

# 1 INTRODUCTION

## Background

Prevention of disease or ill health is a major aim of the health care system. Despite this, monitoring prevention has not previously occurred in a structured way in Australia. Some information relevant to prevention is contained in various documents (for example AIHW 2004, 2008c,d; Britt & Miller 2009; Queensland Health 2008) but a detailed assessment of prevention services and the related outcomes has not previously been undertaken. Internationally, the World Health Organization has focused on the importance of prevention (WHO 2005). Despite this, very few countries appear to be systematically tracking their progress in the area, particularly in the services aimed at prevention.

Expenditure on prevention is low compared with other health care activities. Some information on expenditure by the health system on 'public health' is available (AIHW 2008j), where public health covers communicable disease control, selected health promotion, organised immunisation, environmental health, food standards and hygiene, screening programs, prevention of hazardous and harmful drug use, and public health research. While this definition of public health does not include all aspects of prevention, such as preventive care in general practice, it does give an indication of the relative expenditure on prevention-type activities. The analysis shows that expenditure on public health accounted for 1.9% of total health expenditure in 2006–07, having increased by 5.6% per year between 1999–00 and 2006–07.

## Increased focus on prevention

Prevention has been receiving increased attention in Australia in recent years. This attention has been in a number of areas, including policy discussions and health service planning. However, there has not been a great deal of attention on how Australia monitors its efforts in prevention. There have been calls for the development of performance indicators for prevention services and evaluation of programs (Oldenburg & Harper 2008; Russell et al. 2008), but less about monitoring more broadly, including analysis of prevention services.

The National Preventative Health Taskforce was established in 2008 to provide advice to governments and health providers on prevention, with a particular focus on tobacco, alcohol and obesity. The major discussion paper compiled by the taskforce (NPHT 2008) stressed the importance of monitoring and surveillance but did not include details about how this should be done. An options paper (Moodie et al. 2008) prepared for the National Health and Hospitals Reform Commission proposed a national prevention agency, whose role would include the 'development of national capacity in surveillance of chronic diseases', along with other functions. The commission's final report (NHHRC 2009) also proposed a national prevention agency. The recently released final report of the National Preventative Health Taskforce (NPHT 2009) outlines the National Preventative Health Strategy. The report reiterates the importance of ongoing data, surveillance and monitoring to support the proposed increased focus on prevention.

## Importance of monitoring prevention

Monitoring in the sense it is used here relies on available data systems that can be analysed to assess the size of a problem, who is most affected and whether the situation is changing over time (CSDH 2008:178). It also includes using the information to assess future trends and to measure the costs and effects of a particular problem. This is closely related to surveillance. The main difference between the two is in the time period: surveillance usually refers to continuous assessment that is aimed at very quickly detecting events of concern requiring immediate attention (for example communicable disease outbreaks), whereas monitoring usually refers to longer term assessment that is usually intermittent or episodic, such as for chronic diseases (Last 2001).

Monitoring aims to provide information and evidence of interest to policy makers, service planners and providers, researchers and the wider community. As systematic monitoring of prevention activities has not been undertaken in detail before, there is a need for baseline information that can be used to help assess the changes that result from the increased policy focus on prevention. It is widely expected that other areas of the health care system are monitored, such as care in hospitals and by general practitioners (GPs). It is similarly important that prevention services and interventions are also monitored. With the increased focus on prevention in Australia, it is important that sound systems to independently monitor efforts in this area are established.

## Cardiovascular disease, diabetes and chronic kidney disease

Cardiovascular disease (CVD) is any disease of the heart ('cardio') or blood vessels ('vascular'). The affected blood vessels may be in different parts of the body, including the periphery (manifesting as 'peripheral vascular disease') and the brain (manifesting as 'stroke'). Some forms of CVD are very common in Australia, including hypertension (high blood pressure), coronary heart disease, heart failure and cerebrovascular disease. CVD is one of the leading causes of disability and death in Australia (AIHW 2004). Combining the impact of both premature deaths and the extent of associated disability, CVD was estimated to account for 17% of the overall disease burden in Australia in 2003 (Begg et al. 2007). CVD is the most expensive disease group, in terms of direct health care expenditure, at over \$5.9 billion, which represents 11% of Australia's total allocated health system expenditure in 2004–05 (AIHW 2008e).

