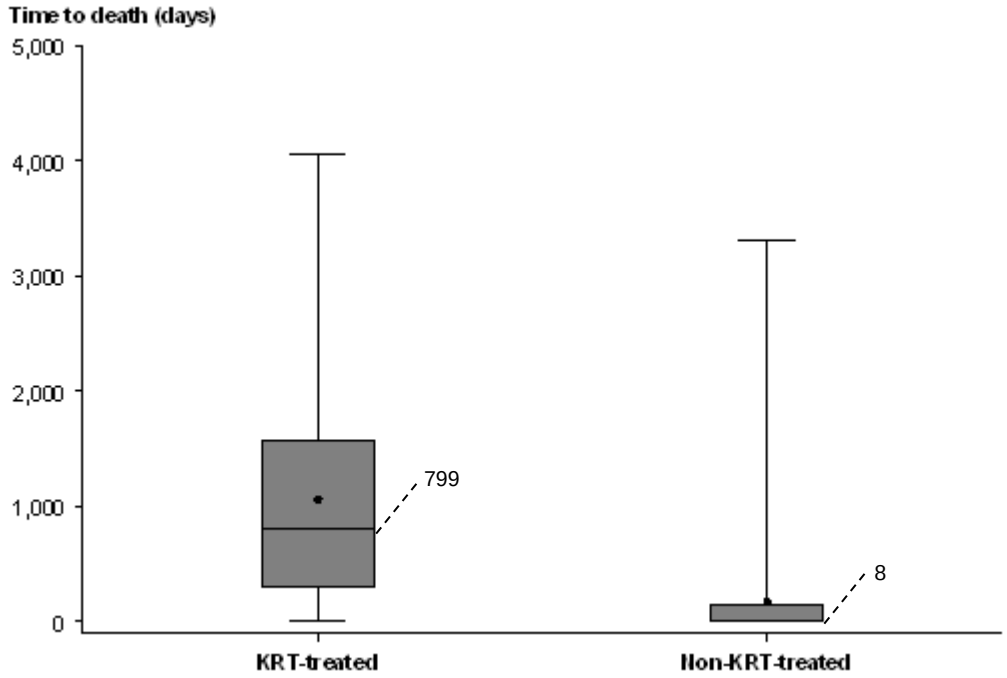
Figure 5.1: People with non-KRT-treated or KRT-treated ESKD, by age and sex at initial ESKD hospitalisation, WA, 1 July 1999 to 31 December 2010

5.2 Interpretation of findings

The time-to-death results (Table 5.1 and Figure 5.1) appear to indicate that survival for non-KRT-treated ESKD patients is short, meaning that the assumption that death date is a proxy for incident date is likely to hold true.

It should be noted that this analysis is likely to include some KRT-treated ESKD cases that are misclassified as non-KRT-treated. These cases may include patients who receive dialysis treatment at home or as a non-admitted patient, or patients with a kidney transplant who were not hospitalised with a KRT code during the analysis period. It is also possible that some KRT-treated cases may also receive dialysis treatment in a different state to where they die (and are hospitalised with a non-KRT code).

The large difference between the median (8 days) and mean (166 days) time to death for non-KRT-treated cases (compared to 799 and 1,057 days, respectively, for treated cases) likely represents some KRT-treated cases being incorrectly identified as not receiving KRT treatment. These cases are probably the cause for the positively skewed time-to-death results for non-KRT-treated cases (Figure 5.2).



Notes

1. The dot in the box represents the mean time to death.
2. The horizontal line in the box interior represents the median time to death (labelled).
3. The length of the box represents the interquartile range (the distance between the 25th and the 75th percentiles).
4. The vertical lines issuing from the box extend to the minimum and maximum time to death values.

Source: AIHW analysis of the WA linked hospitalisation and deaths data set.

Figure 5.2: Box plot of time to death from first ESKD hospitalisation for people who are KRT-treated or non-KRT-treated, WA, 1 July 1999 to 31 December 2010

