Outline of the National Centre for Monitoring Chronic Kidney Disease

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Summary

This report describes the rationale behind establishing the National Centre for Monitoring Chronic Kidney Disease (the National Centre), provides a framework for monitoring chronic kidney disease (CKD) and defines the scope of the National Centre.

Chronic kidney disease has been a public health issue for many years. One of the major risk factors for the disease, diabetes, is increasing in the population and this has led to a recent increase in the most severe form of CKD, end-stage kidney disease (ESKD). However there are many gaps in the information available on CKD in Australia, particularly in relation to the earlier stages of the disease. These gaps need to be properly identified and filled.

The overall objective of the National Centre is to support national surveillance and monitoring of chronic kidney disease in Australia. The National Centre will monitor and report on disease levels, burdens and trends associated with chronic kidney disease in all Australians and in specific populations. By reporting patterns and trends of chronic kidney disease the National Centre will complement other initiatives in monitoring the closely linked chronic diseases of cardiovascular disease and diabetes.

The National Centre aims to identify gaps, consolidate previously separate information and undertake or coordinate efforts for new data analysis.

These activities will facilitate information sharing between key stakeholders such as experts, advocacy groups and policy makers, and promote community discussion with the ultimate aim of informing efforts to help reduce the health, social and economic burden of CKD to individuals and society.

1 Introduction

This report is intended to be a brief outline of the rationale behind establishing the National Centre for Monitoring Chronic Kidney Disease, the structure of the centre, key areas of monitoring and major data sources to be used for monitoring.

Why monitor chronic kidney disease?

Chronic kidney disease (CKD) is a common chronic disease in Australia. The disease is highly preventable, and progression can be slowed by controlling common risk factors and by improving disease treatment and management. In its most severe form CKD can reduce a person's quality of life and cause great expense to the health system. In all forms, it increases cardiovascular risk which in turn increases risk of premature death. Hence, it is important that strategies are developed now to prevent and reduce the burden of the disease, and these need to be monitored.

The National Chronic Disease Strategy endorsed by the Australian Health Ministers' Council in 2005 outlines a broad set of principles and action areas about prevention and care of chronic disease in Australia. One of these principles is to report on measures in order to monitor progress against expected outcomes. Monitoring and improved data quality are important parts of this strategy.

Although CKD has been a public health issue for many years, it is only recently that a clearer definition and conceptualisation of the disease have been developed. As a result, the disease has been receiving increased attention nationally and internationally.

CKD affects a significant number of Australians and is more common among certain population groups, such as Aboriginal and Torres Straight Islander peoples. However what is known about the burden of CKD is largely limited to the more severe stages of the disease, where people have contact with the health system. There is a lack of data on the early stages of CKD, to the extent that it is unclear exactly what the prevalence is, how the disease is being managed and with what population groups the burden lies. In order to assess the current and future magnitude of CKD, a national evidence base is essential for decision and policy makers to draw upon. To do this, an integrated ongoing system is needed to monitor CKD regularly in Australia.

In response to this need, the National Centre for Monitoring Chronic Kidney Disease (the National Centre), was established at the Australian Institute of Health and Welfare in late 2007. The National Centre is largely funded by the Australian Government Department of Health and Ageing.

The burden of CKD in Australia is expected to rise predominantly through the increase of major risk factors such as diabetes, and a greater number of people with high blood pressure because of an ageing population. Work in this area is critical for improving capacity to assess the health impact of CKD, to evaluate progress in disease prevention and management, and therefore to provide evidence for developing policy to reduce the associated burden and outcomes for people at risk of or living with CKD. There is considerable potential for health, social and economic gains through CKD monitoring.

The kidneys

The kidneys are two bean-shaped organs located at the back of the abdomen. Each is about the size of a fist. They continuously filter the bloodstream, playing a vital role in controlling the body's level of water and various chemicals and clearing waste products. They also produce certain essential hormones. The kidneys are highly active and selective filters, with vital substances first being filtered but then being reabsorbed into the bloodstream through the kidneys' 'process line'. This includes glucose (fully reabsorbed) and water and sodium (almost fully). Waste products and any excess water filtered out by the kidneys are eliminated from the body through the bladder in the form of urine.

As outlined later, many things can damage the kidneys. However, the kidneys have great reserves and healthy people can safely do without one of their kidneys, as when they donate one. But when the kidneys are damaged to the point where they no longer work effectively, the body's chemical balance may be changed, waste products may build up in the blood and essential bodily processes may be disrupted. This causes damage to the body's organs and systems, and may result in a range of serious complications.

Chronic kidney disease

Chronic kidney disease is marked by long-term loss and usually irreversible loss of kidney function. In 2002 the United States Kidney Disease Outcome Quality Initiative (K/DOQI) developed a definition (see Appendix 1) and clinical guidelines for CKD (National Kidney Foundation of America 2002). The definition has been widely accepted in Australia and has been endorsed by Kidney Health Australia (see Table 2).

CKD is defined as all conditions of the kidney where a person has had evidence of kidney damage and/or reduced kidney function for at least 3 months (National Kidney Foundation of America 2002). Typically, the onset of symptoms is slow, with kidney function often deteriorating substantially before detection.

An important feature of chronic kidney disease is that symptoms are rare in the initial stages and the damage can be quite severe before any problems are detected. If a person has routine blood or urine testing as part of a check-up, however, signs of damage or reduced function may be picked up fairly early.