Diabetes mellitus (in this report referred to as diabetes) is a chronic condition in which blood glucose levels become too high as a result of the body producing insufficient insulin or being unable to use insulin properly (WHO 1999). Diabetes can lead to a range of complications, including coronary heart disease and stroke, as well as kidney disease and retinopathy (loss of vision) (IDF 2006). Self-reported data in the 2004–05 National Health Survey (NHS) showed that about 699,600 Australians (3.5% of the population) had been diagnosed with diabetes (AIHW 2008d). Diabetes accounted for 5.8% of the overall disease burden in Australia in 2003 (Begg et al. 2007). In 2004, 11,735 deaths in Australia were associated with diabetes.

It is important to note that there are different types of diabetes, and that the role of prevention is quite different for each of these. Type 1 diabetes is thought to be caused by a combination of genetic and environmental factors, and at this stage there is no known way to prevent the disease (Daneman 2006; Devendra et al. 2004). The other main type of diabetes is Type 2, where the main modifiable risk factors

are being overweight and having low levels of physical activity (Shaw & Chisholm 2003). Thus, Type 2 diabetes is highly preventable. The temporary form of diabetes that can occur during pregnancy—gestational diabetes—also shares many of the risk factors for Type 2 diabetes. For all types of diabetes, prevention of complications is a key aim of clinical management.

Chronic kidney disease (CKD) is defined as the occurrence of kidney damage and/or reduced kidney function, lasting for at least 3 months. It is classified into five stages from stage 1 (least severe) to stage 5 (most severe), where patients may need to undergo kidney replacement therapy (dialysis or transplant) as kidney function is not sufficient to sustain life (AIHW 2009a). CKD is common—one in seven Australian adults over the age of 25 years had some degree of CKD in 1999–2000. CKD imposes a substantial burden of disease in Australia, contributing to nearly 10% of all deaths in 2006 and over 1.1 million hospitalisations in 2006–07.

These three diseases share many risk factors, and often coexist. The shared risk factors also promote co-occurrence of these diseases and strengthen the association between them. These risk factors do not just affect the onset of CVD, diabetes and CKD, but also affect their progression and increase the risk of complications. The risk factors include ageing, the person's sex, overweight or obesity, diet, physical activity and socioeconomic conditions.

These diseases are also risk factors for each other. Diabetes is a well-established risk factor for CVD. Diabetes can also lead to kidney damage—a complication known as 'diabetic nephropathy'. CKD has been found to independently increase the risk of hypertension and other cardiovascular diseases, including heart attack, angina, coronary artery disease, stroke and heart failure. CVD, especially hypertension, is one of the major causes of CKD.

## Framework for monitoring prevention

### What is prevention?

Due to the use of different definitions by various groups, there is some lack of clarity in various discussions about prevention as identified by Russell and colleagues (2008). There is particular confusion when the terms primary, secondary and tertiary prevention are used but given different meanings by different groups. For example, in public health and epidemiological work, secondary prevention usually refers to efforts to reduce the prevalence of the disease by shortening its duration, while tertiary prevention aims to reduce the number or impact of complications (Last 2001). In much of the clinical literature, however, secondary prevention is used to mean prevention of recurrences or complications (see for example Reid et al. 2002; Rodríguez-Artalejo & Banegas Banegas 2004; Wells et al. 2008). The Australian Institute of Health and Welfare's (AIHW) definition avoids these problems (AIHW 2008c) and is the one used here:

**Prevention (of disease or ill health)** Action to reduce or eliminate the *onset, causes, complications or recurrence* of disease or ill health. [Italics added.]

## The framework

A framework (Figure 1.1) has been developed to provide a conceptual picture of how this monitoring task could be approached. The framework is based on the definition of prevention given above, following the three main areas where prevention is important in the health care system: prevention of risk factors (causes), prevention of disease (onset), and prevention of progression, complications and recurrence in people with the disease. For each of these three components, there are two main aspects to monitor: the outcomes that are to be prevented, and the prevention services that are being provided.