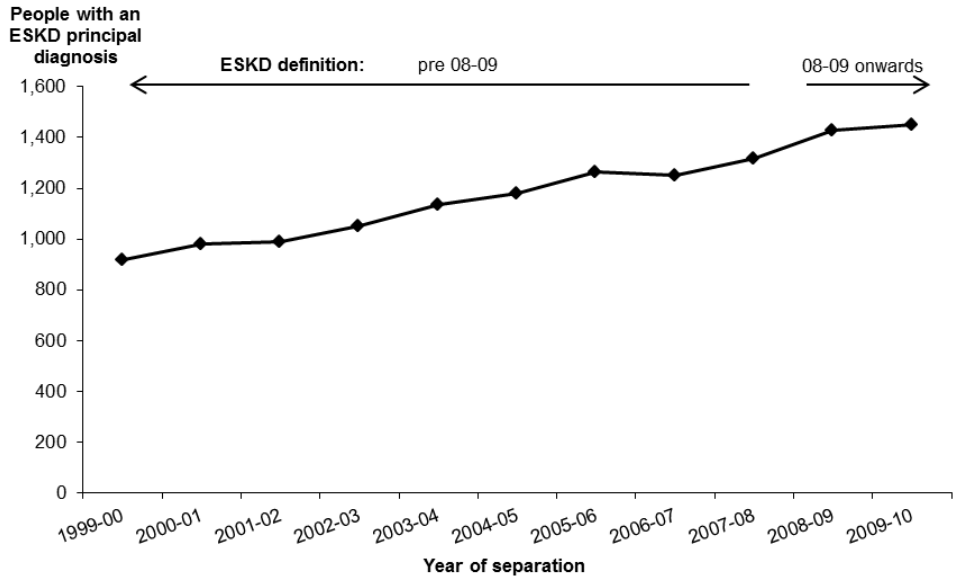
To fully assess the time-to-death results, it is necessary to limit the possibility that any cases identified as non-KRT-treated ESKD are not receiving treatment outside of the hospital setting. Such analysis would require linking hospitalisation and mortality data to the ANZDATA registry.

Appendix A: Supplementary tables and figures

Table A1: ICD-10-AM editions used in hospital data by year

	1st edition	2nd edition	3rd edition	4th edition	5th edition	6th edition
1999–00	x					
2000–01		x				
2001–02		x	x			
2002–03			x			
2003–04			x			
2004–05				x		
2005–06				x		
2006–07					x	
2007–08					x	
2008–09						x
2009–10						x

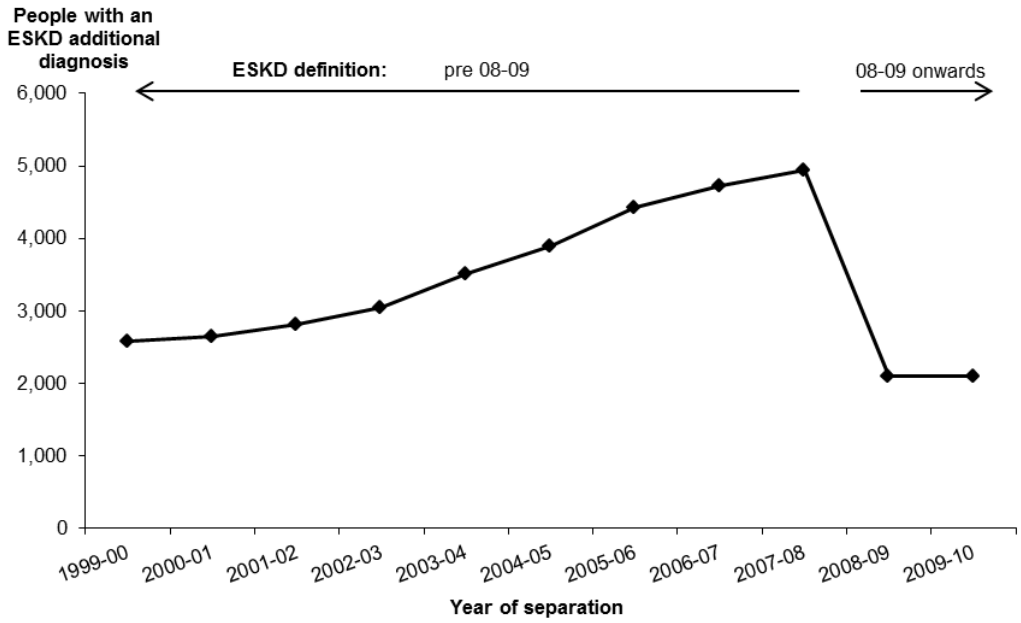
Note: In 2001-02, data from South Australia were reported using the third edition of the ICD-10-AM, all other jurisdictions used the second edition.



Note: Includes all people who were hospitalised, not just those who were hospitalised and died.

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

Figure A1: People with a principal diagnosis of ESKD by year of separation, WA, 1 July 1999–30 June 2010



Note: Includes all people who were hospitalised, not just those who were hospitalised and died.

