Appendix 1. Identification of people with chronic kidney disease; statistical methods; and data sources

Identification of people with chronic kidney disease

Chronic kidney disease has long been recognised as a health problem. However, 'chronic kidney disease' is not used as a medical term in the WHO International Classification of Diseases (ICD), nor is it generally used as a diagnosis in clinical settings. For these reasons, it is impossible to identify CKD patients directly in most existing databases, where the data are collected based on doctors' diagnoses and classified using the ICD system. It is also not possible to identify CKD patients through assessing their kidney function, as most databases do not contain pathology information.

To overcome this barrier, we developed a coding list for chronic kidney disease (Table A1). This coding list contains the primary kidney diseases listed in the International Classification of Diseases version 10 (ICD-10) that are known to cause chronic kidney disease. People can be assumed to have CKD if they have any diagnosis of these primary kidney diseases.

Australian general practice data are classified according to the International Classification of Primary Care, second edition (ICPC-2) (WICC 1997). We developed a list of ICPC-2 codes and (where necessary) more specific ICPC-2 PLUS terms for CKD by considering the chronic disease list developed from ICPC-2 by O'Halloran et al. (2004) and considering all ICPC-2 codes that mapped to the selected ICD-10 codes (Table A2).

The coding lists have been discussed among several nephrologists, experts on disease classification and the researchers who prepared this report. They appear to cover CKD accurately and comprehensively. However, it is not possible to fully identify people with CKD using this method. The coding lists herein only include those diseases that are known to cause CKD. Once people are diagnosed with one of these diseases, they can be identified as having CKD without obtaining further evidence from pathology information. However, some other diseases or conditions, such as calculus of the kidney and ureter, do not always result in CKD. In these cases CKD can not be identified without pathological evidence to indicate that there is kidney damage and/or reduced kidney function. Because administrative databases such as the AIHW National Hospital Morbidity Database do not contain pathology information, these cases have not been identified as CKD in this report, unless they also recorded a diagnosis of one of the diseases contained in the CKD coding list. This may lead to some underestimation of the true burden of CKD in Australia.

ICD-10 code	Description
B52.0^	Plasmodium malariae malaria with nephropathy
D59.3^	Haemolytic-uraemic syndrome
E10.2	Insulin-dependent diabetes mellitus with renal complication
E11.2	Non-insulin-dependent diabetes mellitus with renal complication
E12.2	Malnutrition-related diabetes mellitus with renal complication
E13.2	Other specified diabetes mellitus with renal complication
E14.2	Unspecified diabetes mellitus with renal complication
E85.1^	Neuropathic heredofamilial amyloidosis
112	Hypertensive renal disease
113	Hypertensive heart and renal disease
115.0	Renovascular hypertension
115.1	Hypertension secondary to other renal 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 renal failure
N19	Unspecified renal failure
N25	Disorders resulting from impaired renal tubular function
N26	Unspecified contracted kidney
N27	Small kidney of unknown cause
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 malformation 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*	Dialysis status

Table A1: ICD-10 coding list for chronic kidney disease

^ These codes are to be used for identification in mortality data only.

* These codes are to be used for identification in hospital morbidity data only.

ICPC-2 code	ICPC-2 PLUS code	ICPC-2/ICPC-2 PLUS label
	K87002	Hypertension; renal disease
	K87003	Hypertension; nephropathy
	K87006	Hypertension; cardiorenal
	U28001	Kidney transplant
	U59001	Dialysis; kidney (renal)
	U59007	Dialysis; peritoneal
	U59008	Haemodialysis
	U59009	Dialysis; CAPD
	U85001	Polycystic kidney
	U85003	Duplex kidney
	U85004	Congenital anomaly; urological
	U85005	Congenital anomaly; kidney
U88	(all)	Glomerulonephritis/nephrosis
	U99002	Cyst; renal
	U99016	Uraemia
	U99020	Hypertrophic; kidney
	U99021	Hydronephrosis
	U99022	Insufficiency; renal
	U99023	Failure; renal; chronic
	U99024	Necrosis; renal; papillary
	U99028	Stenosis; artery; renal
	U99030	Failure; renal; not otherwise stated

Table A2: ICPC-2 and ICPC-2 PLUS coding list for chronic kidney disease

References

O'Halloran J, Miller GC & Britt H 2004. Defining chronic conditions for primary care with ICPC-2. Family Practice 21(4):381–6.

