

# A Strategic Framework for action

Consultation paper for the development of the  
Australian National Diabetes Strategy

National Diabetes Strategy Advisory Group

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## PURPOSE OF THIS DOCUMENT

This document has been written by the National Diabetes Strategy Advisory Group (NDSAG) to assist in the development of the National Diabetes Strategy. The document is provided by the NDSAG to support the Government in considering the national response to diabetes and developing the resulting strategy. It represents the collective expertise of the NDSAG and identifies areas for action to improve diabetes prevention and care. The document is released for public consultation to seek submissions from individuals, families, communities, health care services and industry. Consultation feedback, together with the NDSAG advice will inform the development of the draft National Diabetes Strategy.

The National Diabetes Strategy will seek to prioritise Australia's response to diabetes, and to identify approaches to reduce the impact of diabetes in the community. The strategy aims to evaluate current approaches to diabetes services and care; maximise the efficient use of existing, limited healthcare resources; better coordinate health resources across all levels of government; and focus these resources where they are needed most. Please note that this consultation process does not replace or override existing processes established by the Australian health system for assessing the safety, quality and cost-effectiveness of new medicines, devices, tests and procedures.

The document has three sections. Section 1 explains why it is important that we continue to make diabetes a national health priority. Section 2 provides background information on the development of the National Diabetes Strategy. Section 3 introduces the draft strategic framework. This framework is built around five high-level goals that the National Diabetes Strategy will seek to achieve. For each goal, the NDSAG has outlined why the goal is important, suggested metrics that may be used to measure progress and identified potential priority areas for action. At the beginning of Section 3, the NDSAG has listed three broad questions about the areas for action, and it would appreciate feedback related to these questions when public consultation opens.

The online consultation process will open in April 2015, and this process will inform the development of the draft National Diabetes Strategy. The Australian Government Minister for Health, the Australian Health Ministers' Advisory Council (AHMAC) and the Council of Australian Governments (COAG) Health Council will then consider the draft strategy. The National Diabetes Strategy is anticipated for public release in late 2015.

## Executive summary

Diabetes mellitus is a long-term condition that affects at least 1.1 million Australians [1]. It is the seventh and eighth leading cause of death in females and males respectively [2], and the fourth largest contributor to overall disease burden in Australia [3]. The costs associated with diabetes are substantial. The total cost of diabetes annually has been estimated to be as high as \$14 billion [4].

The new National Diabetes Strategy seeks to prioritise the national response to diabetes, identify appropriate approaches to addressing the impact of diabetes in the community, lead the way internationally in diabetes prevention, management and research, and maximise the efficient use of existing, limited healthcare resources. In order to develop this strategy, a National Diabetes Strategy Advisory Group (NDSAG) was established to provide expert policy advice and identify strategies to improve diabetes prevention and care, in consultation with key stakeholders and the Australian Health Ministers' Advisory Council. The resulting strategy will provide a framework for guiding potential healthcare reforms in Australia.

As part of this process, the NDSAG has defined five high-level goals for the National Diabetes Strategy:

- **Goal 1. Reduce the prevalence and incidence of people developing type 2 diabetes.** In order to achieve this goal, the strategy will need to promote a population-based approach to diabetes prevention, including encouragement of healthier lifestyles. Community-based action is recommended, which includes strategies for adults at high risk of developing diabetes and children. It would also include preventative interventions for people at high risk of developing diabetes (e.g. a nationally coordinated detection programme for prediabetes), as well as improved pre-conception parental health and improved care during and after pregnancy.
- **Goal 2. Promote earlier detection of diabetes.** This would facilitate earlier treatment for people with all forms of diabetes, which in turn would reduce their chances of developing complications. A way of measuring the early diagnosis of diabetes will need to be developed in order to track progress towards this goal. In the case of type 1 diabetes, preventing diabetic ketoacidosis could be lifesaving. To achieve this goal, early detection must be promoted and improved. Health providers and the community need to be educated to recognise the signs and symptoms of diabetes.
- **Goal 3. Reduce the occurrence of diabetes-related complications and improve quality of life among people with diabetes.** People with either type 1 or type 2 diabetes require a lifetime of care and those who do not achieve good blood glucose control may be at an increased risk of developing complications [5]. However, the majority of the complications of diabetes which reduce quality of life are preventable, including diabetic ketoacidosis in people with type 1 diabetes [6]. A well-coordinated and integrated primary health care system is required for all chronic diseases, and particularly in diabetes to diagnose and treat diabetes early as well as prevent complications. This should include plans, programmes, monitoring and reporting across primary health networks and the health system more generally encompassing eye damage and blindness, cardiovascular disease and strokes, kidney damage, amputations and mental health problems. To support this, care delivery should be transformed to become more consumer-focused, team-based and proactive. This would require several areas for action, including (among others) involving people with diabetes as active participants in their own care, consolidating nationally agreed clinical guidelines, implementing quality improvement processes, continuing investment in electronic health and technologies, and innovative funding models.
- **Goal 4. Reduce the impact of diabetes in Aboriginal and Torres Strait Islander peoples and other high risk groups.** Aboriginal and Torres Strait Islander people, other culturally and linguistically diverse communities and older Australians are at higher risk of developing type 2 diabetes and its complications. People living in rural and remote locations may experience difficulties accessing care. To prevent

diabetes and improve diabetes management, it is important to ensure that these communities have access to, and can benefit from, diabetes support, education and services. In order to achieve this goal in Aboriginal and Torres Strait Islander communities, culturally relevant programmes (developed in collaboration with the appropriate community) that improve education and awareness about diabetes would need to be developed; healthier choices and lifestyle changes would need to be encouraged and facilitated; and family and child health would need to be improved through pregnancy and early years programmes. Areas for action to achieve this goal in other higher risk groups include developing culturally and linguistically appropriate diabetes education packages, ensuring that guidelines are followed across health and aged care settings, and coordinating regional services.

- **Goal 5. Strengthen prevention and care through research, evidence and data.** Australia needs to continue to progress diabetes research and support access to effective new technologies in order to implement evidence-based practices and make informed health policy decisions. This can be achieved by establishing a national research agenda that focuses, coordinates and translates research into clinical practice. The utilisation and further development of datasets (and building linkages between existing datasets) can inform population-based decision making and facilitate prevention and management of diabetes. Pathways for new technologies to be considered and made accessible should be considered.

Table 1 on the following page summarises these five goals, the associated areas for action and the potential ways to measure Australia's progress towards these goals.

Australia has an opportunity to lead the way in diabetes care, prevention, management and research, and it is hoped that this draft strategic framework will provide a useful foundation for a National Diabetes Strategy that can inform and guide this important work. This document is, first and foremost, a consultation paper, and the National Diabetes Strategy Advisory Group hopes that its contents elicit insights and feedback from across the country on how best to progress diabetes care in Australia.

An online consultation process will open in April 2015, and this process will inform the development of a draft National Diabetes Strategy. The Australian Government Minister for Health, AHMAC and the COAG Health Council will then consider the draft strategy. The National Diabetes Strategy is anticipated for public release in late 2015.

TABLE 1 Summary of the Strategic Framework

Goal	Areas for action	Potential ways to measure Australia's progress towards this goal
1. Reduce the prevalence and incidence of people developing type 2 diabetes	<ul style="list-style-type: none"> <li>■ Reduce the prevalence of modifiable risk factors in the general population</li> <li>■ Identify and provide prevention programmes to people with prediabetes</li> <li>■ Ensure pregnant women and children get optimal care</li> </ul>	<ul style="list-style-type: none"> <li>■ The percentage of the population developing or with diabetes</li> <li>■ The percentage of the population that is overweight or obese</li> <li>■ Annual number of cases of gestational diabetes diagnosed, and the number of these women who receive follow-up preventative services</li> </ul>
2. Promote earlier detection of diabetes	<ul style="list-style-type: none"> <li>■ Improve detection in primary care for type 2 diabetes</li> <li>■ Increase awareness of type 1 diabetes among healthcare providers and the community</li> </ul>	<ul style="list-style-type: none"> <li>■ The number of people screened for risk of diabetes annually</li> <li>■ The percentage of people with type 1 diabetes who present with diabetic ketoacidosis on diagnosis</li> </ul>
3. Reduce the occurrence of diabetes-related complications and improve quality of life among people with diabetes	<ul style="list-style-type: none"> <li>■ Nationally agreed clinical guidelines and local care pathways</li> <li>■ Consumer engagement and self-management</li> <li>■ Quality improvement processes</li> <li>■ Information and communication technology</li> <li>■ Medicines and devices</li> <li>■ Workforce capacity</li> <li>■ Funding reform and incentives</li> <li>■ Mental health care for people with diabetes</li> <li>■ Transition from child to adult services</li> <li>■ High-quality hospital care</li> </ul>	<ul style="list-style-type: none"> <li>■ The number of people having screening for complications</li> <li>■ The percentage of people with diabetes with high HbA1c, cholesterol or blood pressure</li> <li>■ The incidence of complications per thousand people with diabetes</li> <li>■ Quality of life scores for people with diabetes</li> </ul>
4. Reduce the impact of diabetes in Aboriginal and Torres Strait Islander peoples and other high risk groups	<ul style="list-style-type: none"> <li>■ Aboriginal and Torres Strait Islander peoples</li> <li>■ Culturally and linguistically diverse people</li> <li>■ Older Australians</li> <li>■ Australians living in rural and remote areas</li> </ul>	<ul style="list-style-type: none"> <li>■ The number of new cases of diabetes diagnosed each year, per thousand people, in groups at higher risk</li> <li>■ The number of people from groups at higher risk who receive annual testing for complications</li> <li>■ The percentage of people with diabetes in groups at higher risk with high HbA1c, cholesterol or blood pressure</li> <li>■ The incidence of complications per thousand people with diabetes from groups at higher risk</li> <li>■ Quality of life scores for higher risk people with diabetes</li> </ul>
5. Strengthen prevention and care through research, evidence and data	<ul style="list-style-type: none"> <li>■ National research agenda</li> <li>■ Data linking</li> </ul>	<ul style="list-style-type: none"> <li>■ Number of diabetes publications</li> <li>■ Progress against key milestones in developing a national research agenda</li> <li>■ Progress against key milestones in developing national datasets</li> </ul>