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

Figure A2: People with an additional diagnosis of ESKD by year of separation, WA, 1 July 1999–30 June 2010

Table A2: People who have ever had a diagnosis of ESKD in hospital, using the pre-2008–09 definition, and a cause of death of ESKD, by calendar year of death, WA and NSW

Calendar year of death	ESKD cause of death									
	WA[(a)]					NSW[(b)]				
	No		Yes		Total	No		Yes		Total
	Number	%	Number	%		Number	%	Number	%	
1999	280	83.8	54	16.2	**334**	. .	. .	. .	. .	**. .**
2000	685	85.9	112	14.1	**797**	1,271	85.8	210	14.2	**1,481**
2001	762	84.0	145	16.0	**907**	2,850	86.6	441	13.4	**3,291**
2002	859	86.9	130	13.1	**989**	3,415	86.9	513	13.1	**3,928**
2003	956	87.2	140	12.8	**1,096**	3,759	88.1	510	11.9	**4,269**
2004	1,014	89.5	119	10.5	**1,133**	4,226	88.2	564	11.8	**4,790**
2005	1,143	87.9	157	12.1	**1,300**	4,761	89.4	562	10.6	**5,323**
2006	1,226	85.7	205	14.3	**1,431**	5,040	87.6	714	12.4	**5,754**
2007	1,308	85.7	218	14.3	**1,526**	5,176	87.3	753	12.7	**5,929**
2008	1,216	87.2	179	12.8	**1,395**	. .	. .	. .	. .	**. .**
2009	759	81.0	178	19.0	**937**	. .	. .	. .	. .	**. .**
2010	617	82.4	132	17.6	**749**	n/a	. .	. .	. .	**. .**
Total	**10,825**	**86.0**	**1,769**	**14.0**	**12,594**	**30,498**	**87.7**	**4,267**	**12.3**	**34,765**

(a) Data from WA span the period 1 July 1999 to 31 December 2010.

(b) Data from NSW span the period 1 July 2000 to 31 December 2007 for people aged 40 and over.

. . not applicable.

Sources: AIHW analysis of WA and NSW linked hospitalisation and deaths datasets.

Table A3: People who have ever had a diagnosis of ESKD in hospital (between 1 July 2008–31 Dec 2010) using the 2008–09 onwards definition, and a cause of death of ESKD, by calendar year of death, WA

Calendar year of death	ESKD cause of death				
	No		Yes		Total
	Number	%	Number	%	
2008	178	73.9	63	26.1	**241**
2009	333	67.3	162	32.7	**495**
2010	340	69.4	150	30.6	**490**
Total	**851**	**69.4**	**375**	**30.6**	**1,226**

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

Table A4: People who had an ESKD cause of death and at least 1 hospital episode with ESKD (using the pre-2008–09 definition), by calendar year of death, WA and NSW

Calendar year of death	ESKD hospitalisation (ever)									
	WA[(a)]					NSW[(b)]				
	No		Yes		Total	No		Yes		Total
	Number	%	Number	%		Number	%	Number	%	
1999	22	28.9	54	71.1	**76**	. .	. .	. .	. .	**. .**
2000	33	22.8	112	77.2	**145**	72	25.5	210	74.5	**282**
2001	43	22.9	145	77.1	**188**	134	23.3	441	76.7	**575**
2002	60	31.6	130	68.4	**190**	174	25.3	513	74.7	**687**
2003	51	26.7	140	73.3	**191**	184	26.5	510	73.5	**694**
2004	54	31.2	119	68.8	**173**	155	21.6	564	78.4	**719**
2005	44	21.9	157	78.1	**201**	192	25.5	562	74.5	**754**
2006	48	19.0	205	81.0	**253**	186	20.7	714	79.3	**900**
2007	59	21.3	218	78.7	**277**	201	21.1	753	78.9	**954**
2008	70	28.1	179	71.9	**249**	. .	. .	. .	. .	**. .**
2009	95	34.8	178	65.2	**273**	. .	. .	. .	. .	**. .**
2010	91	40.8	132	59.2	**223**	. .	. .	. .	. .	**. .**
Total	**670**	**27.5**	**1,769**	**72.5**	**2,439**	**1,298**	**23.3**	4,267	76.7	**5,565**

(a) Data from WA spans the period 1 July 1999 to 31 December 2010.

(b) Data from NSW spans the period 1 July 2000 to 31 December 2007 for people aged 40 and over.

. . not applicable.

Sources: AIHW analysis of WA and NSW linked hospitalisation and deaths datasets.

Table A5: People who had an ESKD cause of death and at least 1 hospital episode (between 1 July 2008–31 Dec 2010) with ESKD (using the 2008–09 onwards definition), by calendar year of death, WA

Calendar year of death	ESKD hospitalisation (ever)				
	No		Yes		Total
	Number	%	Number	%	
2008	48	43.2	63	56.8	**111**
2009	112	40.9	162	59.1	**274**
2010	91	37.8	150	62.2	**241**
Total	**251**	**40.1**	**375**	**59.9**	**626**

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

Sensitivity analysis (Chapter 4)

Table A6: Concordance between hospital and death data for people with ESKD, by age group (age at death), WA, 1 July 2008 to 31 December 2010