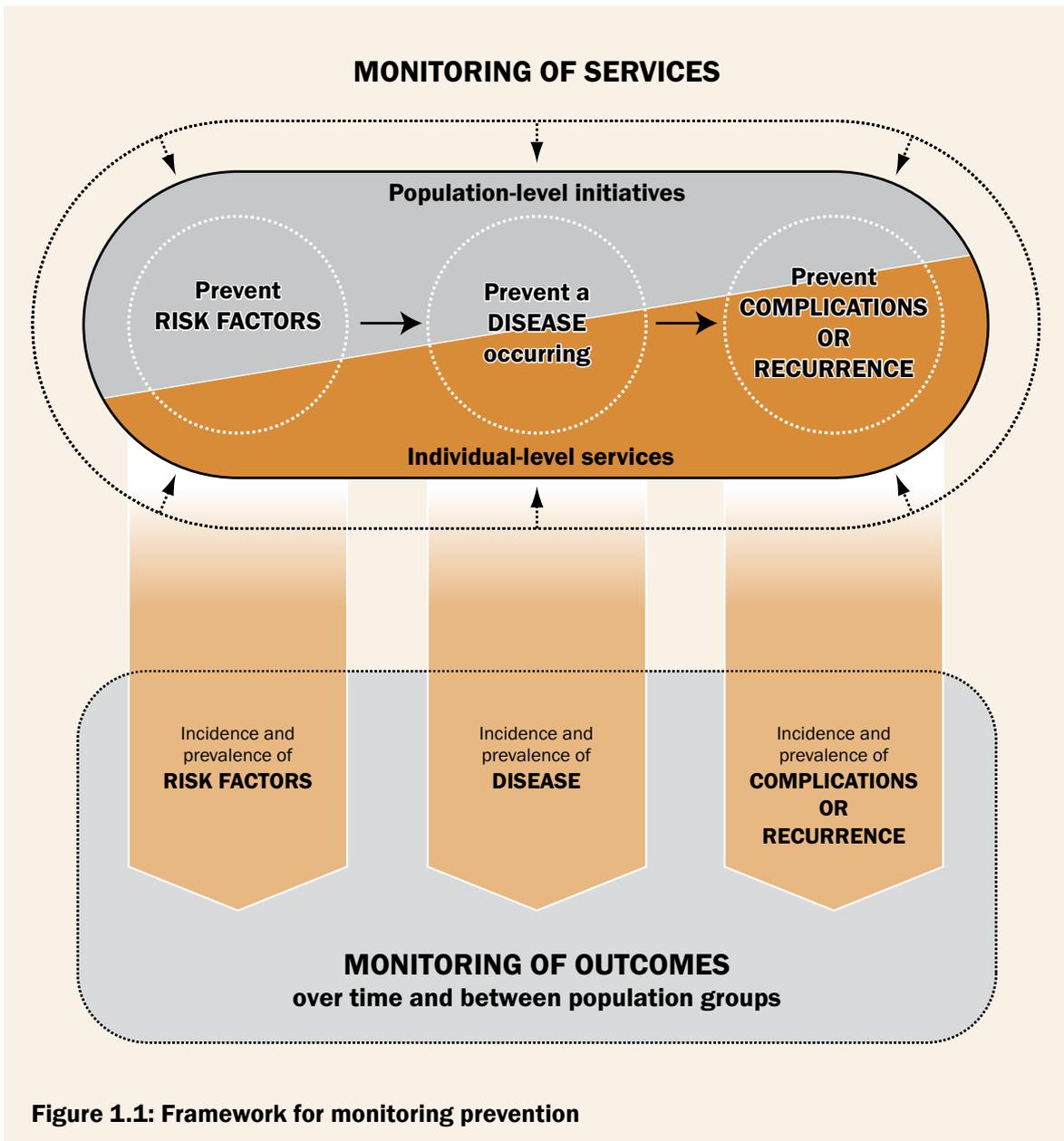


Figure 1.1: Framework for monitoring prevention

In terms of monitoring the outcomes, ideally both the incidence and the prevalence would be monitored for each of the three areas: risk factors, the actual diseases and their complications (including recurrence). These areas need to be monitored in order to assess the size of the problem, and to help in determining whether the prevention activities are having the desired effect. It is therefore important to monitor the results over time, in the population at large, and in high-risk population groups such as Aboriginal and Torres Strait Islander peoples and different socioeconomic groups. It is also useful to compare data from Australia with other comparable countries.