For example, a blood test might find excess levels of waste products that are normally passed into the urine. Hence, there are raised blood levels of urea or creatinine (waste products of protein metabolism). Also, a urine test may find blood substances that would normally not leak out of the kidneys. Hence, proteins show up in the urine (proteinuria or albuminuria), or even blood itself (haematuria) (see Appendix 1).

Such findings suggest that the kidneys are not functioning well. There is also a general measure of function known as the glomerular filtration rate (GFR)—the amount of blood the kidneys clear of waste products in one minute (Box 1.1). (The glomeruli are networks of blood vessels in the kidneys where the blood is filtered and waste products are removed.)

Box 1.1: GFR and eGFR

The glomerular filtration rate (GFR) is a measure of the level of kidney function used to clinically diagnose CKD. Although GFR cannot be measured directly (National Kidney Foundation of America 2002) there are a number of methods which can estimate GFR. The agreed best method for measuring GFR is kidney clearance of inulin, but this is not considered practical for clinical practice (Chadban & Ierino 2005). Because of this, it is current practice to estimate GFR (eGFR) using a formula derived by the Modification of Diet in Renal Disease (MDRD) study which requires measured creatinine levels, age and gender (Levey et al. 1999). Although this method is widely used, it is still being validated for some population groups.

Chronic kidney disease can be classified into five stages of severity based on GFR and evidence of kidney damage (Box 1.2). An individual can move up and down through the first four stages of severity, but once they reach stage five (ESKD) their kidney function cannot improve.

Box 1.2: Stages of chronic kidney disease

Stage 1: Kidney damage with GFR at least 90 mL/min/1.73 m²

People with stage 1 CKD have evidence of kidney damage (structural or functional abnormalities of the kidney), but without decreased GFR. There are usually no symptoms.

Stage 2: Kidney damage with GFR 60 to 89 mL/min/1.73 m²

People with stage 2 CKD have evidence of kidney damage with some reduction in GFR. Most patients at this stage have no symptoms. They usually have hypertension and may have laboratory abnormalities indicating dysfunction in other organs.

Stage 3: GFR 30 to 59 mL/min/1.73 m²*

People with stage 3 CKD have a significant reduction in GFR. They may or may not show other signs of kidney damage. Blood tests will show increased levels of urea and creatinine, and often there will be indications of dysfunction in other organs. Although patients may have symptoms, they often remain asymptomatic even though their kidney function may be reduced by as much as 70%.

Stage 4: GFR 15 to 29 mL/min/1.73 m²*

People with stage 4 CKD have severely reduced kidney function. Blood levels of urea and creatinine increase, and there is greater evidence of dysfunction in other organs. Patients usually have only mild symptoms.

Stage 5: GFR less than 15 mL/min/1.73 m²*

In most cases, stage 5 CKD is marked by a range of symptoms and laboratory abnormalities in several organ systems, which are collectively referred to as uraemia. Patients at this stage may need to be prepared for kidney replacement therapy (dialysis or transplant), which will be required when kidney function is no longer sufficient to sustain life. This is known as 'end-stage kidney disease', and typically occurs at a GFR of around 7–8mL/min/1.73m².

** with or without evidence of kidney damage*

Source: Adapted from Obrador & Pereira 2002.

Despite there being a variety of tests for CKD, many stages of CKD are asymptomatic. The asymptomatic nature of the early stages of CKD is problematic because CKD is linked with greater morbidity and mortality. This is especially due to cardiovascular disease (Amaresan

& Geetha 2008), but also other comorbidities such as anaemia, bone disease and hypertension (Barri 2008; Boydstun 2005; Locatelli et al. 2005). Early diagnosis and intervention can halt or slow progression of the disease and the lack of symptoms does often mean diagnosis is delayed. This leads to use of the health care system, a reduction in quality of life and a large financial burden on both individuals and government (Amaresan & Geetha 2008).

CKD is complex and has many different biomedical causes such as diabetes, hypertension, glomerulonephritis and polycystic kidney disease (Box 1.3). There are also many factors which increase a person's risk of developing CKD, described later in this report in chapter 3.

Box 1.3: Major causes of chronic kidney disease

Diabetes and diabetic nephropathy

Diabetes is a chronic condition in which blood sugar levels are too high and is the most common cause of end-stage kidney disease in Australia (McDonald et al. 2007). Diabetes occurs when the body under produces the sugar-regulating molecule insulin or cannot use it properly. Higher than normal blood sugar levels can cause damage to the blood-filtering capillaries in the kidneys, thereby reducing the kidney's ability to filter the blood.

Glomerulonephritis

Glomerulonephritis is a group of kidney diseases characterised by inflammation within the glomeruli and other parts of the kidney. The inflammation can lead to gradual, progressive destruction of the internal kidney structure. The causes of glomerulonephritis are complex and incompletely understood. Causal mechanisms can be broadly broken down into internal factors, such as autoimmunity and cancer, and external factors, such as infections and drugs (Chadban & Atkins 2005).

High blood pressure and vascular disease

High blood pressure (hypertension) can damage the blood vessels in the kidneys. The walls of these blood vessels become thick and the internal diameter narrowed, leading to reduced blood supply and decreased kidney function. Factors that contribute to increased blood pressure include age, obesity, smoking, high alcohol consumption and high dietary salt intake (National Heart Foundation of Australia 2008).

2 The National Centre for Monitoring Chronic Kidney Disease

The National Centre for Monitoring Chronic Kidney Disease is located at the Australian Institute of Health and Welfare (AIHW). Its main source of funding is the Australian Government Department of Health and Ageing, and it is advised by the Chronic Kidney Disease Monitoring Advisory Committee. The National Centre will draw on a variety of information sources in order to monitor and provide timely CKD information to stakeholders (Figure 1).