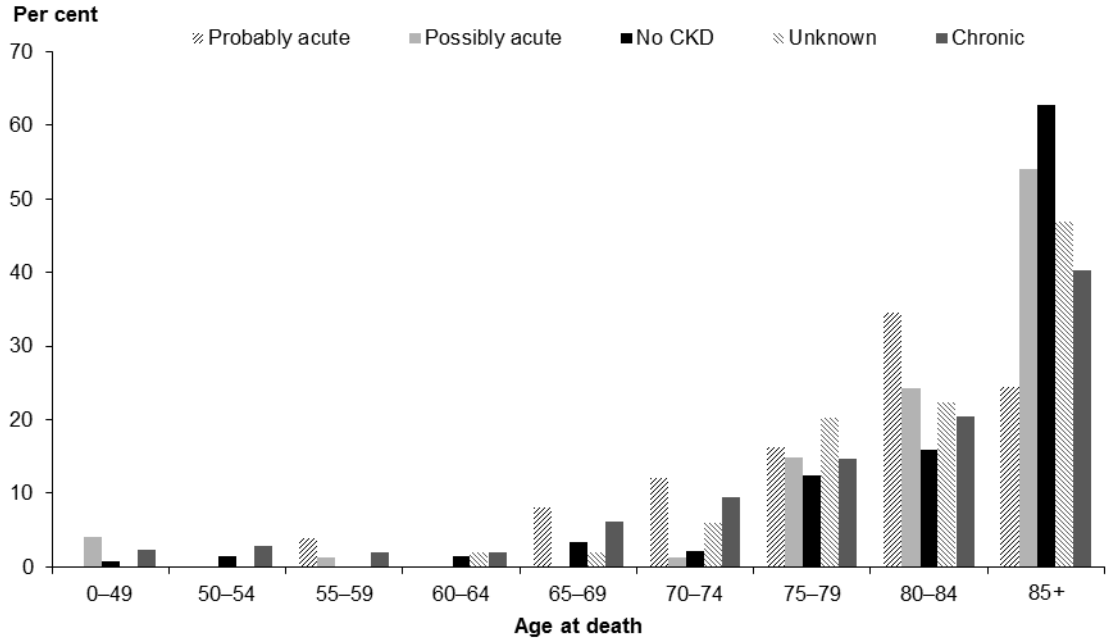
	Proportion of people with an ESKD diagnosis but no ESKD cause of death[(a)]			Proportion of people with an ESKD cause of death but no ESKD diagnosis[(b)]		
ESKD cause of death definition	less than 85	85+	Total	less than 85	85+	Total
Standard	67.7	74.4	69.4	26.3	64.6	40.1
All codes	27.8	28.5	28.0	55.7	77.7	64.5

(a) Forward direction.

(b) Backward direction.

Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

Unspecified kidney failure (N19) analysis (Chapter 4)



Source: AIHW analysis of the WA linked hospitalisation and deaths dataset.

Figure A3: The proportion of people who have a cause of death recorded as 'unspecified kidney failure', by age and category, WA, 1 July 1999–31 December 2010

Appendix B: Methods

ICD-10-AM codes used to define cardiovascular disease, diabetes and chronic kidney disease

Table B1: Definitions of the ICD-10-AM codes used to define CVD, CKD and diabetes in the linked hospitalisation data

Codes	Definition
Cardiovascular disease	
I00–I99	Diseases of the circulatory system
G45	Transient cerebral ischaemic attacks and related syndromes (TIA)
Chronic kidney disease	
E10.2	Type 1 diabetes mellitus with kidney complication
E11.2	Type 2 diabetes mellitus with kidney complication
E13.2	Other specified diabetes mellitus with kidney complication
E14.2	Unspecified diabetes mellitus with kidney complication
I12	Hypertensive kidney disease
I13	Hypertensive heart and kidney disease
I15.0	Renovascular hypertension
I15.1	Hypertension secondary to other kidney disorders
N00	Acute nephritic syndrome
N01	Rapidly progressive nephritic syndrome
N02	Recurrent and persistent haematuria
N03	Chronic nephritic syndrome
N04	Nephrotic syndrome
N05	Unspecified nephritic syndrome
N06	Isolated proteinuria with specified morphological lesion
N07	Hereditary nephropathy, not elsewhere classified
N08	Glomerular disorders in diseases classified elsewhere
N11	Chronic tubulo-interstitial nephritis
N12	Tubulo-interstitial nephritis, not specified as acute or chronic
N14	Drug- and heavy-metal-induced tubulo-interstitial and tubular conditions
N15	Other renal tubulo-interstitial diseases
N16	Renal tubulo-interstitial disorders in diseases classified elsewhere
N18	Chronic kidney disease
N19	Unspecified kidney failure
N25	Disorders resulting from impaired renal tubular function
N26	Unspecified contracted kidney
N27	Small kidney of unknown cause

(continued)

Table B1 (continued): Definitions of the ICD-10-AM codes used to define CVD, CKD and diabetes in the linked hospitalisation data