WICC (Classification Committee of the World Organization of Family Doctors) 1997. ICPC-2: International Classification of Primary Care. Oxford: Oxford University Press.

International Classification of Diseases (ICD)

The International Classification of Diseases (ICD) is used to classify diseases and other health problems recorded on many types of health and vital records including death certificates and hospital records. In addition to enabling the storage and retrieval of diagnostic information for clinical and epidemiological purposes, these records also provide the basis for the compilation of national mortality and morbidity statistics by WHO member states.

ICD was created in the 1850s. The first edition, known as the International List of Causes of Death, was adopted by the International Statistical Institute in 1893. WHO took over the responsibility for the ICD at its creation in 1948 when the sixth revision, which included causes of morbidity for the first time, was published. ICD-10 was endorsed by the Forty-third World Health Assembly in May 1990 and came into use in WHO member states as from 1994. The classification is the latest version in the ICD series.

The ICD has become the international standard diagnostic classification for all general epidemiological and many health management purposes. These include the analysis of the general health situation of population groups and monitoring of the incidence and prevalence of diseases and other health problems in relation to other variables such as the characteristics and circumstances of the individuals affected.

International Classification of Primary Care, second edition (ICPC-2)

The International Classification of Primary Care, second edition (ICPC-2) is used as a classification for primary care or general practice wherever applicable.

ICPC-2 classifies patient data and clinical activity in the domains of general/family practice and primary care, taking into account the frequency distribution of problems seen in these domains. It allows classification of the patient's reason for encounter, the problems/diagnoses managed, interventions, and the ordering of these data in an episode of care structure.

It has a biaxial structure and consists of 17 chapters, each divided into seven components dealing with symptoms and complaints (comp. 1), diagnostic, screening and preventive procedures (comp. 2), medication, treatment and procedures (comp. 3), test results (comp. 4), administrative (comp. 5), referrals and other reasons for encounter (comp. 6) and diseases (comp. 7).

Statistical methods

Age standardisation

This is a method of removing the influence of age when comparing populations with different age structures. Age-standardised rates in this report use direct age-standardisation. The directly age-standardised rate is the weighted sum of age-specific (five-year age group) rates, where the weighting factor is the corresponding age-specific standard population. For this report, the Australian estimated residential population as at 30 June 2001 was used as the standard population. The same population was used for males and females to allow valid comparison of age-standardised rates between the sexes.

Direct age standardisation

Direct age standardisation is the most common method of age standardisation, and is used in this report for prevalence, incidence, hospitalisations and deaths data. This method is generally used when the population under study is large and the age-specific rates are reliable. The calculation of direct age-standardised rates comprises 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 agespecific rate by the corresponding standard population for each age group.
- Step 3: Sum the expected number of cases in each age group and divide this sum by the total of the standard population to give the age-standardised rate.

In interpreting age-standardised rates, some issues need to be taken into consideration:

- The age-standardised rate is for comparison purposes only. The magnitude of an agestandardised rate has no intrinsic value since it is only an index measure. Therefore an age-standardised rate is not a substitute for age-specific rates.
- An age-standardised rate is not only influenced by the frequency of the underlying diseases, but is also dependent on the differences between the age structure of the population of interest and the standard population selected. Therefore, the results of comparisons based on age-standardised rates may not only reflect the difference in the frequency of the diseases compared, but also will be partly dependent on the standard population used. However, since the standard population used in this report is the total Australian population in 2001, the age distribution closely reflects that of the current Australian population. The results of comparison based on these age-standardised rates are valid.

Indirect age standardisation

In situations where populations are small or where there is some uncertainty about the stability of age-specific rates, indirect standardisation is used. This effectively removes the influence of different age structures, but does not provide a measure of incidence or prevalence in terms of a rate. Rather, the summary measure is a ratio of the number of observed cases compared to the number that would be expected if the age-specific rates of

the standard population applied in the population under study. Calculation of these ratios comprises the following steps:

- Step 1: Calculate the age-specific rates for each age group in the standard population.
- Step 2: Apply these age-specific rates to the number of people in each age group of the population under study, and sum these to derive the total expected number of cases in that population.
- Step 3: Sum the observed cases in the population under study and divide this number by the expected number derived in step 2. This is the standardised incidence/prevalence ratio (SIR or SPR). Standardised mortality or morbidity ratios (SMRs) can be calculated similarly.