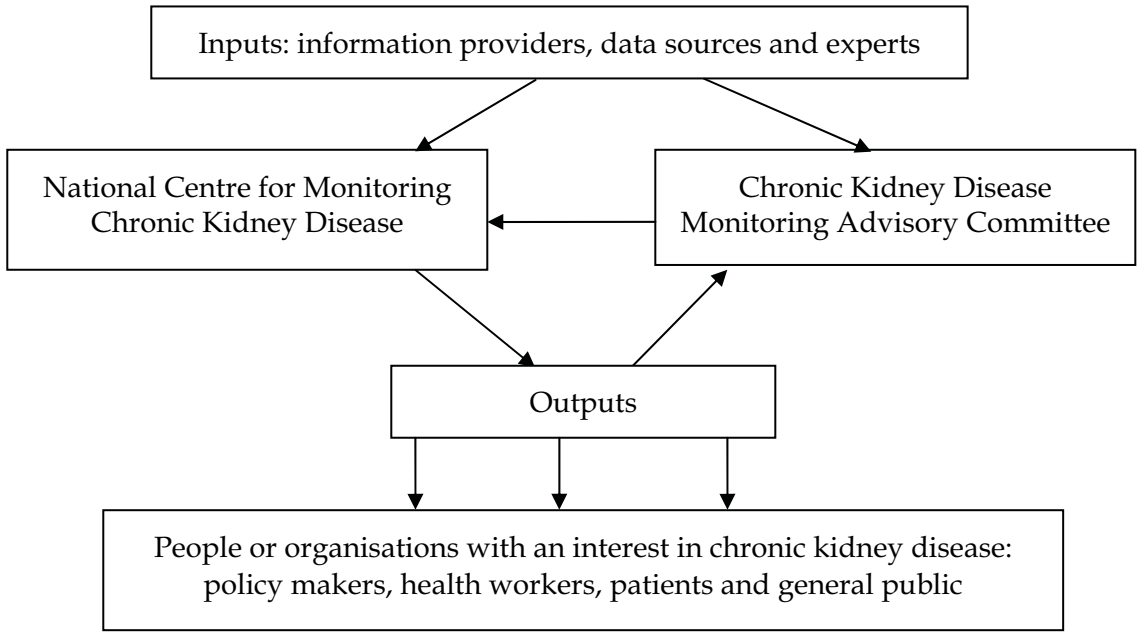


Figure 1: National monitoring of chronic kidney disease in Australia

What is monitoring?

Disease monitoring involves the analysis of trends and patterns in health information systems including risk factors, disease frequency, impact and health service use. Monitoring can help establish the magnitude of the problem, improvement and deterioration relating to disease in the community, and is a process geared towards informing policy makers (Bonnefoy et al. 2007).

Monitoring does not usually attempt to investigate the causal mechanisms underlying a disease or gather evidence for interventions to best reduce the burden of disease (Commission on Social Determinants of Health 2008), but may identify potential areas requiring further research in these areas. As such, the core role of the National Centre for

Monitoring Chronic Kidney Disease is to report on national trends and patterns of CKD using currently available data, and to identify gaps and deficiencies for national reporting, developing data where appropriate.