Codes	Definition
N28	Other disorders of kidney and ureter, not elsewhere classified
N39.1	Persistent proteinuria, unspecified
N39.2	Orthostatic proteinuria, unspecified
Q60	Renal agenesis and other reduction defects of kidney
Q61	Cystic kidney disease
Q62	Congenital obstructive defects of renal pelvis and congenital malformations of ureter
Q63	Other congenital malformations of kidney
T82.4	Mechanical complication of vascular dialysis catheter
T86.1	Kidney transplant failure and rejection
Z49	Care involving dialysis
Z94.0	Kidney transplant status
Z99.2	Dependence on kidney dialysis
Diabetes	
E10	Type 1 diabetes mellitus
E11	Type 2 diabetes mellitus
E13	Other specified DM
E14	Unspecified DM
O24.0	Pre-existing DM, Type 1, in pregnancy
O24.1	Pre-existing DM, Type 2, in pregnancy
O24.2	Pre-existing DM, other specified type, in pregnancy
O24.3	Pre-existing DM, unspecified, in pregnancy

Note: There is some overlap of the codes between the 3 disease groups.

Linked hospitalisations and deaths data

Western Australia

The Department of Health Western Australia (DOHWA) collects and maintains a number of core state-wide data collections such as the Hospital Morbidity Data Collection, which is comprised of around 20,000,000 electronic admitted patient records and includes all hospitals in WA (public and private). Death registrations are also included in the core data sets and consists of all deaths registered in WA, with coded cause of death data updated annually.

Data linkage is a process in which connections are made between different collections of information that are thought to belong to the same person. The Data Linkage Branch (DLB) of DOHWA uses a probabilistic linkage method to identify links and uses demographic information such as name, date of birth, sex and address. The DLB creates, updates, enhances and manages links between the core DOHWA data collections and other administrative data sources. The linkage process produces a set of indexes known as 'linkage keys', which are stored in the Master Links File of the WADLS (Holman et al. 2008) and are kept separate from personal and clinical information. An internal audit in 2002 estimated that the number of chains in the WA Data Linkage System containing 1 or more false positive matches (mismatches) was 0.3% (Rosman et al. 2003). The variables obtained by the AIHW from WA for the analysis are shown in Table B2.

Table B2: Variables obtained from Western Australia for linked hospitalisation and deaths data analysis

Hospitalisations	Deaths
Subset date of birth (MMYYYY)	Subset date of birth (MMYYYY)
Gender	Sex
Care type	Date of death (DDMMYYYY)
Mode of separation	Registration year
Diagnosis codes:	Cause of death:
Principal diagnosis	Underlying cause
Co-diagnosis	Additional cause (up to 19)
Additional diagnoses (up to 20)	
Postcode of residence	Postcode of residence
SLA of residence	SLA of residence
Admission date (DDMMYYYY)	Died in hospital flag
Separation date (DDMMYYYY)	

New South Wales

There were 2 main data sources used for the NSW linked data set: the NSW Admitted Patient Data Collection (APDC) and ABS mortality data. Identifying information such as name, address, date of birth and sex obtained from the NSW APDC are included in the Master Linkage Key (MLK), which was constructed by the CHeReL. No health data are used in this process.

The NSW APDC records were linked using probabilistic record linkage methods and ChoiceMaker software (Goldberg & Borthwick 2004). At the completion of the process, each

record in the Master Linkage Key was assigned a record identification number and a Master Linkage Key Person ID to allow linked records for the same individual to be identified and extracted.

The ABS mortality records were deterministically linked to death records from the NSW Registry for Births, Deaths and Marriages held in the MLK, using death registration number and date of birth. This allowed potential matches to hospitalisation records to be found. Once the linkage was finalised, the CHeReL created a Project Person Number (PPN) for each Person ID and assigned the PPN to all records in the linked data sets. The MLK is regularly checked for false positive linkages and in 2012 the false positive rate was 0.3% (CHeReL 2012). The variables obtained by the AIHW from NSW for the analysis are shown in Table B3.

Table B3: Variables obtained from New South Wales for linked hospitalisation and deaths data analysis

Hospitalisations	Deaths
Subset date of birth (MMYYYY)	Subset date of birth (MMYYYY)
Sex	Sex
Service category (care type)	Date of death (MMYYYY)[(a)]
Mode of separation	Registration year
Diagnosis codes:	Cause of death:
Principal diagnosis	Cause of death
Additional diagnoses (up to 55)	Contributing cause of death
Postcode of residence	State of registration
State of residence	SLA of residence
Admission date	State of usual residence
Separation date	
Transferred from hospital	
Transferred to hospital	
Urgency of admission	
Episode start date	
Episode end date	
Episode sequence number	

(a) Complete date of death was not supplied.