## **ABBREVIATIONS**

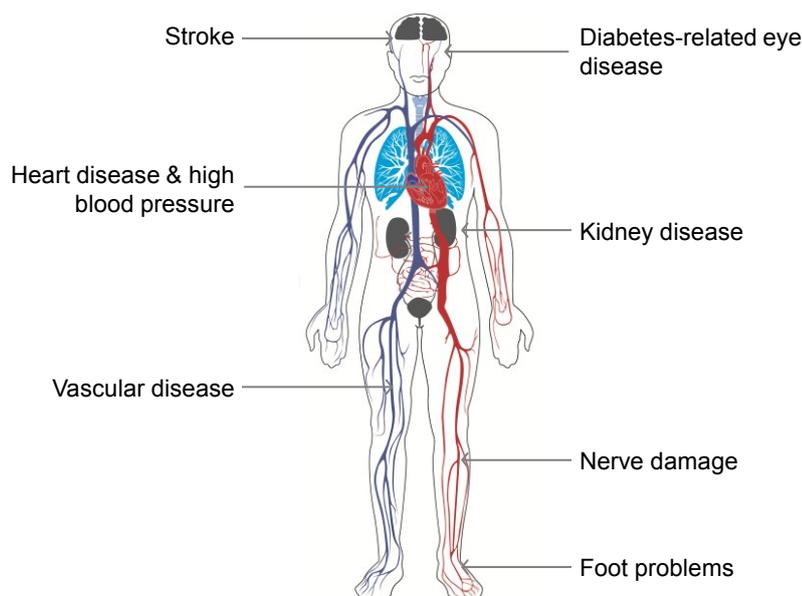
AIHW	Australian Institute of Health and Welfare
AHMAC	Australian Health Ministers' Advisory Council
ARC	Australian Research Council
AusDiab	Australian Diabetes and Lifestyle Study
COAG	Council of Australian Governments
eHealth	Electronic health
GDM	Gestational diabetes mellitus
GP	General practitioner
HbA1c	Glycated haemoglobin
NDSAG	National Diabetes Strategy Advisory Group
NDSS	National Diabetes Services Scheme
NHMRC	National Health and Medical Research Council
PCEHR	Personally controlled electronic health record

# 1 The challenge of diabetes

Diabetes mellitus is a chronic disorder that impedes the body's ability to produce and/or utilise insulin (a hormone produced by the pancreas to regulate blood sugar levels). This results in high blood sugar levels, which lead to serious complications such as strokes, diabetes-related eye disease such as diabetic retinopathy, heart disease, high blood pressure, kidney disease, vascular disease, nerve damage and foot problems (Figure 1). Diabetes often occurs alongside (and shares risk factors with) other chronic diseases, including heart disease and chronic kidney disease [7]. Much of the impact of diabetes is preventable, however, either through improving the health of the population in order to prevent people getting diabetes in the first place, or by optimising how the health system supports people who already have diabetes in order to prevent or delay the onset of complications. Many of the strategies for preventing diabetes and improving patient outcomes are common across chronic diseases, and coordination and cooperation in chronic disease management will assist in maximising the use of Australia's resources.

FIGURE 1

## Complications of diabetes



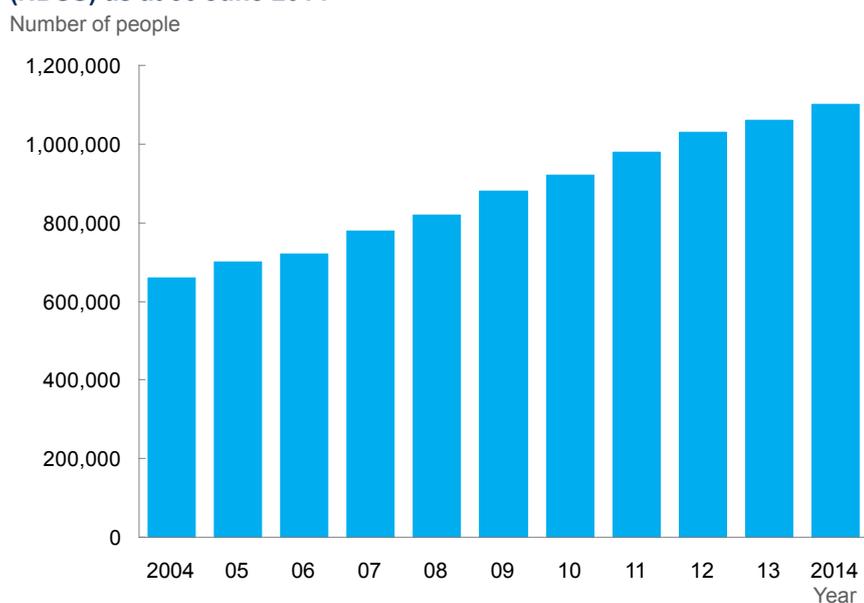
## 1.1 The prevalence of diabetes in Australia

It is difficult to estimate the exact number of people with diabetes in Australia, but it is likely that more than 1.1 million Australians are living with the disease. At present, the best estimates come from three sources: the National Diabetes Services Scheme (NDSS); the Australian Health Survey (National Health Measures Survey [NHMS], 2011–13); and the Australian Diabetes and Lifestyle Study (AusDiab, 1999–2000) [1] [8] [9]. The Australian Health Survey found that, using HbA1c (glycated haemoglobin) as the measure, 5.4 per cent of the population over the age of 18 had diabetes, which translates to almost one million people [8]. The AusDiab study used an oral glucose tolerance test (OGTT) to estimate that 7.5 per cent of Australians over the age of 25 had diabetes, which equates to approximately 1.2 million people [9]. A similar estimate comes from the NDSS,

which has registered over 1.1 million people and gains an extra 263 people every day (Figure 2) [1]. However, it is likely that all three sources underestimate the total number of people affected by diabetes for the following reasons. Firstly, both the AusDiab study and the Australian Health Survey exclude children. Secondly, registration with the NDSS is voluntary, and it is likely that a significant number of people with diabetes are not registered with the NDSS. Thirdly, the AusDiab study was conducted 14 years ago and there has since been a considerable increase in the proportion of people who are overweight and therefore at risk of diabetes.

FIGURE 2 [10] [11] [12]

### Number of people registered with the National Diabetes Services Scheme (NDSS) as at 30 June 2014



There are three commonly recognised types of diabetes:

- **Type 1 diabetes.** Type 1 diabetes is an autoimmune condition that causes the immune system to destroy cells in the pancreas that produce insulin. It can occur at any age, although most cases develop amongst children, teenagers and young adults. There is no cure, and people with type 1 diabetes require daily treatment with insulin for survival. Based on self-reports, approximately 119,000 Australians have been diagnosed with type 1 diabetes (approximately 12 per cent of Australians with diabetes) [13]. It is also one of the most common chronic diseases amongst children. A 2010 report from the Australian Institute of Health and Welfare (AIHW) highlighted that Australia remains in the top ten countries with the highest prevalence and incidence of type 1 diabetes in children aged 0 to 14 years. On average, six new cases of type 1 diabetes are diagnosed in Australia every day [14].
- **Type 2 diabetes.** Type 2 diabetes is the most common form of diabetes, accounting for approximately 85 per cent of people with diabetes [13]. Insulin production by the pancreas becomes progressively slower, and key organs in the body become resistant to the effects of insulin (which means that they are less able to utilise glucose from the blood). People with type 2 diabetes may not experience any symptoms, and the condition is usually managed through diet, physical activity and medication. In the past, type 2 diabetes was typically diagnosed after 50 years of age, but diagnosis in younger adults, adolescents and even children is increasingly common. While genetics play an important role in the occurrence of type 2 diabetes, many cases are preventable through weight reduction, physical activity and healthy eating.

Recent studies also highlight that a healthy environment inside the womb and during the first few years of life can decrease a child's chance of developing diabetes and obesity as an adult [15].

- **Gestational diabetes.** Gestational diabetes mellitus (GDM) first occurs during pregnancy and usually disappears following the birth of the baby, although women who have had GDM are at significant risk of subsequently developing diabetes. Between 12.1 per cent and 13.6 per cent of pregnant women will develop GDM [16]. This equates to approximately 40,000 women with GDM in 2012 [17]. GDM requires careful control of blood sugar levels during pregnancy to avoid complications in the mother and baby, along with postnatal monitoring and the provision of diabetes prevention programmes for the mother. Babies of women with GDM have a higher risk of obesity and type 2 diabetes in adult life [15].