The range of prevention services broadly covers two types of activities. The first is health promotion, which aims to provide individuals and groups with the best chance of maintaining good health and preventing ill health. Health promotion emphasises working with people to enable them to make decisions about their needs and how best to meet them (Naidoo & Wills 2000). Health promotion is the process of enabling people to increase control over and improve their health, or the process of individuals and communities taking control over the determinants of their health (Keleher & Murphy 2004). Prominent targets of health promotion are people's dietary and physical activity patterns, as well as their use of tobacco or alcohol. Health promotion occurs in a variety of ways, such as regulation, public awareness campaigns and community-based programs. Health promotion aims to make healthy choices easier or even automatic or unconscious, to enable control over the determinants of health and to improve health and wellbeing (Keleher & Murphy 2004).

The second activity is the more traditional therapeutic-type health care usually provided under the supervision of a medical practitioner. This can include vaccinations, health checks and prescribing of medications. For risk factor prevention, there is likely to be a relatively large role for health promotion and a smaller, although important, one for health care. This balance then changes across the framework to more health care than health promotion for prevention of complications. Both of these types of activities need to be monitored so that comparisons can be made over time, across population groups and across geographical areas.

Monitoring of health services has most often been associated with individual-level care, that is, services provided directly to individuals. However, for prevention it is also important to monitor services and interventions provided at the population level: those provided to the whole population or population groups rather than to individuals on a one-to-one basis. For example, these can include television advertising campaigns, school-based interventions or taxes. Monitoring these population-level interventions is a relatively new challenge. When these types of interventions have been examined, it has tended to be in the context of evaluations of specific programs (such as tobacco control) rather than for the purpose of monitoring.

The framework is high-level, and thus does not attempt to include all the details that may be relevant to prevention. The simplicity of the framework is intentional, allowing the level of detail to be determined in the implementation of the framework as required. It has been developed to apply to the CVD, diabetes and CKD cluster of diseases. However, it is generic, and is likely to be applicable in other situations.

The framework does not include the causes of the causes in its scope: these factors such as the social, economic and environmental factors that often affect the traditional risk factors (see 'A conceptual framework for determinants of health' in AIHW 2008c:111). These 'up-stream' factors affect many aspects of health, not just particular diseases that may be examined. Thus they fall outside the scope of this framework. This is not to downgrade their importance. Instead, the decision was made to

concentrate on those factors closer in the causal pathway to the diseases—those behavioural and biomedical risk factors related to these specific diseases. There is a strong case for monitoring services and interventions aimed at these wider determinants, but this would be best done in a separate process.

However, there are parts of this framework that are related to these factors. ‘Population groups’ is an important part of this framework: the services and outcomes should be monitored for various groups of the population, including socioeconomic groups. Also, specific environmental aspects relevant to these diseases, such as transport and urban design, are included in the population-level part of the services section.

### **Application to cardiovascular disease, diabetes and chronic kidney disease**

The cluster of closely related diseases, namely CVD, diabetes and CKD, account for around a quarter of the disease burden in Australia (Begg et al. 2007). Sixty-two per cent of deaths in 2004 and 25% of non-dialysis hospitalisations in 2004–05 involved at least one of these diseases (AIHW: Tong & Stevenson 2007). As discussed above, these diseases share many risk factors (including the three that are a focus of the National Preventative Health Taskforce) and some of the diseases are also risk factors for others, such as both diabetes and CKD being risk factors for CVD, and diabetes and CVD being risk factors for CKD. Thus it is preferable to monitor prevention for these diseases together, rather than separately.

This group of diseases is highly preventable, making them an ideal group of diseases to monitor in relation to prevention. For CVD, 70% of the total burden of disease (measured as the combined effect of years of life lost due to premature death and years lived with a disability) in 2003 was due to the 14 risk factors measured in the Australian Burden of Disease Study (Begg et al. 2007). High blood pressure accounted for the largest amount, followed by high blood cholesterol and physical inactivity. Similarly, for diabetes 60% of the total disease burden was due to the 14 measured risk factors, dominated by high body mass (essentially overweight and obesity). Clearly, these risk factors are highly preventable.

Table 1.1 outlines an approach to applying the broad framework to the monitoring of prevention for this cluster of diseases. The aim is to cover the important areas at a high level, rather than to comprehensively cover all possible factors in detail. The top half of the table covers the outcomes that are being targeted for prevention, and the second half covers the relevant services.