Appendix C: Summary tables—WA and NSW linked data sets provided to AIHW

Hospitalisations

Western Australia

Table C1: Total number of hospitalisations by age and sex, WA, 1 July 1999–31 December 2010

	Sex		
Age at separation (years)	**Male**	**Female**	**Total**
< 1	1,988	1,154	**3,142**
1–4	2,162	1,560	**3,722**
5–9	2,478	2,230	**4,708**
10–14	3,550	3,088	**6,638**
15–19	7,520	7,337	**14,857**
20–24	14,877	12,100	**26,977**
25–29	14,905	20,968	**35,873**
30–34	34,361	32,056	**66,417**
35–39	45,944	36,570	**82,514**
40–44	60,875	55,043	**115,918**
45–49	75,134	64,572	**139,706**
50–54	99,736	78,079	**177,815**
55–59	124,483	80,326	**204,809**
60–64	122,161	87,573	**209,734**
65–69	134,814	102,887	**237,701**
70–74	146,627	103,550	**250,177**
75–79	150,320	117,442	**267,762**
80–84	111,512	99,730	**211,242**
85+	68,941	97,377	**166,318**
Total	**1,222,388**	**1,003,642**	**2,226,030**

Source: Government of WA Department of Health.

Table C2: Number of hospitalisations with a diagnosis of ESKD (principal or additional diagnosis) by age and sex, WA, 1 July 1999–31 December 2010

	Sex		
Age at separation (years)	**Male**	**Female**	**Total**
0–14	811	61	**872**
15–19	3,597	1,780	**5,377**
20–24	10,249	4,866	**15,115**
25–29	8,288	11,220	**19,508**
30–34	23,534	18,654	**42,188**
35–39	29,477	18,860	**48,337**
40–44	37,146	33,109	**70,255**
45–49	41,784	36,561	**78,345**
50–54	53,991	44,113	**98,104**
55–59	67,094	41,889	**108,983**
60–64	57,758	45,134	**102,892**
65–69	63,895	54,681	**118,576**
70–74	69,328	45,342	**114,670**
75–79	70,340	47,476	**117,816**
80–84	46,964	29,382	**76,346**
85+	15,663	10,404	**26,067**
Total	**599,919**	**443,532**	**1,043,451**

Source: Government of WA Department of Health.

Table C3: Number of hospitalisations with a principal diagnosis of ESKD by age and sex, WA, 1 July 1999–31 December 2010

	Sex		
Age at separation (years)	**Male**	**Female**	**Total**
0–14	442	11	**453**
15–19	3,441	1,673	**5,114**
20–24	9,971	4,629	**14,600**
25–29	8,047	10,662	**18,709**
30–34	22,786	17,869	**40,655**
35–39	28,464	17,944	**46,408**
40–44	35,683	31,674	**67,357**
45–49	40,219	34,751	**74,970**
50–54	51,604	42,042	**93,646**
55–59	64,767	40,094	**104,861**
60–64	55,609	43,394	**99,003**
65–69	61,675	52,974	**114,649**
70–74	67,428	44,011	**111,439**
75–79	68,595	46,296	**114,891**
80–84	45,745	28,486	**74,231**
85+	15,002	9,875	**24,877**
Total	**579,478**	**426,385**	**1,005,863**

Source: Government of WA Department of Health.

New South Wales

Table C4: Total number of hospitalisations by age (40+) and sex, NSW, 1 July 2000–31 December 2010

	Sex		
Age at separation (years)	**Male**	**Female**	**Total**
40–44	126,028	91,909	**217,940**
45–49	193,932	136,640	**330,574**
50–54	259,869	184,018	**443,887**
55–59	337,955	230,168	**568,125**
60–64	408,797	285,518	**694,316**
65–69	449,871	332,023	**781,896**
70–74	531,848	438,595	**970,454**
75–79	566,153	484,392	**1,050,556**
80–84	452,974	425,973	**878,951**
85+	304,716	444,845	**749,577**
Total	**3,632,149**	**3,054,083**	**6,686,303**

Note: Total includes 79 records with missing/unknown/not reported age/sex.

Source: NSW Ministry of Health.

Table C5: Number of hospitalisations with a diagnosis of ESKD (principal or additional diagnosis) by age (40+) and sex, NSW, 1 July 2000–31 December 2010

	Sex		
Age at separation (years)	**Male**	**Female**	**Total**
40–44	61,140	36,483	**97,623**
45–49	89,008	53,953	**142,961**
50–54	111,268	74,453	**185,721**
55–59	135,743	91,420	**227,163**
60–64	166,639	121,185	**287,824**
65–69	178,907	137,595	**316,502**
70–74	228,229	199,737	**427,968**
75–79	240,367	184,078	**424,449**
80–84	176,725	113,239	**289,965**
85+	75,307	54,547	**129,855**
Total	**1,463,333**	**1,066,690**	**2,530,034**

Note: Total includes 11 records with missing/unknown/not reported sex.