Prediabetes is a condition in which people have blood sugar levels that are higher than normal but not sufficiently high to diagnose type 2 diabetes [18]. This was examined as part of the AusDiab study, which found that 16.4 per cent of adults over the age of 25—approximately 2.5 million people—have prediabetes [19]. People with prediabetes are at higher risk of developing type 2 diabetes, although this is not inevitable. Between 15 and 30 per cent of people with prediabetes are likely to develop type 2 diabetes within five years [20].

## 1.2 Aboriginal and Torres Strait Islander peoples and other high risk groups

Australia has enormous cultural and social diversity, and while diabetes is increasingly common across the country, it is particularly problematic within certain communities. As with the general population, it is difficult to estimate the exact number of Aboriginal and Torres Strait Islander peoples with diabetes, and prevalence estimates vary considerably. A review of the prevalence of diabetes among Aboriginal and Torres Strait Islander peoples found that across the 24 studies conducted, reported prevalence ranged from 3.5 per cent to 33.1 per cent [21]. The Australian Health Survey (National Aboriginal and Torres Strait Islander Health Measures Survey [NATSIHMS], 2012–13), found that 20.4 per cent of Aboriginal and Torres Strait Islander peoples over the age of 25 have diabetes [22]. This compares with rates of between 5.5 and 7.5 per cent of the general population in the same age group (taken from the Australian Health Survey and AusDiab study, respectively) [8] [9]. These data demonstrate that Aboriginal and Torres Strait Islander peoples experience a disproportionate share of the burden of diabetes as a result of these considerably higher diabetes rates.

There are several other groups that are at a high risk of diabetes. People from Southeast Asia, North Africa and the Middle East, Oceania (excluding Australia), and southern and eastern Europe have higher rates of diabetes than other Australians [23]. Older Australians also have higher rates of diabetes (particularly type 2 diabetes) and experience higher rates of disability associated with the disease [23]. Finally, people with diabetes who live in rural and remote communities have more difficulty accessing health services to manage their diabetes. For example, in 2013–14, nearly one in three people who live in outer regional, remote or very remote areas waited longer than they felt was acceptable to get an appointment with a general practitioner (GP), compared with just over one in five people who live in major cities [24].

## 1.3 The impact of diabetes on Australia's health

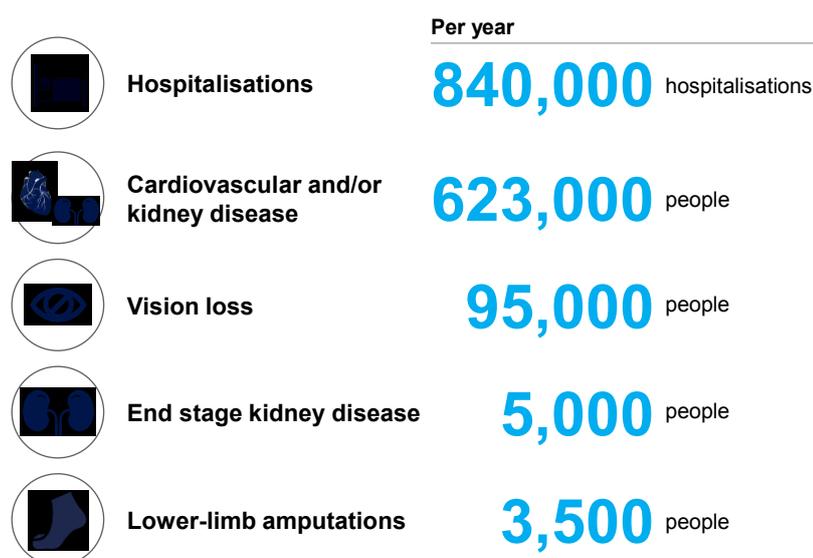
Diabetes has a significant, and often preventable, impact on the health and wellbeing of the Australian population. In 2011, diabetes was the underlying cause of three per cent of all deaths and an underlying or associated cause of ten per cent of all deaths [7]. In 2003, it was the fourth largest contributor to overall

disease burden in Australia [3]. There are a significant number of diabetes-related complications, many of which are preventable. They include heart attacks, strokes, amputation, blindness, kidney failure, depression and nerve disease.

Figure 3 outlines examples of the annual impact of diabetes on Australia’s health, including hospitalisations and some of the major complications.

FIGURE 3 [25]

### Examples of the annual impact of diabetes on Australia’s health



## 1.4 The economic and social impact of diabetes

It is difficult to estimate the total economic and social impact of diabetes. Healthcare that is directly attributable to diabetes costs approximately \$1.7 billion per year [26]. However, this estimate only includes the costs associated with healthcare activity that can be *directly* linked to diabetes. The full cost of diabetes may be as high as \$14 billion per year, including direct healthcare and non-healthcare activity plus government subsidies [4]. Costs are heavily concentrated in particular sub-groups of people with diabetes. Annual direct costs for people with diabetes complications are more than twice as much as for people without complications; \$9,600 compared with \$3,500 [4]. The condition also has a significant social impact on carers and families who support people with diabetes. These indirect costs include reduced productivity, absence from work, early retirement and premature death and bereavement [4]. Other costs that contribute to the financial impact of diabetes (on both the individual and the family) include the costs associated with blood sugar self-monitoring, insulin needles, syringes and pump consumables.

## 1.5 Opportunities to improve care integration and self-management

Diabetes is a complex, chronic condition, and people living with the disease require care from a variety of different healthcare providers. The continuum of care requires that people with diabetes are encouraged and

facilitated to optimally manage diabetes on a day to day basis. New technologies, information exchange, and community and workplace are important resources in achieving this goal.

The link to overall chronic disease management should also be recognised, given that many people with diabetes also live with or share risk factors for other chronic diseases. While the overall level of care provided in Australia is high by international standards, there are nonetheless a number of opportunities to improve diabetes care. These include:

- Increasing the proportion of people with diabetes who receive care in accordance with the recommended clinical guidelines. In 2009–10, only 18 per cent of Australians with diabetes had a claim made by their GP for an annual cycle of care (indicating that they had completed a series of up to 12 steps, such as HbA1c measurement, eye examination, blood pressure check, and foot check) [27]. Similarly, it has been estimated that the relevant clinical guidelines are not followed in 37 per cent of diabetes-related clinical encounters [28].
- Increasing the percentage of people with diabetes that achieve the recommended clinical targets. In 2011–12, 45 per cent of Australian adults with known diabetes did not achieve the recommended glycaemic targets, almost two thirds of people had high blood pressure (i.e. blood pressure that falls outside the recommended range), and 87 per cent of people with diabetes were outside the ideal body mass index (BMI) range [29].
- Improving the quality and coordination of care. Australians with chronic disease experience gaps in care coordination: 55 per cent have experienced gaps in hospital or surgery discharge planning, 34 per cent reported that a pharmacist or doctor had not reviewed their medication in the past year, and 19 per cent have seen a specialist who lacked their medical history or have a regular doctor who is not informed about specialist care they are receiving [30].

These opportunities to improve care for people with diabetes have informed and guided the development of this strategic framework.

## 2 A national diabetes strategy for Australia

The new National Diabetes Strategy seeks to prioritise Australia's response to diabetes, and to identify approaches to reduce the impact of diabetes in the community.

### 2.1 Key national milestones

Australia is an international leader in diabetes research and care. It was one of the first nations to introduce universal, government-supported assistance for self-monitoring of blood sugar and self-management (through the National Diabetes Services Scheme), and Australian researchers are at the forefront of research into public health and epidemiology, the causes of type 1 and type 2 diabetes, islet cell transplantation and translational research into improving diabetes treatment.

While Australia has made significant contributions towards diabetes research and improving diabetes prevention and care, there is still progress to be made.

FIGURE 4

#### Key national milestones



<sup>1</sup> National Diabetes Strategy Advisory Group

### 2.2 Context and government commitment

Following the 2013 federal election, the Australian Government made a commitment to develop a new National Diabetes Strategy, in recognition of the social and economic burden of the disease. Developing a new National Diabetes Strategy provides a valuable opportunity to evaluate current approaches to diabetes services and care; consider the role of governments at all levels, as well as other stakeholders; evaluate whether current efforts and investments align with identified needs; maximise the efficient use of existing, limited healthcare resources; and articulate a vision for preventing, detecting, and managing diabetes and for diabetes research efforts. The strategy will also seek to better coordinate health resources across all levels of government, and to

focus these resources where they are needed most. The National Diabetes Strategy will form part of the Government's overall strategic framework for managing chronic diseases, which recognises the shared health determinants, risk factors and multi-morbidities (i.e. co-occurring diseases) that exist across a broad range of chronic conditions (including heart disease, diabetes and kidney disease). It will also provide an opportunity to consider how best to facilitate coordinated, integrated and multidisciplinary care, improve utilisation of primary healthcare services, and recognise patient needs across the continuum of care.

Developing a new National Diabetes Strategy provides a valuable opportunity to incorporate the approach that has been adopted in the Global Action Plan for the Prevention and Control of Non-Communicable Diseases (WHO Global Action Plan) and the Global Monitoring Framework for Non-Communicable Diseases (the WHO NCD Monitoring Framework) that were developed by the World Health Organization in 2013.