**Table 1.1: Application of the prevention monitoring framework to cardiovascular disease, diabetes and chronic kidney disease**

**Outcomes of prevention**

<b>Risk factors</b>	<b>Diseases</b>	<b>Complications</b>
<p><b>Prevalence (and incidence where possible) of:</b></p> <ul style="list-style-type: none"> <li>• overweight and obesity</li> <li>• physical inactivity</li> <li>• poor diet</li> <li>• tobacco smoking</li> <li>• excessive alcohol</li> <li>• high blood pressure</li> <li>• impaired glucose regulation</li> <li>• abnormal blood lipids</li> <li>• depression</li> <li>• low birthweight.</li> </ul> <p><b>Prevalence of multiple risk factors</b></p> <p><b>Prevalence of absolute risk</b></p>	<p><b>Prevalence (and incidence) of:</b></p> <ul style="list-style-type: none"> <li>• overall CVD</li> <li>• coronary heart disease</li> <li>• cerebrovascular disease</li> <li>• diabetes (by type)</li> <li>• CKD.</li> </ul> <p><b>A measure of severity where possible:</b></p> <ul style="list-style-type: none"> <li>• CVD events (heart attacks and strokes)</li> <li>• HbA1c levels for diabetes</li> <li>• GFR levels for CKD.</li> </ul> <p><b>Functioning for people with the diseases</b></p>	<p><b>Prevalence of comorbidities between CVD, diabetes and CKD</b></p> <p><b>Prevalence of diabetes complications:</b></p> <ul style="list-style-type: none"> <li>• CVD</li> <li>• CKD</li> <li>• eye problems</li> <li>• foot problems</li> <li>• deaths.</li> </ul> <p><b>Prevalence of CVD complications:</b></p> <ul style="list-style-type: none"> <li>• CKD</li> <li>• case fatality of events</li> <li>• deaths.</li> </ul> <p><b>Prevalence of CKD complications/progression:</b></p> <ul style="list-style-type: none"> <li>• end-stage kidney disease</li> <li>• deaths.</li> </ul>

**Services for prevention**

<b>Risk factors (prevent or improve risk factors)</b>	<b>Diseases (prevent disease or detect early)</b>	<b>Complications (prevent complications in people with disease)</b>
<p><b>Population level:</b></p> <ul style="list-style-type: none"> <li>• laws and regulations</li> <li>• tax and price interventions</li> <li>• public awareness campaigns</li> <li>• improving the built environment</li> <li>• community-based interventions.</li> </ul> <p><b>Individual level:</b></p> <ul style="list-style-type: none"> <li>• GP and health provider services (e.g. health advice, education, referral, risk assessment, opportunistic screening/monitoring)</li> <li>• community-based programs (e.g. quit smoking, exercise)</li> <li>• medications for risk factor</li> <li>• surgery (e.g. gastric banding).</li> </ul>	<p><b>Population level:</b></p> <ul style="list-style-type: none"> <li>• screening programs</li> <li>• guidelines.</li> </ul> <p><b>Individual level:</b></p> <ul style="list-style-type: none"> <li>• health care provider services (monitoring for disease/opportunistic screening)</li> <li>• medications to prevent disease</li> <li>• health care according to guidelines.</li> </ul>	<p><b>Population level:</b></p> <ul style="list-style-type: none"> <li>• guidelines.</li> </ul> <p><b>Individual level:</b></p> <ul style="list-style-type: none"> <li>• health care according to guidelines on preventing complications.</li> </ul>

HbA1c = glycated haemoglobin; GFR = glomerular filtration rate (usually estimated using the eGFR).

## Monitoring outcomes

In monitoring prevention, it is important to track the outcomes that are being targeted, to see how large the problem is, and to determine whether the situation is getting better or worse and whether there are particular problems for some population groups.

Table 1.1 (column 1) identifies three main types of information about risk factors that need to be monitored: individual risk factor frequency, prevalence of multiple risk factors and prevalence of absolute risk. Individual risk factor frequency includes measures of incidence (where available) and prevalence of the main risk factors for these three diseases, including behaviours such as physical inactivity and tobacco smoking, and biomedical ones such as obesity and high blood pressure. If possible, it is better to present information on the distribution of the population for a particular risk factor, rather than just the proportion of people above a particular cut-off point. An example of this is presenting the population distribution across body mass index (BMI) levels, rather than just the proportion of people who are overweight or the proportion who are obese. This concept is known as 'continuous risk'. Most of the risk factors in this list are associated with increased risk for at least two of the diseases of interest. Prevalence of multiple risk factors measures the number of people with two or more of these individual factors, and is included because it is associated with an even greater risk of the diseases. Finally, absolute risk provides a numerical measure of an individual's risk of these diseases, taking into account the actual level of each of the relevant risk factors. This information can then be compiled as a prevalence measure, such as the number of people with a particular risk level.