An SIR/SMR of 1 indicates the same number of observed cases as were expected, suggesting rates in the two populations are similar. An SIR greater than 1 indicates more cases observed than were expected, suggesting rates in the population under study are higher than in the standard population.

In this report, the indirect method is used in Chapter 6 when comparing Indigenous and other Australians.

Moving averages

Moving averages are used for smoothing of trend data, to even out the small seasonal or cyclic variations which occur from one time point to the next so that the underlying trend can be clearly seen. In this report, three-year moving averages are calculated to show trends in the age-standardised incidence rates of end-stage kidney disease. To calculate each moving average observation, the age-standardised rates for three consecutive years are combined and divided by three. This average is then used as the value for the middle year of the three points used to calculate the average.

Age-specific rates

Age-specific rates were calculated by dividing the number of events (such as deaths, disease cases or hospital separations) occurring in each specified age group by the estimated resident population for the corresponding age group. The rates are expressed as events per 1,000 or per million population.

Prevalence

Prevalence refers to the number or proportion (of cases, instances, etc.) present in a population at a given time.

Incidence

Incidence refers to the number of new cases (of a disease, condition or event) occurring during a given period.

Data sources

Most of the information on mortality, health services use and health expenditure in this report is drawn from administrative databases, such as the AIHW National Mortality Database and the AIHW National Hospital Morbidity Database. In recent years, administrative databases have been increasingly used for statistical analysis by health officials and academics, both at the national and international level. The data in these databases were collected systematically and regularly with broad population coverage. However, because the data are based on doctors' diagnoses, diseases that are likely to be under-diagnosed in the clinical setting, such as chronic kidney disease and diabetes, are also likely to be under-represented in these databases. Therefore it is likely that the burden of chronic kidney disease calculated from these databases will be an underestimate.

The administrative databases and other major data sources used in this report are briefly described below.

Administrative data sources

AIHW Disease Expenditure Database contains information on direct health expenditure in 2000–01 for around 200 different disease and injury categories. Estimates are available by age group, sex and area of expenditure – hospitals, high-level residential aged care, medical services, other professional services, pharmaceuticals and research. Capital expenditures, expenditure on community health (except community mental health), public health programs (except cancer screening), health administration and health aids and appliances were not allocated by disease group.

AIHW National Hospital Morbidity Database contains demographic, diagnostic, procedural and duration of stay information on episodes of care for patients admitted to hospital. The data collection is maintained by the AIHW using data supplied by state and territory health authorities. The database is episode-based and it is not possible to count patients individually. In this report, disease data relate to the principal diagnosis reported for hospitalisations unless otherwise specified. Data presented in this report were extracted in July 2005.

AIHW National Mortality Database contains information on the cause of death supplied by the medical practitioner certifying the death or by a coroner. Registration of deaths is the responsibility of the state and territory registrars of Births, Deaths and Marriages. Registrars provide the information to the ABS for coding of cause of death and the encoded data are then provided to AIHW. In this report, unless otherwise specified, death data relate only to the underlying cause of death. Data presented in this report were extracted in June 2005.

Register data sources

Australia and New Zealand Dialysis and Transplant Registry (ANZDATA) collects information to monitor dialysis and transplant treatments from all renal units in Australia and New Zealand on all patients receiving kidney replacement therapy where the intention to treat is long term. Cases of acute kidney failure are excluded. The Registry is coordinated within the Queen Elizabeth Hospital (South Australia) and is funded by the Australian Government Department of Health and Ageing.

Survey data sources

Australian Diabetes, Obesity and Lifestyle Study (AusDiab) (1999–00), conducted by the International Diabetes Institute, was designed to provide estimates of the prevalence of diagnosed and undiagnosed diabetes and self-reported chronic conditions such as heart disease and high blood pressure. It also provided national measurements of blood pressure, blood lipids, blood glucose, body fat, height and weight, and waist and hip circumference, as well as self-reported information on diet, smoking, alcohol consumption, physical activity, and general health and wellbeing. The study collected information in urban and non-urban areas in all states and the Northern Territory and sampled over 20,000 people aged 25 years and above, of whom more than 11,000 underwent a physical examination.

BEACH (Bettering the Evaluation and Care of Health) Survey of General Practice, an ongoing national survey looking at aspects of general practice in Australia, is conducted by the General Practice Statistics and Classification Unit (an AIHW collaborating unit within the Family Medicine Research Centre, University of Sydney). BEACH began in April 1998 and involves a random sample of approximately 1,000 general practitioners per year, each of whom records details regarding 100 consecutive patient encounters.