Source: NSW Ministry of Health.

Table C6: Number of hospitalisations with a principal diagnosis of ESKD by age (40+) and sex, NSW, 1 July 2000–31 December 2010

	Sex		
Age at separation (years)	**Male**	**Female**	**Total**
40–44	57,904	34,307	**92,211**
45–49	84,464	50,588	**135,052**
50–54	105,146	70,141	**175,287**
55–59	127,390	85,825	**213,215**
60–64	155,791	114,054	**269,845**
65–69	165,434	128,494	**293,928**
70–74	210,125	186,811	**396,936**
75–79	217,427	167,711	**385,138**
80–84	153,332	96,379	**249,711**
85+	51,014	31,312	**82,326**
Total	**1,328,027**	**965,622**	**2,293,649**

Source: NSW Ministry of Health.

Deaths

Western Australia

Table C7: Number of deaths by age and sex, WA, 1 July 1999–31 December 2010

	Sex		
Age at death (years)	**Male**	**Female**	**Total**
< 1	124	99	**223**
1–4	67	35	**102**
5–9	38	23	**61**
10–14	41	33	**74**
15–19	106	72	**178**
20–24	118	94	**212**
25–29	183	123	**306**
30–34	292	203	**495**
35–39	456	295	**751**
40–44	774	493	**1,268**
45–49	1,243	815	**2,058**
50–54	1,811	1,047	**2,858**
55–59	2,499	1,395	**3,895**
60–64	3,448	1,783	**5,231**
65–69	4,811	2,528	**7,340**
70–74	6,596	3,955	**10,551**
75–79	9,085	6,145	**15,230**
80–84	10,061	9,201	**19,262**
85+	13,866	23,573	**37,439**
Not reported	39	25	**64**
Total	**55,658**	**51,937**	**107,598**

Note: Total includes 1 death where sex was unregistered and 2 deaths where sex was unknown.

Source: Government of WA Department of Health.

Table C8: Number of deaths with ESKD as a cause of death (underlying or associated) by age and sex, WA, 1 July 1999–31 December 2010

	Sex		
Age at death (years)	**Male**	**Female**	**Total**
0–49	52	47	**99**
50–54	36	30	**66**
55–59	46	36	**82**
60–64	53	43	**96**
65–69	87	55	**142**
70–74	133	95	**228**
75–79	228	139	**367**
80–84	313	226	**539**
85+	402	601	**1,003**
Total	**1,352**	**1,273**	**2,625**

Note: The total includes 3 cases where age at death was not reported.

Source: Government of WA Department of Health.

Table C9: Number of deaths with ESKD as an underlying cause of death by age and sex, WA, 1 July 1999–31 December 2010

	Sex		
Age at death (years)	**Male**	**Female**	**Total**
0–49	29	13	**42**
50–54	18	16	**34**
55–59	24	15	**39**
60–64	26	16	**42**
65–69	43	25	**68**
70–74	76	56	**132**
75–79	175	113	**288**
80–84	274	199	**473**
85+	369	570	**939**
Total	**1,036**	**1,024**	**2,060**

Note: The total includes 3 cases where age at death was not reported.

Source: Government of WA Department of Health.

New South Wales

Table C10: Number of deaths by age (40+) and sex, NSW, 1 July 2000–31 December 2007

	Sex		
Age at death (years)	**Male**	**Female**	**Total**
40–44	2,696	1,534	**4,230**
45–49	4,098	2,376	**6,474**
50–54	5,533	3,389	**8,922**
55–59	7,787	4,698	**12,485**
60–64	10,483	6,176	**16,659**
65–69	13,932	8,350	**22,282**
70–74	19,858	12,317	**32,175**
75–79	27,492	19,967	**47,459**
80–84	30,106	29,064	**59,170**
85+	40,764	72,511	**113,275**
Total	**163,161**	**160,658**	**323,819**

Note: Total includes 688 records in which age was not reported.

Source: NSW Registry of Births, Deaths, and Marriages.

Table C11: Number of deaths with ESKD as a cause of death (underlying or associated) by age (40+) and sex, NSW, 1 July 2000–31 December 2007

	Sex		
Age at death (years)	**Male**	**Female**	**Total**
40–44	23	9	**32**
45–49	29	13	**42**
50–54	42	29	**71**
55–59	56	45	**101**
60–64	98	77	**175**
65–69	168	111	**279**
70–74	248	235	**483**
75–79	480	437	**917**
80–84	695	613	**1,308**
85+	1,081	1,600	**2,681**
Total	**2,921**	**3,170**	**6,091**

Note: Total includes 2 records in which age was not reported.