At the World Diabetes Congress in December 2013, the Minister for Health, the Hon. Peter Dutton MP, announced the formation of a National Diabetes Strategy Advisory Group, co-chaired by the Hon. Judi Moylan and Professor Paul Zimmet AO. Advisory Group members have a wide range of experience and expertise in diabetes-related healthcare, research and population health, as well as links with key stakeholders.

This draft National Diabetes Strategy consultation paper will provide a framework for guiding potential reforms in diabetes care over the coming years. These reforms will take place within a healthcare system that is itself undergoing change, and some of the current areas of focus—which are unfolding in parallel with the development of the National Diabetes Strategy—are likely to both inform and be informed by the strategy. These areas of focus include:

- The establishment of new Primary Health Networks
- Ongoing work on the implementation of electronic health records
- A post-market review of products used in the management of diabetes that are subsidised under the Pharmaceutical Benefits Scheme (PBS)
- An evaluation of the Diabetes Care Project
- Development of a new national strategic framework for chronic conditions, as a revision to the National Chronic Disease Strategy (2005).

## **2.3 National Diabetes Strategy Advisory Group: Terms of reference**

### **Purpose**

The purpose of the National Diabetes Strategy Advisory Group is to provide expert policy advice to the Government that prioritises the national response to diabetes within the broader context of prevention and primary healthcare, supports patients with complex health conditions and recognises the burden of chronic disease on our health system.

### **Roles and objectives**

Specifically, the Advisory Group will advise on:

1. The scale and extent of diabetes in Australia, as well as key clinical and policy challenges
2. Australian diabetes outcomes compared with international evidence

3. Gaps in diabetes prevention and care, including service coordination and integration, research and monitoring
4. Strategies to:
  - Improve early identification of diabetes and those at future risk of diabetes
  - Enable optimal management of patients by general practice and the primary healthcare sector
  - Improve health literacy and support for patient self-care, including applications to enhance monitoring of an individual's condition
  - Ensure timely responses to prevent and manage complications caused by diabetes (for example, kidney and heart health, eye and foot complications)
  - Focus on those most at risk (for example, Aboriginal and Torres Strait Islander peoples, pregnant women)
5. Approaches to strengthening the evidence base through research and the translation of research into practice, including enhanced use of clinical practice guidelines, standards and pathways

The Advisory Group will provide advice in consultation with the Australian Health Ministers' Advisory Council (AHMAC), taking relevant activities into account (including work on chronic disease and common risk factors). This may include advice on opportunities for jurisdictions to partner with the Commonwealth to develop and support approaches for diabetes prevention and control.

## **2.4 The consultation process**

The National Diabetes Strategy Advisory Group met four times during 2014. Between August and October 2014, seven face-to-face consultation workshops took place with key stakeholders—including State and Territory public health officials—in Melbourne, Canberra, Perth, Brisbane, Sydney, Alice Springs and Hobart.

This consultation paper has been prepared to guide and inform an online public consultation process, which will open in April 2015. Key stakeholders (including State and Territory health officials, participants in the consultation workshops, diabetes organisations and stakeholders who have registered their interest with the secretariat) will be advised when the consultation opens.

A draft of the National Diabetes Strategy will be considered by the Minister for Health, following analysis of public consultation responses. The draft strategy will then be reviewed by the AHMAC and the COAG Health Council, with the goal of publicly releasing the final National Diabetes Strategy in late 2015.

## 3 Key goals for a national diabetes strategy for Australia

This section describes five high-level goals for the National Diabetes Strategy. For each goal, the NDSAG have described why the goal is important, outlined potential areas for action, and suggested ways in which progress against the goal could be measured.

As you read each section, please keep in mind the terms of reference and the questions listed below. The NDSAG would appreciate feedback related to these questions during the public consultation period.

- Which of the areas for action described for this goal would be most appropriate and why?
- Are there any additional actions you would like to see the governments and/or other stakeholders take and why?
- Please describe any existing programmes, initiatives or activities relevant to this goal that you think are working well and why? (Please indicate if you are aware of an evaluation report, and how it may be obtained)
- Are there any existing activities, services or systems relevant to this goal that you think are not working well (please explain why, and discuss any barriers to their effectiveness?).
- The Paper outlines some potential ways to measure Australia's progress towards this goal. What do you think would be the most appropriate ways to measure this goal and why?
- In relation to the impact of diabetes in Aboriginal and Torres Strait Islander peoples and other high risk groups, please describe any barrier in accessing health services and/or education?

### 3.1 Goal 1: Reduce the prevalence and incidence of people developing type 2 diabetes

As noted in Section 1, approximately 1.1 million people with diabetes have registered with the NDSS, and an additional 263 people register every day [1]. In order to reduce the percentage of people that are newly diagnosed with type 2 diabetes each year (i.e. the incidence of diabetes), the strategy needs to provide a community-based approach for the entire population, with additional focus on two particular groups: adults at high risk of developing diabetes, and children. Adults who are considered at high risk of developing type 2 diabetes are those with prediabetes as well as certain risk factors and the strongest evidence of effective prevention is in this group. Additionally, AUSDRISK is the recommended screening tool for identifying people at high risk of developing type 2 diabetes. Individual risk factors can be non-modifiable, such as age or a family history of type 2 diabetes, or they can be potentially modifiable and hence areas where action can be taken (See table 2).

TABLE 2 – POTENTIALLY MODIFIABLE RISK FACTORS FOR TYPE 2 DIABETES MELLITUS

Potentially modifiable risk factors
■ Overweight & obesity, including increased waist circumference
■ Sedentary behaviour
■ Physical inactivity
■ Diet
■ Impaired glucose tolerance or impaired fasting glucose
■ Gestational diabetes
■ Intrauterine environment and early life nutrition
■ Smoking
■ Medication (e.g. steroids, anti-psychotics, diuretics)
■ Hypertension
■ Dyslipidaemia

The three groups targeted by this community-based approach (the general population, adults at high risk of developing diabetes, and children) are discussed below.

- **The general population.** In order to reduce the prevalence of diabetes, Australia must focus its efforts on improving the Australian diet, encouraging Australians to undertake physical activity more frequently and lead a less sedentary lifestyle, and reducing overweight and obesity across the general population. A relatively small reduction in weight (approximately five per cent) has been shown to successfully reduce the risk of developing diabetes in individuals who are overweight or obese [31].
- **Adults at high risk of developing diabetes.** Approximately 20 per cent of the adult population are considered to be at high risk of developing diabetes, and this group is expected to account for 50 per cent of new diabetes diagnoses over the next decade [32]. For women with a past history of GDM, in the Australian population, the risk of developing type 2 diabetes within 15 years is in the order of 25.8% [33].
- **Children.** It is critical that all Australian children are given the best possible start in life. There is increasing evidence that pre-conception parental health, the environment inside the womb and a child's first few years of life have a significant impact on his or her chances of developing diabetes and obesity as an adult [15]. It is therefore essential that the National Diabetes Strategy considers how best to support families in providing a healthy start for their children.

Potential areas for action for each of these groups are outlined on the following page.

### 3.1.1 Areas for action

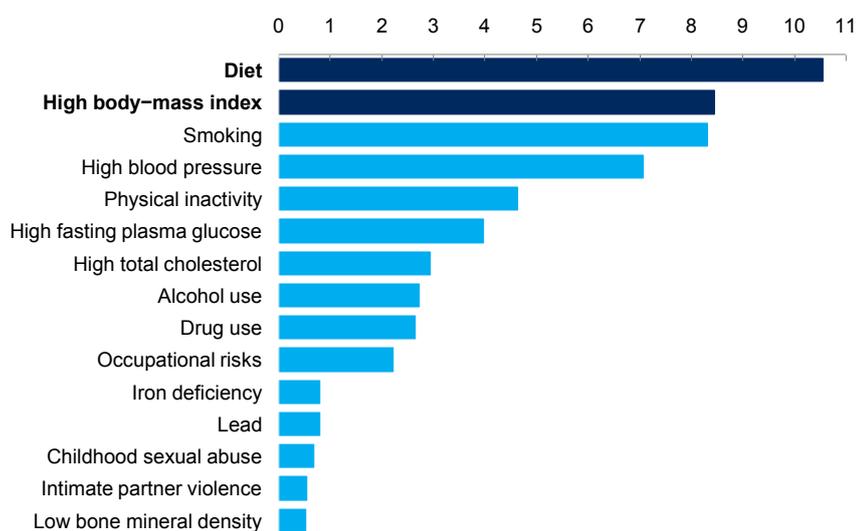
#### Reduce the prevalence of modifiable risk factors in the general population

Modifiable risk factors such as overweight and obesity, poor diet and lack of physical activity have a significant impact on a person's health. At present, 63 per cent of Australian adults over the age of 18 are overweight or obese, as are approximately 25% per cent of children aged between 5 and 17 [34], and these rates are even higher among people from low socioeconomic backgrounds. This makes Australia the fourth most overweight (including obese) country in the Organisation for Economic Co-operation and Development (OECD) [35]. This problem is growing quickly, and diet and obesity are now the number one and two risk factors for ill-health in Australia (as measured by disability-adjusted life years lost), eclipsing other risks such as tobacco and alcohol use (Figure 5) [36]. Reducing rates of overweight and obesity will not only have an impact on diabetes, but also on other diseases such as osteoarthritis, heart disease, obstructive sleep apnoea and some cancers.