National Drug Strategy Household Survey (2004) was conducted between July and November 2004 and includes data on almost 30,000 Australians aged 12 years and older. This was the eighth survey in a series that began in 1985. Respondents were asked about their knowledge of drugs, their attitudes towards drugs, their drug consumption histories and related behaviours.

National Health Survey (2001), conducted by the ABS, included around 26,900 people of all ages. Collection occurred between February and November 2001 across urban and rural areas of Australia. Non-private dwellings (e.g. hospitals, nursing homes, hotels and boarding houses) were excluded. The survey collected information on long-term health conditions, use of health services, and health risk factors and behaviours.

National Nutrition Survey (1995), conducted by the ABS, was the largest and most comprehensive Australian survey of food and nutrient intake, dietary habits and body measurements. The survey collected information from a subsample of respondents from the 1995 National Health Survey, approximately 13,800 people from urban and rural areas of Australia. The National Nutrition Survey was conducted over a 13-month period from February 1995 to March 1996.

National Physical Activity Surveys (1997, 1999 and 2000). The 2000 survey was conducted to give an assessment of physical activity patterns and knowledge of the benefits of physical activity among adult Australians after the Olympics in Sydney (September 2000). The survey collected information from a national sample of 3,590 people aged 18–75 years during November and December 2000. This survey follows on from the 1997 (the Active Australia Baseline survey) and 1999 National Physical Activity Surveys. The 1997 survey collected information from a national sample of 4,821 people in November and December 1997. The 1999 survey collected information from a national sample of 3,841 people in November and December 1999.

Risk Factor Prevalence studies (1980, 1983 and 1989), a series of surveys conducted by the National Heart Foundation of Australia, were designed to obtain national information on biomedical and behavioural risk factors in Australia and to monitor trends over time. The studies collected information from a sample of around 22,000 adults living in capital cities of Australia (Canberra and Darwin were not included in the 1980 and 1983 surveys), between May/June and December of the survey year.

Appendix 2. Adequacy of haemodialysis

Table A3: Adequacy of haemodialysis, 2000 and 2004

Indicator	CARI guideline	Achievement at 31 March 2000	Achievement at 31 March 2004
Urea reduction ratio (URR)	The target URR should be equal or over 65%.	79% of haemodialysis- dependent patients achieved this target.	87% of haemodialysis-dependent patients achieved this target. This is an 8% increase over 5 years.
Frequency	Three times per week.	97% of patients dialysed three times per week.	93% of patients dialysed three times per week. This is a 4% decrease over 5 years.
Duration	Minimum 4 hours for each treatment session.	92% of patients were dialysing for 4 hours or longer for each treatment session. The median weekly treatment period was 12 hours; range 4–26 hours.	91% of patients were dialysing for 4 hours or longer for each treatment session. The median weekly treatment period was 12 hours; range 3–50 hours.
Membranes	High flux membranes were recommended for patients expecting prolonged dialysis (more than 5 years).	About 8% of patients received dialysis with high flux membranes.	36% of patients received dialysis with high flux membranes. This is a 28% increase over 5 years.
Blood flow rate	No guideline existing.	65% of patients were prescribed a blood flow rate of 300 mL/min or higher.	76% of patients were prescribed a blood flow rate of 300 mL/min or higher.
Vascular access	Creation of a native arteriovenous fistula is paramount.	Data not available.	39% of patients whose treatment began between 1 October 2003 and 31 March 2004 have a native haemodialysis access. This is a 30% increase from 2000.
Haemoglobin (Hb) concentration	The minimum recommended Hb concentration in chronic dialysis patients is 110 g/L.	Data not available.	66% of patients were at or above the minimum recommended Hb concentration at 31 March 2004.
Calcium x phosphate product	Serum albumin- corrected calcium x phosphate product should not exceed 5.8 mmol/L.	Data not available.	87% of patients had calcium x phosphate product level less than 5.8 mmol/L.
			60% of patients had calcium x phosphate product level less than 4.2 mmol/L.
	The ideal target is less than 4.2 mmol/L.		

Source: Excell L, Marshall M & McDonald S 2005. Haemodialysis. In: Excell L & McDonald SP (eds). ANZDATA Registry report 2004. Adelaide: ANZDATA, 35–52.