Source: NSW Registry of Births, Deaths, and Marriages.

Table C12: Number of deaths with ESKD as an underlying cause of death by age (40+) and sex, NSW, 1 July 2000–31 December 2007

	Sex		
Age at death (years)	**Male**	**Female**	**Total**
40–44	11	6	**17**
45–49	16	7	**23**
50–54	22	16	**38**
55–59	32	21	**53**
60–64	46	38	**84**
65–69	109	70	**179**
70–74	178	174	**352**
75–79	371	359	**730**
80–84	613	540	**1,153**
85+	1,023	1,552	**2,575**
Total	**2,422**	**2,784**	**5,206**

Note: Total includes 2 records in which age was not reported.

Source: NSW Registry of Births, Deaths, and Marriages.

Glossary

associated cause(s) of death: Any condition(s), diseases and injuries—other than the underlying cause—considered to contribute to a death. See also **cause of death**.

cause of death: From information reported on the medical certificate of cause of death, each death is classified by the underlying cause of death according to rules and conventions of the 10th revision of the International Classification of Diseases. The underlying cause is defined as the disease that initiated the train of events leading directly to death. Deaths from injury or poisoning are classified according to the circumstances of the fatal injury, rather than to the nature of the injury. See also associated cause(s) of death.

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

data linkage: The bringing together (linking) of information from 2 or more different data sources that are believed to relate to the same entity, for example, the same individual or the same institution. This can provide more information about the entity and in certain cases provide a time sequence, helping to 'tell a story', show 'pathways' and perhaps unravel cause and effect. The term is used synonymously with 'record linkage' and 'data integration'.

diabetes (diabetes mellitus): A chronic condition in which the body cannot properly use its main energy source, the sugar glucose. This is due to a relative or absolute deficiency in insulin, a hormone that is produced by the pancreas and helps glucose enter the body's cells from the bloodstream and then be processed by them. Diabetes is marked by an abnormal build-up of glucose in the blood, and it can have serious short- and long-term effects.

diabetic nephropathy: Disease of the capillaries of the glomeruli resulting from diabetes.

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

glomerulonephritis: Inflammation of the glomeruli, which are a component of the basic filtering unit in the kidney.

haemodialysis: A method of removing waste products and water from the blood, as well as regulating the levels of circulating chemicals. A machine is connected to a person's bloodstream to filter the blood externally to the body.

hospitalisation: Synonymous with admission and separation; that is, an episode of hospital care that starts with the formal admission process and ends with the formal separation process. An episode of care can be completed by the patients being discharged, transferred to another hospital or care facility, or dying, or by a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation).

ICD-10-AM: See **International Statistical Classification of Diseases and Related Health Problems.**

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

inter-hospital contracted care: An episode of care for an admitted patient whose treatment and/or care is provided under an arrangement (either written or verbal) between a hospital purchaser of hospital care (contracting hospital) and a provider of an admitted service

(contracted hospital) and for which the activity is recorded by both hospitals. METeOR identifier: 270409.

International Statistical Classification of Diseases and Related Health Problems: The World Health Organization's internationally accepted classification of death and disease. The 10th Revision (ICD-10) is currently in use. The 10th revision, Australian Modification (ICD-10-AM) is currently in use in Australian hospitals for admitted patients.

kidney replacement therapy (KRT): Includes having a functional kidney transplant or receiving regular dialysis.

linkage key: An index that is produced during the **data linkage** process, which is used to enable health records to be joined together for research. The linkage keys are held separately from any personal demographic information.

mortality: Death.

peritoneal dialysis: A solution is pumped into the abdominal cavity where the body's own peritoneum membrane acts as a dialysis filter to remove waste products and water.

principal diagnosis: The diagnosis listed in hospital records to describe the problem that was chiefly responsible for **hospitalisation**.

satellite dialysis: Dialysis performed in centres that are usually located away from their parent hospital so as to decrease the travel burden sometimes associated with accessing certain dialysis services.

separation: The formal process where a hospital records the completion of an episode of treatment and/or care for an admitted patient. In this paper, described by the term hospitalisation. See **hospitalisation**.

underlying cause of death: The condition, disease or injury initiating the sequence of events leading directly to death; that is, the primary or main cause. Compare with **associated cause(s) of death**.

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Monitoring the impact of end-stage kidney disease (ESKD) is important in planning for future health needs of the population. This working paper uses linked data from Western Australia and New South Wales to assess the likelihood that a patient who is hospitalised with ESKD will have ESKD recorded on their death record, in order to establish whether mortality records in Australia reflect the actual disease pattern of people with ESKD.

The study confirms that the ESKD codes used in the mortality data to estimate ESKD incidence are likely to underestimate the impact of ESKD—there is a high proportion of patients who are hospitalised with ESKD who do not have ESKD recorded on their death certificates.