FIGURE 5 [36]

#### Diet and weight are the top two risk factors in Australia

Percent of Australian disability-adjusted life years (DALYs) attributable to risk factors



Reducing overweight and other modifiable risk factors across the population is a difficult task, however, and no single solution will work. The prevention of obesity and type 2 diabetes requires coordinated policy and possibly regulatory changes, with greater attention given to the urban environment, transportation infrastructure, health education and opportunities for improved diet and increased physical activity. A multidisciplinary, coordinated approach across health, finance, education, sport and agriculture sectors can contribute towards reversing the underlying causes of diabetes. The strategy should seek to improve people's awareness and understanding of modifiable risk factors, increase the availability of healthier alternatives and encourage people to make healthier lifestyle choices. It is important that Australia evaluates the effectiveness of current initiatives in this area and develops a comprehensive, systems-based, preventative programme that:

- Supports a healthier environment that encourages people to increase levels of physical activity (for example, through urban redesign efforts that encourage individual and community activities such as walking and cycling)

- Increases the availability of (and demand for) healthier food, or reduces the availability of (and demand for) unhealthy food including through continued implementation and targeted education on the Front-of-Pack Labelling - Health Star Rating system that provides at-a-glance nutritional information using a five star rating scale to help consumers make healthier food choices. Other ideas include providing low-calorie options and designing supermarket layouts to encourage healthier choices
- Incorporates education and social media campaigns to encourage people to increase their levels of physical activity and healthy eating (for example, focused on educating parents about nutrition and physical activity)
- Reduces the exposure of children and others to marketing, advertising, promotion and sponsorship of energy-dense, nutrient-poor foods and beverages (for example, through voluntary or compulsory advertising codes of conduct)
- Strengthens and upskills the primary healthcare and public health workforces to support people to make healthy choices (for example, by improving access to services that provide weight loss and dietary support) and provides culturally appropriate advice and care for Aboriginal and Torres Strait Islander communities and people from other culturally and linguistically diverse communities
- Addresses family and child health, enhancing early life and growth patterns (for example, through education of families from pre-conception through early childhood)

#### **Identify and provide prevention programmes to people with prediabetes**

Potential actions for preventing progression from prediabetes to type 2 diabetes will be supported by those for reducing the prevalence of modifiable risk factors in the general population (outlined above). In addition, evidence based interventions exist, are effective and should be considered for the high-risk group. This could include a nationally coordinated detection programme for prediabetes using AUSDRISK, a screening tool acknowledged as the primary mechanism for identifying people at high risk for inclusion in diabetes prevention programmes [37]. This can be integrated with risk assessment for other chronic conditions including absolute cardiovascular risk assessment and kidney disease risk assessment. The programme could also involve integrated social marketing initiatives. A coordinated intervention for identified high-risk individuals should be considered, which might include the establishment of a national telephone riskline service (similar to the Quitline for tobacco) to encourage people to access prevention services if they are at risk of developing diabetes. In addition to actions aimed at reducing the prevalence of modifiable risk factors in the general population, targeted lifestyle programmes should be considered for people at a high risk of developing diabetes.

#### **Ensure pregnant women and children get optimal care**

Diabetes during pregnancy places women and their children at significant risk during and after the pregnancy. Fetal and infant death is four times more likely among women who have diabetes prior to pregnancy, [38] and it is important that steps are taken to mitigate this risk prior to pregnancy (i.e. through pre-conception care for both men and women), during pregnancy, and following delivery. Potential actions to ensure that pregnant women receive the best care, and that each child has the best start to life, include pre-pregnancy programmes to address risk factors prior to pregnancy, identifying women with high blood sugar levels before they become pregnant, ensuring that women with diabetes in pregnancy have access to a diabetes educator, providing advice on diet and physical activity, and providing affordable home glucose monitoring. While all women should be included in general preventative care, women with gestational diabetes in previous pregnancies warrant a particular focus in terms of health and lifestyle. In addition, the provision of expert advice on appropriate treatment options could be improved by enhancing the capacity of maternity service providers to manage

diabetes in pregnancy, creating evidence-based guidelines for the management of diabetes in pregnancy. The provision of ongoing support and care after pregnancy is essential to help prevent the development of type 2 diabetes.

### **3.1.2 Potential ways to measure Australia's progress toward this goal**

#### **The percentage of the population developing or with diabetes**

As discussed in Section 1, it is difficult to estimate the percentage of the population with diabetes. The best option would be to conduct a periodic survey (for example every five years) of the population (such as the Australian Health Survey). An alternative would be to use the NDSS database, although at present, there are a number of problems with these data, including under-representation of certain populations (including Aboriginal and Torres Strait Islander peoples) and inclusion of non-resident visitors.

#### **The percentage of the population that is overweight or obese**

In addition to monitoring the percentage of people with diabetes, it is important to identify targets for reducing the percentage of people that are overweight or obese, as well as a means of monitoring progress toward these targets. Again, the best option would be to conduct the periodic survey of the population as suggested above (such as the Australian Health Survey), although more work needs to be done to identify the best methodology for collecting these data consistently over time.

#### **Annual number of cases of gestational diabetes diagnosed, and the number of these women who receive follow-up preventative services**

The NDSS National Gestational Diabetes Register can be used to estimate the number of cases of gestational diabetes. Approximately 24,700 women were newly registered with gestational diabetes in the year ending September 30, 2014 [39]. Sixty-eight women with gestational diabetes were registered every day [39].

## **3.2 Goal 2: Promote earlier detection of diabetes**

It is estimated that for every 100 people with a diagnosis of type 2 diabetes in Australia, at least another 25 may be living with undiagnosed type 2 diabetes [40] [9]. This has serious implications for their health. People who have not been diagnosed with diabetes are typically unaware of their condition and are therefore not accessing the necessary treatment. This increases their chances of developing potentially serious, diabetes-related complications.

Failure to recognise the early symptoms of type 1 diabetes —such as fatigue and thirst—can lead to diabetic ketoacidosis, which is an acute, life-threatening complication that can lead to long-term disability.

Approximately 20 to 25 per cent of people who are newly diagnosed with type 1 diabetes only learn about this upon presenting to hospital with diabetic ketoacidosis [41].

### **3.2.1 Areas for action**

#### **Improve detection in primary care for type 2 diabetes**

Undiagnosed type 2 diabetes is relatively common in Australia [9]. As such, Australia has an opportunity to enable earlier detection of the disease, resulting in earlier treatment and a corresponding reduction in the adverse impact of diabetes on health and productivity. Actions to support improved early detection include

educating primary healthcare practitioners about who should be screened; promoting increased use of the AUSDRISK screening tool among all age groups (this may require further calibration of the tool for different age ranges) which should be integrated with the Australian absolute cardiovascular disease risk assessment for appropriate age groups; and focusing attention on those who score highly on the AUSDRISK screening tool, women who are planning a pregnancy, and people from at-risk communities (for example, those with a strong family history of type 2 diabetes).

#### **Increase awareness of type 1 diabetes among healthcare providers and the community**

Increased awareness and recognition of the symptoms of type 1 diabetes facilitates early diagnosis, which can prevent the onset of diabetic ketoacidosis and reduce the risks associated with undiagnosed type 1 diabetes. Actions to support early diagnosis of type 1 diabetes include educating primary healthcare practitioners and members of the community—including parents, teachers and others involved in the care of children—to recognise the symptoms and signs of type 1 diabetes.

### **3.2.2 Potential ways to measure Australia’s progress towards this goal**

#### **The number of people screened for risk of diabetes annually**

This is likely to be difficult to measure. One potential way is to count the number of people who use the AUSDRISK screening tool. Another potential way is to count Medicare claims data for tests in people who do not have diabetes, including oral glucose tolerance tests, fasting plasma glucose and diagnostic HbA1c tests.

#### **The percentage of people with type 1 diabetes that present with diabetic ketoacidosis on diagnosis**

The percentage of people diagnosed with type 1 diabetes that present at hospital with diabetic ketoacidosis is not tracked nationally. However, data from Western Australia would suggest that about 25 per cent of people with type 1 diabetes present with diabetic ketoacidosis [41]. In the short term, the data from Western Australia could be used to monitor progress toward this goal, but a national register would be preferable.

### **3.3 Goal 3: Reduce the occurrence of diabetes-related complications and improve quality of life among people with diabetes**

The majority of the complications of diabetes are potentially preventable and the primary care system should be more strongly oriented towards preventing complications. This would include plans, programmes, monitoring and reporting across primary health networks and the health system more generally encompassing:

- Eye damage and blindness
- Cardiovascular disease and strokes
- Kidney damage
- Amputations
- Mental health problems including depression

The issue of diabetes management has attracted a lot of research. Every year, new treatments are released and improved clinical guidelines are developed. The challenge, however, is ensuring that these guidelines are applied consistently across the population. At present, a significant proportion of people with diabetes do not receive all the recommended checks. Half of people with diabetes do not receive recommended eye

examinations and approximately two thirds fall outside recommended clinical targets for blood pressure or cholesterol levels [8]. Ensuring that recommended care is consistently applied has the potential to slow the progress of diabetes and delay the onset of diabetes-related complications, both of which have positive implications for the health and wellbeing of people with diabetes.