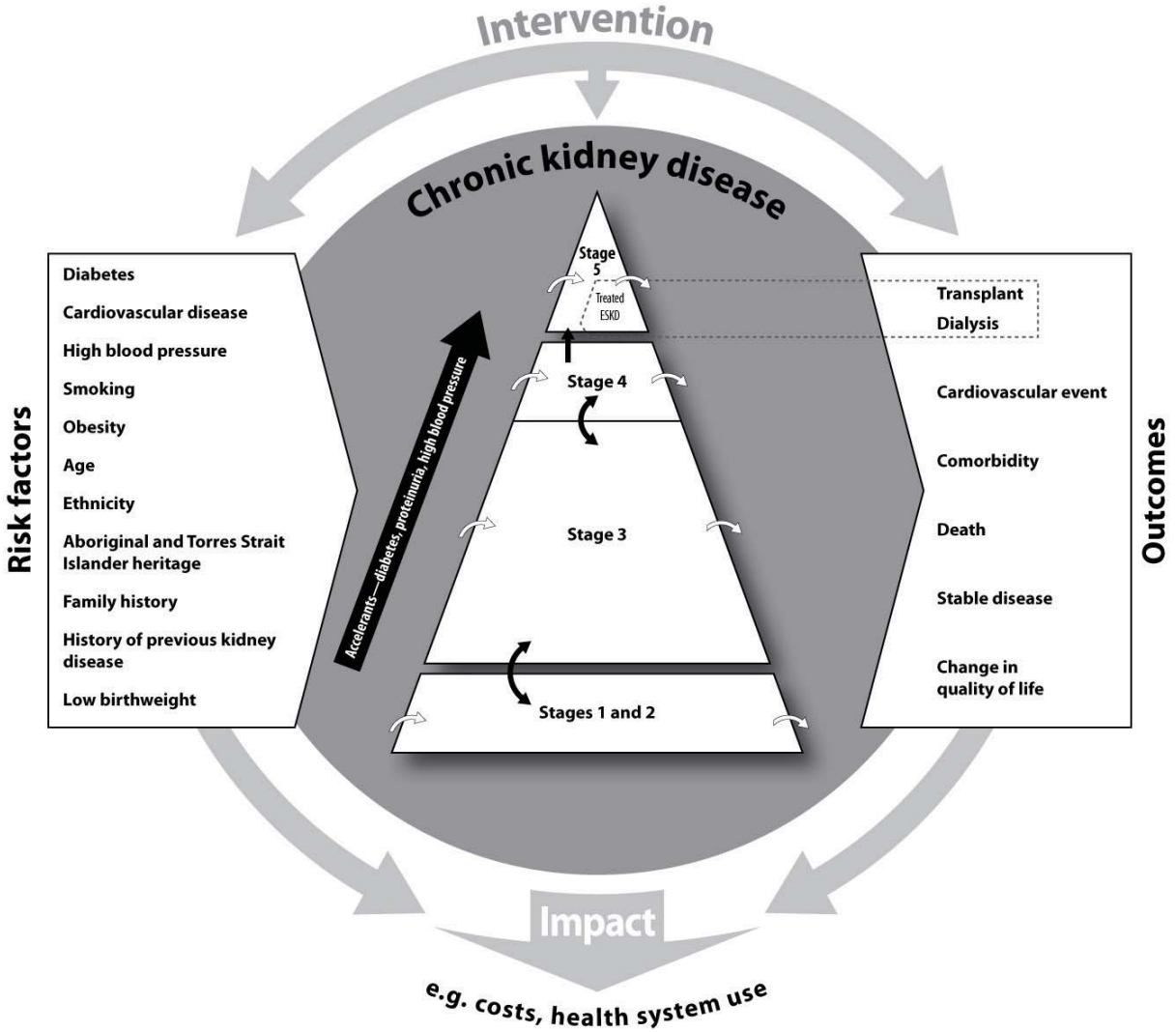
Aim and scope of the National Centre

The National Centre for Monitoring Chronic Kidney Disease aims to develop, collate, analyse, interpret and disseminate information relevant to CKD prevention, detection, management and care to inform stakeholders such as policy makers, health professionals, advocacy groups and the public.

The National Centre will help to fill in gaps where reporting has not previously occurred and quantify as much as possible the burden of CKD in the population. It will also enable a link for information sharing between key stakeholders such as experts, advocacy groups and policy makers. It is a way of consolidating previously separate information, identifying gaps and coordinating effort to perform new analyses, thereby facilitating the aim of reducing the burden of CKD on individuals and society.

The scope of the monitoring centre is to report on national trends and patterns of CKD in areas such as risk factors, disease frequency, impact and health service use. This includes trends and patterns among different population groups (e.g. socioeconomic groups, Aboriginal and Torres Strait Islander peoples, immigrant groups, men and women, regions), over time and international comparisons.

Based on the recommendations made by the National Chronic Disease Strategy, a framework for monitoring CKD in Australia was first proposed in 2005 (AIHW 2005). The main aim of the strategy is strengthening activity across the continuum of chronic disease prevention and care. The current framework has been modified based on advice from the Chronic Kidney Disease Monitoring Advisory Committee and is intended to be a guide for the National Centre in monitoring CKD (Figure 2).



Note: ESKD = End Stage Kidney Disease.

Figure 2: A framework for national chronic kidney disease monitoring

The framework does not presume to be all encompassing of factors affecting CKD rather, its aim is to show visually the key risk factors, stages and outcomes of CKD important for monitoring the disease at a national population level. The National Centre aims to monitor these major aspects of CKD which also include other key areas such as health care (including prevention and treatment) and impact set out in the framework and Table 1.

Table 1: Key areas for monitoring chronic kidney disease

Key area	Population group	Major components
Risk factors	People at risk of CKD, whose condition is not clinically apparent, and people with CKD.	Diabetes Cardiovascular disease High blood pressure Smoking Age Ethnicity Family history Obesity History of previous kidney disease Intrauterine growth restriction
Disease frequency	People with CKD	Prevalence Incidence
Impact of CKD	People with CKD	Expenditure Mortality Morbidity Comorbidity Disability Quality of life – effect on carers
Health service use	People with CKD	Prevention Detection Management – dialysis and transplant

The National Centre aims to monitor these areas through:

- collating data on chronic kidney disease across the health continuum
- addressing gaps and deficiencies, and undertaking data development
- providing data for planning and policy development to improve prevention, early detection, management and treatment interventions
- undertaking data analysis and dissemination
- promoting and applying uniform statistical standards, methods and definitions.

The National Centre intends to adapt and extend its role to meet new demands for data. It will use current data sources, and identify those areas where data development is required while seeking to minimise duplication of effort.

The National Centre will report on data in AIHW publications (reports, bulletins) and journal articles and will present at conferences.

Information providers

Various organisations and groups provide information which will be used by the National Centre. The roles of the key national information providers are outlined in Table 2. A description of key data sources can be found in Appendix B.