To monitor the actual disease level (column 2), three areas are outlined in the table. The first is measures of prevalence and incidence of the disease, including each of the three diseases plus some key subgroups such as coronary heart disease, cerebrovascular disease (including stroke and transient ischaemic attack) and type of diabetes. The second is measures of disease severity (or an indicator of it) such as event rates for CVD, HbA1c levels in people with diabetes and GFR levels for CKD. These are important to help determine whether any increases in incidence and prevalence are in the less or more severe stages of these diseases. For example, increases in the less severe cases could suggest improvements in early detection, and may not actually be an increase in underlying disease levels. The third area for monitoring population-level disease is to measure functioning, such as ability with activities of daily living or employment status, to see what effects the diseases are having.

The outcomes for complications of each of these diseases (column 3) would be measured within the population with the disease. That is, the denominator for each of the measures would be the number of people with the disease. The first complication to monitor is the presence of comorbidities between these diseases—the number of people with at least two complications. There are also specific complications for each of the three diseases. The measure of deaths is a case fatality rate, as it would be reported as the number of deaths among people with the disease. An important aspect is monitoring these complications in different age groups, as the aim is to prevent or at least delay the complications.

## Monitoring services

There are two broad areas to monitor in prevention services: those delivered to whole populations and those delivered to individuals (second half of Table 1.1). Population-level services need to be counted and described at the population level, while individual-level services need to be counted according to their effect on individuals (such as the number of individuals receiving a particular service).

While there is overlap between these two categories in the programs and services covered, it is the counting approach that most distinguishes the two.

Population-level interventions and services are most relevant for risk factor prevention (column 1). The structure used here to organise the areas to monitor is based on the approach used by the World Health Organization (WHO 2005), and covers laws and regulations; taxation and price mechanisms; public awareness campaigns; approaches through the built environment; and community, school and workplace interventions. Population-level programs for prevention or early detection of the disease (column 2) could include organised screening or risk assessment programs, and clinical guidelines. Similarly, clinical guidelines for complication prevention (column 3) would be a population-level initiative. Monitoring population-level services has not been the focus of health service monitoring in the past. In general, services have been measured at the individual level—the tendency is to count the number of people receiving a service. As it is difficult in many cases to measure the number of individuals exposed to a particular population level program, these programs have not usually been included in more traditional monitoring. However, it is possible to monitor the presence of these initiatives, although some development of the required types of data collections may be needed.

Monitoring individual-level prevention services takes a more traditional health-service monitoring approach. Despite this, little monitoring in this area has been undertaken for prevention. Areas that need to be monitored for the prevention of risk factors (column 1) include GP and health provider services, community-based programs, medications and surgery. Similarly, for services that aim to prevent the disease or complications (columns 2 and 3), services provided by health care providers and medications need to be included. It is also important to monitor whether health care is being provided according to guidelines, for preventing both the disease and its complications.

## This report

This report focuses on the prevention of *risk factors* for CVD, diabetes and CKD—the first component of the framework described above. The report is intended to be a baseline report, to assess where Australia is now in the prevention of these risk factors, to inform future monitoring of prevention for these conditions, and to track progress. The prime focus of the report is at the national level. There are some parts of the framework where data are not currently readily available. This is particularly the case for the population-level services. Information is included where possible, but in this first report gaps do remain.

## Main questions

The analyses presented in this report focus on three main questions:

1. What is the national prevalence of the main risk factors for CVD, CKD and diabetes?
2. What population-level initiatives are in place that aim to prevent each of these risk factors in people without them and improve or remove them in people with them?
3. What individual-level services are being used to prevent each of these risk factors in people without them and improve or remove them in people with them?

Where possible, these three questions consider specific population groups, including Aboriginal and Torres Strait Islander peoples, people living in rural and remote locations, and people from different socioeconomic groups.

## Structure

This report has three main chapters covering each of the questions outlined above. Chapter 2 presents new analysis using the available information on the risk factors. Chapter 3 covers population-level interventions, and Chapter 4 presents information on the individual-level services. Chapter 5 is a discussion of the main issues raised by these findings.