The Government is currently supporting initiatives in primary care such as the planned Primary Health Networks and electronic health records. Further action is planned through the development of a strategic framework for chronic conditions. Nonetheless, opportunities remain to further improve the care delivered to people with diabetes and other chronic conditions. For example, optimal care requires integrated and coordinated healthcare services because people with diabetes often see a number of different health professionals across primary, community and specialist care services. It has been shown, both in Australia and overseas, that best-practice, high-quality diabetes care can only be achieved when these healthcare professionals work as a team, alongside the person with diabetes. Achieving this will not be easy, however, because it will require a transformation in the way care is delivered in order to make it more consumer focused, team-based, and proactive.

### **3.3.1 Areas for action**

#### **Nationally agreed clinical guidelines, local care pathways and complications prevention programmes**

There are currently over 20 different diabetes-related clinical guidelines, backed by a range of organisations, which leads to confusion and unnecessary debate about standards of care [42]. A single set of national guidelines could be developed, most likely based on the current National Health and Medical Research Council (NHMRC) approved guidelines, which include eight diabetes-related guidelines [43]. At the same time, Primary Health Networks will need to develop locally tailored pathways of care that reflect local service configuration and population needs, particularly for the management of all chronic conditions. Additionally, complications prevention programmes should be strengthened in Primary Health Networks and across the health system more generally. These may be integrated programmes covering multiple complications, or even single complication prevention programmes. Databases such as the NDSS and initiatives such as personally controlled electronic health records (PCEHR) should be utilised to facilitate such programmes.

#### **Consumer engagement and self-management**

Optimal health and wellbeing can only be achieved and sustained when people with diabetes are involved as active partners in their own diabetes care [44]. There are two main ways to achieve this. Firstly, structured self-management education programmes can be developed and implemented for people with diabetes, with a particular focus on the newly diagnosed, people starting insulin, children in transition to adult services, and older people and their carers [45]. These education programmes could also be extended to include teachers and schools in order to allow children with diabetes to participate fully and safely in the school experience. Secondly, steps could be taken to ensure that all people with diabetes have opportunities to participate in peer support programmes (either face to face, by telephone or online). Research suggests that participating in these programmes can be highly effective in improving outcomes for people with diabetes [46]. Steps taken should be inclusive, accessible and available to all, including people with disability.

#### **Quality improvement processes**

People affected by diabetes and all healthcare providers who care for people with diabetes should be involved in quality improvement processes. These processes should involve the systematic collection of data on providers' adherence to clinical guidelines and clinical outcomes for example, screening for diabetic

retinopathy, gestational diabetes and renal disease as well as peer comparison of these data (albeit with appropriate adjustment for patient mix and risk levels). In time, these data could also be reported publicly at local and national levels. It is likely that Primary Health Networks would play a pivotal role in facilitating these processes, and that the Australian Commission on Safety and Quality in Health Care could monitor them. Developing the capacity to link data from different sources at an individual level will also support quality improvement efforts by offering care providers a more complete picture of an individual's health and wellbeing, and providing people with diabetes with an up-to-date record of their care. Data linking has the potential to improve clinical care at the individual level, and to offer benefits at a population level by providing data to inform research and health policy. Data linking is discussed further in Goal 5.

### **Information and communication technology**

Electronic health has the potential to revolutionise care for people with diabetes. The Australian Government has begun the process of building the infrastructure necessary for a fully technologically enabled system that includes universal patient identifiers, secure messaging technologies and PCEHR. Measures undertaken will need to include a range of formats in order to be inclusive to people with disability. Priority areas for future investment could include the following:

- Encouraging the uptake and meaningful use of PCEHR by people with diabetes and their healthcare providers
- Harnessing PCEHR for care planning activities when implemented
- Enabling more flexible telemedicine consultations (for example, for eye screening in rural and remote locations, telephone-based lifestyle coaching)
- Creating patient engagement and education platforms
- Trialling remote monitoring technologies
- Creating consumer reminder and recall systems, including online appointment scheduling

### **Medicines and devices**

PBS expenditure on diabetes medicine increased by 12 per cent per annum between the 2006 and 2013 financial years, driven both by the growing prevalence of diabetes and the increased availability and use of newer, more expensive diabetes medicines [47]. At the same time, there is a need to increase accessibility of newer technologies, such as insulin pumps, new efficacious medicines and continuous glucose monitors. For people with type 1 diabetes, insulin pump therapy can be a life-changing and potentially life-saving intervention. Pathways for assessment, evaluation and funding to enable access and availability of new diabetes treatments and technologies should be designed to be as timely and efficient as possible.

Please note that the National Diabetes Strategy consultation process does not replace or override existing processes established by the Australian health system for assessing the safety, quality and cost-effectiveness of new medicines, devices, tests and procedures.

### **Workforce capacity**

At present, there is a shortage of appropriately qualified and certified allied health professionals across the care spectrum, this shortage is more apparent in rural and remote areas. Workforce capacity needs to be explored for the following allied health professions: psychologists, podiatrists, dieticians, exercise physiologists, orthotics and prosthetics. In addition, there are other professions who also have a shortage of qualified practitioners, this includes diabetes educators and practice nurses. In 2010, for example, the Credentialed Diabetes Educator (CDE) workforce in Australia was capable of servicing only 57 per cent of all people diagnosed with diabetes [48]. Solving this workforce capacity issue will require upskilling of the existing workforce, a significant increase in the workforce population, a redistribution of some diabetes care activities to different roles (e.g. CDEs might perform care planning activities traditionally undertaken by doctors), and standardisation of core competencies in the diabetes health workforce. New workforce approaches need to be considered including voluntary peer support with trained peer leaders supporting people affected by diabetes in their prevention and management efforts.

### **Funding reform and incentives**

An exclusively fee-for-service funding model for the primary care of people with diabetes is unlikely to lead to optimal outcomes. The fee-for-service model does not incentivise long-term follow up or the proactive care of people with chronic conditions. As such, more innovative funding models are needed that combine fee-for-service reimbursement with other payment types, such as population-based payments and quality-based payments. The Government could consider exploring (potentially through demonstration projects) an innovative combination of payment models, such as pooled funds, 'medical homes,' capitation payments, pay for performance, and pay for quality and outcomes based on performance indicators. It is also worth considering funding arrangements for allied health professionals and CDEs.

### **Mental health care for people with diabetes**

Attending to behavioural and mental health factors is crucial to preventing complications, maximising outcomes and minimising costs in diabetes care. People with diabetes should be monitored for mental health issues, and mental health screening should be undertaken upon diagnosis of diabetes and added to the annual cycle of care. A quality of life measure should also be added to the mental health screen.

### **Transition from child to adult services**

Transitioning from paediatric to mainstream adult services (that is, 'the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented health care systems') is often challenging [49], and mainstream services are often ill-equipped to meet the special needs of young adults. Young people with diabetes who are in transition may disengage from the health system as well as their treatment regimes. There are a number of effective transition programmes in place today which assist young people with chronic conditions (including diabetes) with the transition from paediatric to adult care [50]. Programmes like this should be considered to address this issue with monitoring, reporting and accountability.

### **High-quality hospital care**

It has been estimated that 15 to 35 per cent of public hospital admissions are diabetes-related admissions [51]. Specialist diabetes teams are important, not only for patient care and safety but also as a potential means of shortening the duration of admissions, and all hospital staff involved in the care of people with diabetes should be appropriately trained to access expert help when needed. Australia has high quality hospital based diabetes

services through the National Accredited Diabetes Centres programme and the capacity of these services should be supported and better utilised. In certain hospitals in the United States, a system of 'Diabetes Champions' has been developed [52], to address the growing number of patients who require inpatient diabetes education, as well as the training needs of bedside nurses who are increasingly called on to educate these patients. This is a voluntary system and it has resulted in shorter admissions, improved care and a better transition back to the home environment.

### **3.3.2 Potential ways to measure Australia's progress towards this goal**

#### **The number of people having screening for complications**

This includes eye, kidney, foot, cardiovascular disease and mental health complications. One practical measure of this is the number of people claiming a Medicare annual cycle of care payment, which requires general practices to have completed all of these screening checks (aside from mental health) in the period recommended by the National Health and Medical Research Council (NHMRC) Guidelines.

#### **The percentage of people with diabetes with high HbA1c, cholesterol or blood pressure**

These metabolic indicators are good predictors of a person's long-term likelihood of developing diabetes-related complications. There is currently no nationally standardised way to collect these data and the Government should strive to identify and implement a mechanism for doing so.

#### **The incidence of complications per thousand people with diabetes**

Measured complications could include lower limb amputations, starting dialysis, blindness, heart attacks and strokes. There is currently no standardised way of tracking all diabetes-related complications and these particular complications have been suggested for pragmatic reasons (i.e. they are easier to track). In the future, it may be possible to track earlier stages of developing complications, such as eye disease and early stage kidney disease.

#### **Quality of life scores for people with diabetes**

There is no standardised way of collecting these data. A periodic survey of people who are registered with the NDSS could be considered.