Table 2: Key information providers

Organisation/group	Activities related to national monitoring
Australian Institute of Health and Welfare (AIHW)	Home of the National Centre for Monitoring Chronic Kidney Disease, and custodian of the National Death Index, AIHW National Hospital Morbidity Database, AIHW National Mortality Database, the Bettering the Evaluation and Care of Health (BEACH) data, the National Diabetes Register and other relevant data sets. The AIHW also has access to the National Health Survey, the National Diabetes Services Scheme data and the AusDiab data. Coordinates, develops, analyses and disseminates national statistics on CKD, its risk factors, complications and effects.
Australian Government Department of Health and Ageing (DoHA)	Key funder of the National Centre. Has provided funding for various other research, intervention and monitoring activities, such as the Australian Diabetes, Obesity and Lifestyle study (AusDiab) and the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA). Custodians of the Medical Benefits Scheme and Pharmaceutical Benefits Scheme data.
Australian Bureau of Statistics (ABS)	Collects and disseminates census and survey data, including the National Health Survey and Survey of Disability, Ageing and Carers. Also compiles the cause of death data collection.
Australian and New Zealand Dialysis and Transplant Registry (ANZDATA)	Collects data and reports on people receiving kidney replacement therapy (dialysis and kidney transplant).
Australian and New Zealand Society of Nephrology (ANZSN)	Coordinates the preparation of best-practice clinical guidelines and supports research related to kidney disease.
Kidney Health Australia (KHA)	Coordinates activities aimed at increasing awareness of chronic kidney disease, the preparation of best-practice guidelines and supports research related to kidney disease.
States and territory governments	Conduct various health surveys within the states and territories and provide data for national data collections.

Role of the Chronic Kidney Disease Monitoring Advisory Committee (CKDMAC)

The CKDMAC consists of relevant stakeholders, which include clinicians, policy makers, researchers, consumers and others appointed for their expertise in the fields of CKD and related research. The terms of reference for the CKDMAC are as follows:

- Within the scope of the National Centre for Monitoring Chronic Kidney Disease, identify the national information needs and requirements for data reporting on chronic kidney disease, in order to provide advice to the AIHW on the strategic directions (aims, objectives, core activities and priorities) and work program for the National Centre.
- Provide expert advice to the AIHW regarding individual projects on the National Centre's work program. This will include, where appropriate, the scope and content of forthcoming publications and subsequent review of draft publications, provided in a timely manner.
- Work collaboratively with staff of the National Centre.
- Contribute to data and indicator development undertaken by the National Centre, when required.

- Report annually (from the Chair of the committee) to the Director of the AIHW in relation to the work of the National Centre, including any recommendations for future priorities.

3 Review of key areas for monitoring chronic kidney disease

This section describes the key areas for monitoring and identifies the currently available data sources in these areas. The National Centre will monitor these areas at a national level and also in specific population groups where the data are available. A key role of the monitoring centre will be to identify gaps in data available for monitoring CKD; however, this is not done in detail here.

Risk factors

Risk factors are characteristics that increase the chance of a person developing a disease. Risk factors for CKD can be grouped into three broad categories: fixed risk factors, behavioural risk factors and biomedical risk factors.

Fixed risk factors are those which cannot be modified. They include demographic risk factors such as age, sex and ethnicity as well as genetics or family history. Although these factors cannot be changed, it is important that people with fixed risk factors are aware that they are at increased risk of disease so they can focus on ensuring they manage modifiable risk factors. It is important to monitor these risk factors so that populations at high risk of CKD can be identified, and prevention and treatment programs can be implemented in appropriate areas.

Other risk factors for CKD include behavioural risk factors such as smoking, and biomedical risk factors such as high blood pressure and obesity. Having a history of kidney disease or a low birthweight (intrauterine growth retardation) also increases a person's chance of developing CKD. Most behavioural and biomedical risk factors for CKD are also risk factors for other chronic diseases such as cardiovascular disease and diabetes, which in turn are risk factors for CKD.

Behavioural risk factor prevention has been the target of a number of health promotion campaigns. Monitoring behavioural and biomedical risk factors will help predict future rates of CKD and inform policy on further preventive care and programs. Detailed information on the behavioural and biomedical risk factors considered major for CKD is outlined below.

Smoking

Smoking is known to be a large contributor to sickness and deaths in Australia. Until recently, a lack of good-quality data meant that smoking could not be confirmed as an independent risk factor for CKD. However, recent prospective studies have shown that smoking is an independent risk factor for all stages of CKD (Orth & Hallan 2008). In addition, if a person has other risk factors such as diabetes or high blood pressure, smoking further increases the risk of developing CKD.

Overweight and obesity

Excess weight can increase a person's risk of developing CKD. Obesity further increases risk. A recent systematic review estimated that the risk of kidney disease was almost 1.5 times as

high for an overweight but not obese (BMI 25 to 30) person and was almost double for an obese (BMI > 30) person. In addition, obese women had a higher risk of developing CKD than obese men (Wang et al. 2008).

High blood pressure

High blood pressure (hypertension) can damage the blood vessels in the kidneys and lead to kidney disease. The link between high blood pressure and CKD is complex because high blood pressure has been shown to be an independent risk factor for kidney disease (Barri 2008) and conversely kidney disease can cause high blood pressure. Moreover, the presence of high blood pressure in a patient with kidney disease is associated with progression of the disease and an increased risk of cardiovascular events (Barri 2008). Nearly 8% of the burden of disease in Australia in 2003 could be attributed to high blood pressure, making it a major public health issue (AIHW 2008a). Blood pressure can often be reduced by a change in diet (particularly reducing salt intake), increased physical activity and use of medications.

Diabetes

Diabetes is one of the major risk factors for CKD (Amaresan & Geetha 2008). It is thought that increased blood sugar levels damage the blood vessels eventually leading to a decreased ability by the kidneys to filter the blood. This is known as diabetic nephropathy.

One-third of people starting treatment for end-stage kidney disease in Australia do so because of their diabetes (McDonald et al. 2007). Many of the risk factors mentioned above for CKD are also risk factors for Type 2 diabetes, which is one of the leading causes of chronic disease in Australia (AIHW 2008b). If these other risk factors are controlled, Type 2 diabetes is largely preventable. People with diabetes can reduce their risk of developing CKD by controlling high blood pressure and blood sugar (Kidney Health Australia 2007).