Appendix 3. Potential chronic kidney disease indicators and monitoring framework

Health indicators are tools that that can turn complicated data into relevant and easily understood information. They are measurements that are indicative of the impacts of diseases on communities and also reflect the result of efforts both of health service provision and intervention. Such information helps policy makers and others identify trends and patterns of the diseases, provides evidence for decision making and supports evaluations of progress towards addressing health challenges. It can also be used to highlight areas for possible intervention action. These indicators can be used for the regular surveillance and monitoring of the occurrence and development of diseases. They underpin strategies aimed at prevention and management of diseases and their risk factors.

Although national monitoring systems and health indicators have been developed for a number of chronic diseases, these do not yet exist for CKD. This appendix contains a set of potential health indicators and a monitoring framework for chronic kidney disease. They are presented with the hope of stimulating further development of this important issue.

Potential chronic kidney disease indicators

1 Disease incidence and prevalence

- 1.1 Prevalence rates for chronic kidney disease in:
 - general population
 - Indigenous population
 - people from culturally and linguistically diverse backgrounds.
- 1.2 Incidence and prevalence rates for treated end-stage kidney disease in:
 - general population
 - Indigenous population
 - people from culturally and linguistically diverse backgrounds.

2 Risk factors for chronic kidney disease and associated complications

- 2.1 Prevalence rates for obesity (as measured by BMI) in the general population.
- 2.2 Prevalence rates for diabetes in the general population.
- 2.3 Prevalence rates for smoking among people with chronic kidney disease and in the general population.

- 2.4 Prevalence rates for physical inactivity among people with chronic kidney disease and in the general population.
- 2.5 Prevalence rates for high blood pressure among people with chronic kidney disease and in the general population:
 - ≤140 mmHg systolic and/or 90 mmHg diastolic and/or receiving treatment for high blood pressure in the general population
 - ≤130 mmHg systolic and/or 85 mmHg diastolic and/or receiving treatment for high blood pressure among people with chronic kidney disease.

3 Chronic kidney disease comorbidities

- 3.1 Proportion of people with chronic kidney disease who have diabetes.
- 3.2 Proportion of people with chronic kidney disease who have hypertension.
- 3.3 Proportion of people with treated end-stage kidney disease who have diabetes.
- 3.4 Proportion of people with treated end-stage kidney disease who have coronary artery disease.
- 3.5 Proportion of people with treated end-stage kidney disease who have peripheral vascular disease.
- 3.6 Proportion of people with treated end-stage kidney disease who have cerebrovascular diseases.

4 Hospital separations for chronic kidney disease

- 4.1 Hospital separation rates for chronic kidney disease as the principal diagnosis and as an additional diagnosis in:
 - general population
 - Indigenous population.
- 4.2 Hospital separation rates for care involving dialysis in:
 - general population
 - Indigenous population.
- 4.3 Hospital separation rates for:
 - cardiovascular disease as the principal diagnosis and chronic kidney disease as an additional diagnosis
 - cardiovascular disease as an additional diagnosis and chronic kidney disease as the principal diagnosis.

5 Mortality

- 5.1 Death rates for chronic kidney disease as underlying or associated cause of death in:
 - general population
 - Indigenous population.

- 5.2 Death rates for:
 - cardiovascular disease as the underlying cause of death with chronic kidney disease as an associated cause of death
 - cardiovascular disease as an associated cause of death with chronic kidney disease as the underlying cause of death.
- 5.3 Death rates among people with treated end-stage kidney disease.

6 Screening

- 6.1 Proportion of people with chronic kidney disease who have annual:
 - blood pressure measurement
 - urinalysis: microalbuminuria dipstick (or albumin/creatinine ratio) in people with diabetes and proteinuria dipstick in people without diabetes
 - GFR measurement (calculated using serum creatinine).

7 Management of kidney replacement therapy

- 7.1 Management of dialysis:
 - prevalence of treated end-stage kidney disease patients receiving dialysis treatment
 - proportion of dialysis patients receiving haemodialysis
 - proportion of dialysis patients receiving peritoneal dialysis
 - 1, 5 and 10 year survival of dialysis-dependent patients.
- 7.2 Management of kidney transplant:
 - incidence rate for kidney transplant
 - prevalence rate of functioning kidney transplant
 - 1, 5 and 10 year survival rates of grafts
 - 1, 5 and 10 year survival rates of patients
 - proportion of cadaveric and live donors
 - proportion of treated end-stage kidney disease patients on kidney transplant waiting list
 - average waiting time for kidney transplant.