## **3.4 Goal 4: Reduce the impact of diabetes in Aboriginal and Torres Strait Islander peoples and other high risk groups**

Australia is socially and culturally diverse and this has important implications for the development of a National Diabetes Strategy. While the areas for action that have been suggested for all Australians under Goals 1 to 3 also apply to communities with a higher prevalence of diabetes, Aboriginal and Torres Strait Islander peoples in particular, and other culturally and linguistically diverse communities, older Australians, and rural and remote communities warrant particular attention, and may require different policy or health system approaches. Firstly, it is important to consider how the National Diabetes Strategy will engage with those at higher risk of developing diabetes in a culturally appropriate and relevant way. Secondly, it is likely that specific attention will need to be given to these groups when developing actions for the prevention, diagnosis and management of diabetes and its complications. These are critical targets for input from the consultation process and feedback/advice from patients, community members, health and social service providers and representative

organisations is essential to developing a comprehensive and culturally responsive national approach to diabetes.

### Aboriginal and Torres Strait Islander peoples

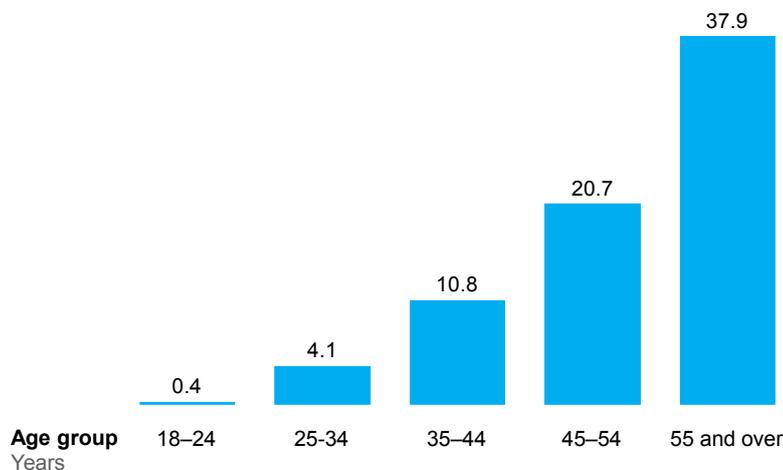
Approximately 20 per cent of Aboriginal and Torres Strait Islander peoples over the age of 25 have type 2 diabetes [22]. Figure 6 shows the prevalence of type 2 diabetes by age group. Diabetes is also increasingly diagnosed in children, adolescents and young adults within Indigenous communities [53]. The rapid progression and severity of diabetes-related complications among Aboriginal and Torres Strait Islander peoples is a particular concern [54].

Aboriginal and Torres Strait Islander peoples may also experience cultural and linguistic barriers, as well as geographic and socioeconomic barriers, that limit their access to diabetes-related services and education. Indigenous communities have many unique languages and traditions, as well as varying needs and existing capacities. This cultural diversity, along with varying local and regional circumstances, needs to be recognised, respected and should inform the development of action that serves to reduce the burden and impact of diabetes.

FIGURE 6 [55]

#### Prevalence of diabetes in Australian Aboriginal and Torres Strait Islander persons (18+) by age group

Percent



### Culturally and linguistically diverse people

People from some culturally and linguistically diverse backgrounds are at higher risk of developing type 2 diabetes (perhaps reflecting a predisposition to diabetes in their environmental or genetic backgrounds). In 2004-05, the prevalence of diagnosed diabetes was three per cent among people born in Australia and four per cent among those born overseas [23]. However, the prevalence was much higher among people born in some regions of the world. For example, the prevalence of diabetes was approximately seven per cent among people born in North Africa and the Middle East, approximately six per cent among people born in Southeast Asia, and approximately five per cent among people born in both Oceania (excluding Australia) and southern and eastern

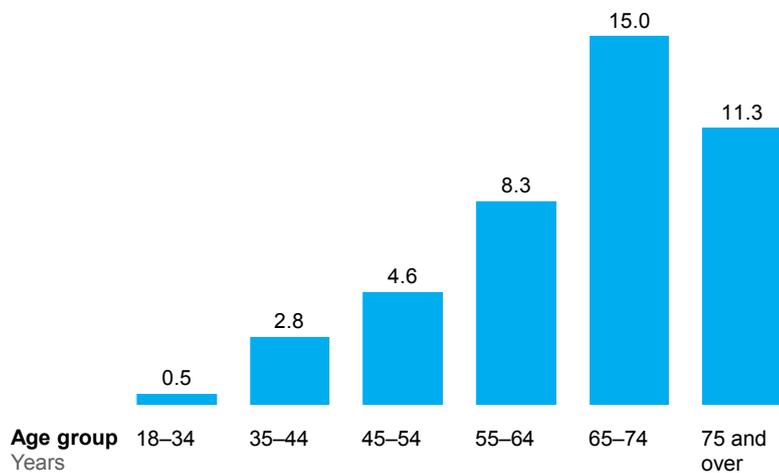
Europe [23]. People from these backgrounds who have diabetes may also experience cultural and linguistic barriers that limit their access to diabetes-related services and education.

### Older Australians

Diabetes (particularly type 2 diabetes) is more prevalent among older Australians (Figure 7) [23] [56]. Furthermore, older people with diabetes experience higher rates of comorbidity (i.e. higher rates of diagnosis with other medical conditions alongside diabetes) and disability, as well as earlier onset of functional decline and frailty [57].

FIGURE 7 [56]

**Prevalence of diabetes in Australian adults (18+) by age group**  
Percent



### Australians living in rural and remote areas

People with diabetes who live in rural and remote communities may experience geographical barriers that limit their access to services [24]. Rural and remote communities also include people from all ethnic and cultural backgrounds, some of whom may experience additional cultural and linguistic barriers to accessing services.

Areas for action for each of these groups are outlined on the following page.

## 3.4.1 Areas for action

### Aboriginal and Torres Strait Islander peoples

There are many potential actions that will reduce the impact of diabetes among Aboriginal and Torres Strait Islander peoples. The disparate burden of disease, the significant barriers that exist to accessing and receiving necessary care, and the high priority placed in reducing the disadvantage experienced by Aboriginal and Torres Strait Islander communities, mean that a specific national approach to diabetes could be considered. This is not to suggest that actions targeted towards all Australians do not also apply to specific high-risk populations, but

their greater level of need requires specific consideration. As a starting point, this consultation document seeks discussion around several key targets for action.

There is need to improve the level of awareness and delivery of health education services to these communities. This can be improved by developing and implementing appropriate community-wide, culturally relevant awareness programmes that communicate the seriousness of diabetes and its complications. This should include a specific focus on school education programmes, and pre-natal and antenatal education and patient and family diabetes education. Education should be provided in a culturally and linguistically sensitive manner, which includes providing information and translation services in relevant languages and through peer support.

The creation and sustaining of health promoting environments are essential for disadvantaged communities to prevent and manage diabetes. Healthier choices should be encouraged and supported through community interventions that increase the availability, affordability and consumption of healthy foods and maximise opportunities for regular physical activity.

The long-term prevention of diabetes requires recognition of the importance of the health of children and the whole family. This should involve the establishment and funding of pre-conception, pregnancy and early years programmes that enhance education and the health of Aboriginal and Torres Strait Islander men and women; detect gestational and previously undiagnosed diabetes and manage it through pregnancy; and coordinate follow-up and postnatal care for parents and their babies.

There remains a critical workforce shortage in Aboriginal and Torres Strait Islander and rural and remote communities. Increasing the number of diabetes educators working with and within Aboriginal primary care settings, and supporting the capacity development of the existing workforce will improve access to essential, high quality evidence-based diabetes care. Any new programmes or services should give consideration as to how they will work within or alongside existing services, particularly Aboriginal Controlled Community Health Organisations.

### **Culturally and linguistically diverse people**

Potential actions for supporting culturally and linguistically diverse people focus on removing barriers that limit access to services and education. Steps can be taken to ensure that resources are made available in the appropriate languages (identified by analysing data that monitor emerging national or local priority languages) and that appropriate interpretation services are available during healthcare encounters. Diabetes education packages that are culturally and linguistically appropriate could also be developed, rolled out, evaluated and (where necessary) adapted to ensure the successful transfer of information on diabetes prevention and management.

### **Older Australians**

Potential actions for older Australians include ensuring that the relevant guidelines on managing diabetes in older people inform care and clinical decision making across health and aged care settings (for example, the McKellar guidelines) [58]. Steps can also be taken to link the services that provide diabetes care and support to older Australians through the implementation of eHealth (electronic health) records and Primary Health Networks. In addition, transitioning care between services is a key area of vulnerability in the management of diabetes among older Australians and there is a high risk for medication mismanagement and increased hypoglycaemia or hyperglycaemia [59]. Facilitating early discharge planning and communication to the outpatient diabetes care team and/or a person's treating GP is essential.

### **Australians living in rural and remote areas**

Rural and remote communities include people from a variety of ethnic and cultural backgrounds and age groups. As such, the areas for action for Aboriginal and Torres Strait Islander peoples, culturally and linguistically diverse communities and older Australians (outlined above) are applicable to remote and rural communities. In addition to these actions, however, it is important to address the geographical barriers that can limit access to diabetes services and education in these communities. This may be achieved by coordinating regional services across primary, secondary and tertiary care to ensure access to care and the necessary support services; streamlining referral pathways; supporting community-based health workers including through additional training; and collaboratively planning and implementing integrated, multidisciplinary care. Additionally, facilitating an expansion of telehealth into the primary health care sector and internet medical services and peer support has the potential to deliver accessible and cost-effective services to people in rural and remote communities.