Cardiovascular disease

CKD is a well-established risk factor for cardiovascular disease (McCullough et al. 2008). However, the relationship is complex because both CKD and cardiovascular disease share common risk factors such as obesity, smoking and high blood pressure. Recent evidence has also shown cardiovascular disease to be an independent risk factor for kidney function decline and the progression of kidney disease (Elsayed et al. 2007).

Intrauterine growth restriction (low birthweight)

Intrauterine growth restriction describes poor fetal growth. Specifically, it refers to a fetus whose weight is below the tenth percentile for gestational age (Vandenbosche & Kirchner 1998). Where gestational age is not known, low birthweight is usually defined as < 2500 grams (AIHW: Sullivan et al. 2007). Evidence suggests that people whose growth was restricted and/or had a low birthweight are at a greater risk of developing CKD (Al Salmi et al. 2008; Vikse et al. 2008).This is possibly due to the association between birthweight and the number of nephrons a person has (Al Salmi et al. 2008).

Inflammation

Systemic inflammation has been hypothesised to be an independent risk factor for CKD (Erlinger et al. 2003; Wetmore et al. 2005), and there is considerable research to support this.

Inflammation can also be a symptom of CKD and can increase cardiovascular risk (Shlipak et al. 2003).

Physical inactivity

Inadequate physical activity has been shown to increase the risk of CKD, independent of obesity, the other risk factor it is usually linked to (Stengel et al. 2003). However, not doing enough physical activity also increases a person's risk of developing diabetes and high blood pressure; hence the relationship of inadequate activity to increasing risk of CKD is complex.

Proteinuria

Proteinuria (protein in the urine), as discussed in Chapter 1, is a sign of kidney disease. There is a large body of evidence that proteinuria is a risk factor for the progression on CKD (Taal & Brenner 2006). Proteinuria has also been shown to significantly increase the risk of cardiovascular disease. A recent systematic review found that people with proteinuria had about a 50% increased risk of developing coronary heart disease (Perkovic et al. 2008).

Other risk factors

There are other risk factors which have been shown to be associated directly or indirectly with CKD. These include poor nutrition (particularly a high salt intake) (De Francisco et al. 2005), a previous case of kidney disease, trauma or accident, and the overuse of some pain-killers (NKUDIC 2007).

Monitoring risk factors

Data on fixed risk factors such as age, sex, ethnicity and country of birth (a useful substitute for ethnicity) at a national population level are collected in the Census of Population and Housing. The National Health Surveys, run by the Australian Bureau of Statistics also provide similar information linked with information on other risk factors. There is a lack of national information on family history and genetic predisposition for chronic kidney disease.

Self-reported data on behavioural risk factors at a national level such as smoking can be found in the National Household Drug Strategy Survey. Other self-reported information on smoking and physical inactivity is also collected via the National Health Surveys. Self-reported information is useful but can be subject to bias because it relies on individual understanding and recall. Measured data for risk factors such as high blood pressure can be found in the 1999–2000 Australian Diabetes, Obesity and Lifestyle Study (AusDiab), but this study is now almost 10 years old, and there is no more recent information using measured data. Measured data from a representative survey is the most reliable way of collecting this data.

Further self-reported information on diabetes and cardiovascular disease can also be found in the National Health Surveys. Information on birthweight for babies can be found in the National Perinatal Data Collection and other information on for babies born in hospital can be found in the National Hospital Morbidity Database.

Self-reported information on most fixed and behavioural risk factors in Indigenous Australians can be found in the National Aboriginal and Torres Strait Islander Health Surveys.

Disease frequency

Knowing the level of disease in a population is invaluable for policy makers. Commonly, disease frequency is reported as either prevalence or incidence. Prevalence is all cases of a disease in a population at a point in time whereas incidence is the number of new cases in a population in a given time period. Having estimates of the prevalence and incidence of a disease in the population is useful for guiding discussion and decision making. In particular, prevalence and incidence data can help researchers identify specific population groups at risk of disease, shape the development of effective prevention strategies, monitor the effectiveness of these strategies, and examine the impact of disease on the health system.

Estimation of the incidence and prevalence of all stages of CKD is difficult because the disease often remains undetected until the late stages. National monitoring of the prevalence of diseases in Australia often relies on self-reported information from surveys such as the National Health Survey. In the case of CKD, any self-reported information is unlikely to accurately reflect the true prevalence of the earlier stages of the disease. A nationally representative survey which collects measured data is needed to assess the true prevalence of the disease.

Once people make contact with the health system in the later stages of CKD it is easier to estimate prevalence and incidence. End-stage kidney disease (ESKD) or stage 5 kidney disease requires kidney replacement therapy (KRT) in the form of regular dialysis or kidney transplant. Information on all people receiving KRT in Australia is compiled by the Australia and New Zealand Dialysis and Transplant Registry (ANZDATA). Owing to its comprehensive coverage, ANZDATA is a valuable and accurate data source, useful for monitoring the incidence and prevalence of treated ESKD in Australia.

Monitoring disease frequency

The two main sources of prevalence and incidence data for chronic kidney disease currently available are the 1999–2000 AusDiab study and the annual data collection of the ANZDATA registry. ANZDATA collects information from all persons receiving kidney replacement therapy in Australia and New Zealand, excluding treatment resulting from acute kidney failure. Hence, this data source is valuable for monitoring end-stage kidney disease (stage 5).

A representative survey which collects measured data is the best approach to estimate the prevalence and incidence of CKD across all five stages. The most recent such survey conducted in Australia is the 1999–2000 AusDiab study. This study was a population-based cross-sectional survey which estimated the glomerular filtration rate (eGFR) of 10,949 Australian adults, as well as other indicators of kidney damage such as proteinuria and haematuria at baseline. The same information was collected at 5-year follow-up. Consequently, the study has been able to estimate CKD prevalence at baseline and estimate incidence of CKD for those subjects followed up. The estimation of eGFR in the initial study used the Cockcroft-Gault formula; however, the Australasian Creatinine Consensus Working Group now recommends the use of the Modification of Diet in Renal Disease (MDRD) '175' formula. Adjusted CKD prevalence estimates and incidence estimates based on this recommendation have now been calculated, but the work is not yet published.

Impact and health service use

Chronic kidney disease affects many aspects of life and can cause much suffering, disability and premature death. Specifically, it can decrease the health status of individuals, affect quality of life and lead to or increase the risk of developing other diseases. Treating CKD is also very costly to individuals and society through use of health services.

Monitoring the impact of chronic kidney disease

Monitoring the impact of CKD on health status, quality of life and comorbidity relies on kidney disease being diagnosed. As discussed previously, the prevalence of CKD is often underestimated because of the asymptomatic nature of early stage CKD limiting early diagnosis. Two potentially useful national sources of health status and quality of life for CKD—the National Health Survey and the Survey of Disability, Ageing and Carers—do not currently include specific questions on CKD. Hence there is only limited information in this area.

It is possible to get some idea of morbidity and comorbid conditions in people with diagnosed kidney disease by analysing records of people who have attended hospital and by looking at death certificates. However, these data are likely to include people with more advanced CKD rather than people with earlier stages of the disease. This is because, in the early stages of CKD, people are often asymptomatic and, if they are aware they have CKD, management is more likely to occur out of hospital.

Monitoring the health service use of people with chronic kidney disease

Health service use can include out-of-hospital services such as visits to a general practitioner (GP) or medical specialist, hospital visits or use of preventive services.

National monitoring of hospital service use by people with chronic kidney disease can be done through the AIHW National Hospital Morbidity Database (NHMD). Dialysis is the most common form of admission to hospital for patients with CKD, and can often swamp the admissions, with many patients being admitted for same-day dialysis treatment 3 or more times a week. As the NHMD is event-based (recording each hospitalisation), it is important to separate dialysis and other reasons for admission when monitoring CKD hospital admission. When a patient is admitted for a reason other than dialysis, it is more likely that CKD will be coded as an additional diagnosis, rather than as a principal diagnosis, because CKD patients are often admitted for other reasons such as coronary heart disease. This, too, must be considered when monitoring hospital admissions for CKD. Monitoring hospital service use (including dialysis) for CKD will become easier in the future because of a coding change implemented in July 2008. This change will see CKD stages recorded.

General practitioners are often the source of first-contact for medical problems and monitoring the number of encounters with GPs and their managing practices can be useful in understanding the scope of CKD. The BEACH Survey of General Practice (see Appendix 2), an ongoing survey looking at aspects of general practice, can be used for this purpose.

Referrals to specialist services for kidney disease patients often occur for diagnosis or advice. Some of this information can also be found in the BEACH survey, but there is limited information on referrals from non-general practitioners. An estimate of the supply of

specialist services can be found in the AIHW Medical Labour Force Survey and from state and territory medical registration boards.

Expenditure on CKD can be monitored through the AIHW Disease Expenditure Database. Expenditure can be reported for hospital and out-of-hospital services as well as for pharmaceuticals subsidised by the Pharmaceutical Benefits Scheme. Treatments for later stages of the disease, dialysis and transplant are expensive, with regular dialysis currently the largest single contributor to hospital separations in Australia (AIHW 2008a).

Preventive health services are difficult to monitor as systematic monitoring at a national level has not been done in this area. Furthermore, preventive services are generally state-based and these services do not necessarily target CKD but risk factors for chronic diseases in general. Prevention of chronic disease is currently receiving more focused attention.

4 Database codes used for monitoring chronic kidney disease

The National Centre will draw on a number of data sources to monitor CKD. Many of these databases use the WHO International Classification of Diseases (ICD) to code data. The version currently in use is the ICD-10.

In Australia, different versions of the ICD-10 are used. In most medical encounters, the Australian modification (ICD-10-AM) is used. However, in some cases, such as on death certificates, the standard version is used. Hence identification of CKD using both versions is necessary.

'Chronic kidney disease' is not used as a medical term in the ICD-10, nor is it generally used as a diagnosis in clinical settings. The most recent Australian modification (ICD-10-AM 6th edition) has rectified this problem and it was implemented for hospital data on 1 July 2008. However, current databases have used earlier editions of ICD-10-AM which do not identify the disease. In addition, databases using the standard version of ICD-10 (e.g. mortality) will not have a specific category for CKD. For these reasons, it is not possible to identify CKD patients directly in most existing databases. It is also not possible to identify CKD patients through assessing their kidney function, as most databases do not contain the relevant pathology information.

To overcome this problem, a coding list for chronic kidney disease was developed for the AIHW report *Chronic kidney disease in Australia 2005* (AIHW 2005) using ICD-10 codes known to cause CKD (see Table 3). A list for identifying CKD using the International Classification of Primary Care, 2nd edition (ICPC-2) codes was also developed (see Table 4), as this coding list does not identify CKD directly either. The ICPC-2 list is currently under review due to some coding changes.