## **3.4.2 Potential ways to measure Australia's progress towards this goal**

### **The number of new cases of diabetes diagnosed each year, per thousand people, in groups at higher risk**

As discussed in Goal 1, there is currently no definitive way of counting the number of people with diabetes in Australia. The best option would be to conduct a periodic survey of the population (such as the Australian Health Survey), although more work needs to be done to identify the best methodology for collecting these data consistently over time. Although the National Diabetes Services Scheme may be used in the short term, many people with diabetes from at-risk communities are not currently registered with the NDSS. Increasing the number of people from groups at higher risk of diabetes who register with the NDSS needs to be encouraged and facilitated. National key performance indicators measured by the AIHW may also be used to quantify aspects of diabetes care provided by Indigenous specific primary health care services.

### **The number of people from groups at higher risk who receive annual testing for complications**

As with the general population, this includes eye, kidney, foot, cardiovascular disease and mental health complications.

### **The percentage of people with diabetes in groups at higher risk with high HbA1c, cholesterol or blood pressure**

As with the general population, these metabolic indicators are good predictors of a person's long-term likelihood of developing diabetes-related complications. At present, there is no nationally standardised way to collect these data and the Government is encouraged to identify and implement a mechanism for doing so.

### **The incidence of complications per thousand people with diabetes from groups at higher risk**

As with the general population, measured complications could include lower limb amputations, use of dialysis, heart attacks and strokes. At present, there is no standardised way to collect these data (see Goal 3 for further discussion of this issue).

### **Quality of life scores for people with diabetes**

As with the general population, there is no standardised way of collecting these data. A periodic survey of people who are registered with the NDSS could be considered.

## 3.5 Goal 5: Strengthen prevention and care through research, evidence and data

Diabetes has a significant impact on Australia's health and productivity, and research into the condition—including the basic science of the disease, its social and economic impacts, and appropriate clinical responses—is an important priority. Although Australia currently has multiple diabetes research funding streams, research efforts need to be further focused on strengthening evidence-based practice for the prevention of diabetes and its complications, identifying a cure for diabetes, informing health policy decisions, and potentially offering access to newer and improved medications. To achieve this, an internationally relevant and nationally coordinated Australian diabetes research agenda could be developed to focus, coordinate and translate research into clinical practice, and steps taken to develop new datasets (and enable linkages between existing datasets) that can inform population-based health decisions.

### 3.5.1 Areas for action

#### National research agenda

At present, a number of organisations fund diabetes research, including government bodies such as the Australian Research Council (ARC) and the NHMRC; non-government organisations such as the Diabetes Australia Research Trust (funded through Diabetes Australia), the Juvenile Diabetes Research Foundation (and its associated Australian Type 1 Diabetes Clinical Research Network) and the Australian Diabetes Society; and other private sector and philanthropic bodies. While each organisation makes a vital contribution to diabetes research, steps could be taken to better coordinate their efforts.

One possible step is the development of a nationally coordinated research agenda, designed specifically to coordinate diabetes research across multiple funding streams. This agenda could guide research on a range of relevant topics, including the basic science of diabetes, clinical practice, prevention, complications, implementation and translation, health service delivery, lifestyle changes, and the social, economic, demographic and environmental impacts of the disease. Working with the NHMRC and ARC, and with other funders and organisations, could identify current research activities, as well as areas in need of further research. Examples of priority areas for the national agenda could include:

- Identifying both the cause(s) of type 1 diabetes and how to cure, treat and prevent the condition (including research into the potential benefits of stem cell technology and islet cell transplantation)
- Identifying both the cause(s) of type 2 diabetes and ways to improve outcomes for people with the condition (including research that explores why certain medicines for type 2 diabetes work better in some individuals than in others, and how best to identify which people will respond favourably to these medicines)
- Preventing and managing type 2 diabetes in Aboriginal and Torres Strait Islander peoples, including children and adolescents
- Within the recognised legislative and privacy requirements, linking existing data sets, to provide de-identified aggregate data to understand how people develop diseases (including diabetes); how diseases progress under different preventive and treatment strategies; and how health dollars can be more efficiently and effectively focused
- Undertake health services research, to examine the barriers to best practice and the availability and access to appropriate health services with a view to developing specific ways to address and overcome these barriers.

## **Data linking**

Healthcare policies relating to chronic diseases such as diabetes should be informed by robust evidence generated for the Australian setting. Since 1992, every Australian who has consulted a doctor, had a medical test or been prescribed a medication has contributed to recorded health data. As a result, there are a number of existing datasets and databases, including the NDSS, the National Diabetes Register, the National Gestational Diabetes register, the Pharmaceutical Benefits Scheme, Medicare records, the AIHW, PCEHR, hospitals, and birth and death registries. Within the recognised legislative and privacy requirements, de-identified aggregate data derived from these linked datasets have the potential to provide valuable information about how people develop diseases (including diabetes); how diseases progress under different preventive and treatment strategies; and how health dollars can be more efficiently and effectively focused. Undertaking a regular national health survey that collects biomedical data (including diabetes data) every five years is also recommended in order to collect additional data that can inform and underpin health policy.

## **3.5.2 Potential ways to measure Australia's progress towards this goal**

### **Number of diabetes publications**

While it may be difficult to measure the true success of a national research agenda, possible proxies for the effect of such an agenda are the number of publications produced on diabetes research (and its translation into clinical practice) by Australian institutions plus the impact factor of each publication, which is a measure of how many times the article is cited by other scientists.

### **Progress against key milestones in developing national research agenda**

A set of milestones, in addition to the number of diabetes publications, could be created to monitor progress of the development of the national research agenda. These milestones are yet to be developed

### **Progress against key milestones in developing national datasets**

A series of milestones could be created in order to monitor progress toward meeting national dataset needs, and a regular national health survey that collects biomedical data (including diabetes data) could be undertaken every five years. Potential milestones are yet to be determined, however these may include the number of research studies accessing the datasets and should encompass evidence of progress toward implementing the National Diabetes Strategy.

## **NEXT STEPS**

Australia has an opportunity to further enhance its already excellent healthcare system and lead the way in diabetes care, prevention, management and research. This will require a coordinated effort from governments and other parts of the community including people with diabetes, health care professionals, researchers, families, carers, communities, and industry. It is hoped that this draft strategic framework and consultation process will provide a useful foundation for a National Diabetes Strategy that can inform and guide this important work.

This document is, first and foremost, a consultation paper, and the National Diabetes Strategy Advisory Group hopes that its contents elicit insights and feedback from across the country on how best to progress diabetes care in Australia. An online consultation process will open in April 2015, and this process will inform the development of a draft National Diabetes Strategy. The draft strategy will be considered by the Minister for

Health and then reviewed by the AHMAC and the COAG Health Council. The final National Diabetes Strategy is anticipated for release in late 2015.

## **NATIONAL DIABETES STRATEGY ADVISORY GROUP MEMBERS**

On December 2, 2013, the Minister for Health and Minister for Sport, the Hon. Peter Dutton MP, announced the formation of an Advisory Group to provide advice on all aspects of the National Diabetes Strategy development process.

The Advisory Group is co-chaired by the Hon. Judi Moylan and Professor Paul Zimmet AO.

Members of the National Diabetes Strategy Advisory Group are listed below:

- The Hon. Judi Moylan – President, Diabetes Australia
- Professor Paul Zimmet AO – Emeritus Director, Baker IDI Heart and Diabetes Institute
- Professor Stephen Colagiuri – Professor of Metabolic Health, Boden Institute of Obesity, Nutrition, Exercise and Eating Disorders, The University of Sydney
- Professor John McCallum – Head of Research Translation Group, National Health and Medical Research Council (Ms Samantha Robertson, Executive Director of Evidence, Advice and Governance Branch attended 2 meetings as Professor McCallum’s proxy)
- Professor Andrew Palmer – Head of Health Economics Research Unit, Menzies Research Institute Tasmania
- Professor Alex Brown – Indigenous Health Research Theme Leader, South Australian Health and Medical Research Institute
- Ms. Donna Ah Chee – Chief Executive Officer, Central Australian Aboriginal Congress
- Ms. Tracy Ayles – President, Australian Diabetes Educators Association
- Mr. Mike Wilson – Chief Executive Officer, Juvenile Diabetes Research Foundation
- Dr. Susan Alberti AO – Chairman, Susan Alberti Medical Research Foundation
- Mr. Nathan Smyth – First Assistant Secretary of the Population Health Division, Australian Government Department of Health

Expert advisors to the National Diabetes Strategy Advisory Group include:

- Professor Jeremy Oats – Professorial Fellow, Melbourne School of Population and Global Health, The University of Melbourne
- Professor Hugh Taylor AC – Chair, Indigenous Eye Health Unit, Melbourne School of Population and Global Health, The University of Melbourne
- Dr. Rob Grenfell – National Medical Director, BUPA Australia New Zealand
- Associate Professor Tim Mathew AM – Consultant Nephrologist and Medical Director, Kidney Health Australia

- Adjunct Professor Greg Johnson - Chief Executive Officer, Diabetes Australia and Adjunct Professor, Deakin University
- Professor Martin Silink AO – Professor of Paediatric Endocrinology, Institute of Endocrinology and Diabetes, The University of Sydney

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