Table 3: ICD-10 and ICD-10-AM (fifth edition) coding list for chronic kidney disease

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
I12 Hypertensive renal disease
I13 Hypertensive heart and renal disease
I15.0 Renovascular hypertension
I15.1 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

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

* These codes are to be used for identification in ICD-10-AM (fifth edition) data only.

Table 4: ICPC-2 PLUS coding list for chronic kidney disease

ICPC-2 PLUS code	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

Appendix 1: Defining and detecting CKD

Box A.1: A definition of chronic kidney disease

1.Kidney damage for 3 months or more, as defined by structural or functional abnormalities of the kidney, with or without decreased glomerular filtration rate (GFR), manifest by either:

– pathological abnormalities; or

– markers of kidney damage, including abnormalities in the composition of the blood or urine, or abnormalities in imaging tests.

2. GFR <60 mL/min/1.73 m^2 for 3 months or more, with or without other markers of kidney damage (National Kidney Foundation of America 2002).

Box A.2: Signs of kidney disease

Proteinuria – abnormal levels of protein in the urine. If the kidneys are functioning properly, they do not normally remove protein when filtering the blood. Therefore proteinuria is likely to reflect a decline in kidney function.

Albuminuria – a type of proteinuria, where the protein albumin is in the urine.

Haematuria – blood in the urine. This may reflect a decline in kidney function.

Urea in the blood – a waste product made when the body breaks down protein. Raised levels of urea in the blood are likely to reflect a decline in kidney function.

Creatinine in the blood – a waste product usually removed from the blood by the kidneys. If kidneys are not functioning properly, there can be raised levels of creatinine in the blood.

Appendix 2: Major data sources

AIHW Disease Expenditure Database is a comprehensive database that allows expenditure estimates to be produced by source of funds (that is, Commonwealth, state or private) for each area of expenditure. Utilisation measures such as bed-days, separations, number of medical encounters and services and pharmaceutical scripts can also be estimated. The database is updated approximately every 3 to 4 years, with the most recent data coming from 2005–05. There are some key exclusions in the 2004–05 health expenditure data, compared with material presented in previous reports. High-level residential aged care expenditure (which was $5,807 million in 2004–05) has now been reclassified from health expenditure to welfare expenditure. Also note that expenditure by disease for non-admitted hospital services, other health practitioner services (excluding optometry) and over-the-counter pharmaceuticals was unable to be allocated in 2004–05.

AIHW National Hospital Morbidity Database contains demographic, diagnostic, procedural and duration of stay information on episodes of care for patients admitted to hospital. This annual data collection is maintained by the AIHW using data supplied by state and territory health authorities. The database is episode-based, so it is not possible to count patients individually.

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. The database is updated annually.

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, New Zealand Ministry of Health, and Kidney Health Australia. The data are published annually.

Australia and New Zealand Organ Donation Registry (ANZOD) collects information on all organ donations in Australia and New Zealand. The Registry is coordinated within the Queen Elizabeth Hospital (South Australia) and is funded by the Australian Government Department of Health and Ageing, New Zealand Ministry of Health, and Kidney Health Australia. The data are published annually.

The Australian Diabetes, Obesity and Lifestyle Study (AusDiab) (1999–2000), conducted by the International Diabetes Institute, was designed to provide national estimates of the prevalence of diagnosed and undiagnosed diabetes. 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 cardiovascular disease, anti-hypertensive and lipid-lowering medication use, diet, smoking, alcohol consumption, physical activity, and general health and wellbeing. The study collected information in urban and non-urban areas in all states and the Northern Territory for more than 11,000 people aged 25 years and over who underwent a physical examination. This represents a response rate of 37% (Dunstan et al. 2002).

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.

Medicare Benefits Schedule (MBS) covers medical services and tests subsidised by the Australian Government. Where a service is billed to Medicare Australia, this is recorded on a central database. Services include pathology and imaging testing.

National Health Survey (NHS) run by the Australian Bureau of Statistics, collects information on long-term health conditions, use of health services, and health risk factors and behaviours.

The NHS was designed to obtain national information on the health status of Australians, their use of health services and facilities, health risk factors and behaviours, and health-related aspects of their lifestyle. The most recent NHS was conducted in 2004–05, and it included 25,906 people of all ages across urban and rural areas of Australia. Questions regarding long-term health conditions, including cardiovascular conditions and diabetes, were asked of the respondents at interview. Because it targeted the non-institutionalised population, non-private dwellings (e.g. hospitals, nursing homes, hotels and boarding houses) were excluded. Because it is a self-reported survey, the results were influenced by the questionnaires used, and knowledge and awareness of specific conditions in the population. The next NHS is currently being conducted and is expected to be available for analysis in mid-2009.

Pharmaceutical Benefits Data System held at the Australian Government Department of Health and Ageing (DoHA) is used to monitor expenditure and use of prescription medicines subsidised by the Pharmaceutical Benefits Scheme (PBS) and the Repatriation PBS (RPBS). The database contains information pertinent to the payment of claims for pharmaceuticals from Medicare Australia for medicines subsidised by the PBS and the RPBS. Inpatient hospital prescribing is not included. The data are based on the date of supply or dispensing of prescriptions.

Survey of Disability, Ageing and Carers (SDAC) collects information about people of all ages with a disability, older people (aged 60 years and over) and people who provide assistance to older people with disabilities. The most recent SDAC was conducted throughout Australia from June to November 2003. The survey included people in both private and non-private dwellings, including people in cared-accommodation establishments, but excluded those in gaols and correctional institutions. Another SDAC is expected to be run in 2009.

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