



National Diabetes Strategy Advisory Group

A Strategic Framework for Action

Advice to Government on the Development of the Australian National Diabetes Strategy

2016–2020

August 2015

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Purpose of this document

The National Diabetes Strategy Advisory Group (NDSAG) prepared this document to provide advice to the Government as it develops its National Diabetes Strategy. It represents the collective expertise of the NDSAG and identifies areas for action to improve diabetes prevention and care. A paper was released for public consultation in May 2015 to seek submissions from individuals, families, communities, health care services and industry. This document incorporates feedback received during this consultation process along with NDSAG advice to inform the development of the National Diabetes Strategy.

The document has three sections: Section 1 explains why it is important to recognise diabetes as a national health priority, Section 2 provides background information on the development of the National Diabetes Strategy, and Section 3 introduces a strategic framework for action. This framework is built around 7 high-level goals that the National Diabetes Strategy seeks to achieve. The NDSAG has summarised the rationale behind each goal, identified priority areas for action and suggested metrics for measuring progress.

The National Diabetes Strategy seeks to prioritise Australia's response to diabetes and its complications and comorbidities, and to reduce the impact of diabetes in the community. Specifically, it aims to evaluate current approaches to diabetes services and care; maximise the efficient use of existing, limited health care resources; better coordinate health care resources across all levels of government; and focus resources where they are needed most. It will 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 Australian Government Minister for Health, the Australian Health Ministers' Advisory Council (AHMAC) and the Council of Australian Governments (COAG) Health Council will consider the proposed National Diabetes Strategy, which is anticipated for public release in late 2015.

Executive summary

Diabetes mellitus has become one of Australia's most significant health issues. This long-term condition affects at least 1.2 million Australians (as well as a further 1.5 million people with prediabetes), and it is the seventh and eighth leading cause of death in females and males, respectively. It is also the fourth largest contributor to the overall disease burden in Australia.³ The costs associated with diabetes are substantial, with estimated total annual costs of \$14.6 billion.

There are three recognised forms of diabetes mellitus: type 1 diabetes, type 2 diabetes and gestational diabetes. All three forms of diabetes are increasing in prevalence, and all three are addressed in this Strategic Framework for Action.

Addressing the challenge of diabetes and reversing Australia's underlying diabetes epidemic requires a multidisciplinary, coordinated approach across a number of sectors and involving all levels of government, including health, finance, education, research, sport, food production and manufacturing. The new National Diabetes Strategy will prioritise a national response to diabetes and guide potential health care reforms for diabetes and related disorders.

To assist with the development of this strategy, a National Diabetes Strategy Advisory Group (NDSAG) was established to provide expert policy advice on diabetes prevention and care, in consultation with key stakeholders and the Australian Health Ministers' Advisory Council. The NDSAG recognises that Australia is a diverse nation (with some 5.5 million people born overseas, in over 200 different countries) and the advice it presents acknowledges and reflects this diversity.

The NDSAG has defined 7 high-level goals for the National Diabetes Strategy:

- **Goal 1. Reduce the number of people developing type 2 diabetes.** In order to achieve this goal, the National Diabetes Strategy will need to promote a population-based approach to diabetes prevention that encourages and enables healthier lifestyles. Community-based action is recommended, including efforts to reduce the risk determinants of diabetes and related chronic disorders among adults, adolescents and children; preventative interventions for people at high risk of developing diabetes (e.g., a nationally coordinated detection and intervention programme for prediabetes); and improved pre-conception health and care during and after pregnancy.
- **Goal 2. Promote earlier detection of type 1 and type 2 diabetes.** This goal will facilitate earlier diagnosis—and therefore earlier treatment—for people with all forms of diabetes, which, in turn, will reduce their chances of developing serious and sometimes life-threatening complications. For people with type 1 diabetes, for example, early recognition and diagnosis of diabetic ketoacidosis could be lifesaving. To achieve this goal, early detection must be promoted, improved and documented, and health providers and the community must be better 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.** The majority of diabetes-related complications are potentially preventable, including diabetic ketoacidosis in people with type 1 diabetes. Reducing the occurrence of these complications requires a well-coordinated and integrated primary health care system, which facilitates early diagnosis and treatment and prevents complications. This should include pathways, programmes, monitoring and reporting across Primary Health Networks and the broader health care system, encompassing eye damage and blindness, cardiovascular disease and strokes, kidney damage, amputations and mental health issues. To support this, care delivery should be transformed to become more consumer focused, team-based and proactive, and Primary Health Networks should identify efficient and effective care coordination for people with diabetes as one of their key priorities. Areas for action include (among others)

involving people with diabetes as active participants in their own care, establishing a set of nationally agreed clinical guidelines, implementing quality improvement processes, continuing investment in electronic health and technologies, and implementing innovative funding models. Improved pathways for accessing new therapies and technologies should also be developed.

- **Goal 4. Reduce the impact of diabetes among Aboriginal and Torres Strait Islander peoples.** Australia's Indigenous community has one of the highest rates of diabetes and its complications, both nationally and globally. In order to reduce the impact of diabetes among Aboriginal and Torres Strait Islander peoples, culturally relevant programmes (developed in collaboration with the communities) must be developed and implemented to improve health literacy, as well as education and awareness about diabetes. To prevent diabetes and improve diabetes management, it is important to ensure that Aboriginal and Torres Strait Islander communities have access to, and can benefit from, diabetes support, education and services as integral parts of their primary health care services, especially through Aboriginal Community Controlled Health Services (where they exist). Food security, healthier choices and lifestyle changes also need to be encouraged and facilitated, and family and child health need to be improved through pregnancy and early years programmes.
- **Goal 5. Reduce the impact of diabetes among high-risk and vulnerable groups.** This goal is directed at culturally and linguistically diverse people, older Australians and people living in remote and rural areas, all of whom are at higher risk of developing type 2 diabetes and its complications. 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. Areas for action to achieve this goal 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 6. Reduce the impact of pre-existing and gestational diabetes in pregnancy.** Diabetes places women and their children at significant risk during and after pregnancy, and fetal and infant death is 4 times more likely among women who have diabetes prior to pregnancy. It is important that steps are taken to mitigate this risk prior to pregnancy (through pre-conception care), during pregnancy and following delivery. All pregnant women should be screened for gestational diabetes, and women with a history of gestational diabetes—who are at high risk of developing diabetes in the future—should be provided with health and lifestyle advice.
- **Goal 7. Strengthen prevention and care through research, evidence, data and national oversight.** In order to implement evidence-based practices and make informed health policy decisions, Australia needs to progress diabetes research and support access to effective new technologies. This can be achieved by establishing a national research agenda that focuses, coordinates and translates research into clinical practice, and by utilising and developing data sets (and building connectivity between existing data sets) that can inform population-based decision making and facilitate the prevention and management of diabetes.

Table 1 summarises the rationale for these goals, the associated areas for action and potential metrics for measuring Australia's progress towards these goals.

Our nation has an opportunity to lead the way in diabetes care, prevention, management and research, and it is hoped that this Strategic Framework for Action provides a useful foundation for the National Diabetes Strategy and can inform and guide this important work. The NDSAG recommends establishing a National Diabetes Commission to oversee, report on and integrate national diabetes activities, and to provide leadership to ensure that all Australians with or at risk of diabetes achieve the best possible attention and outcomes.

TABLE 1. Summary of the strategic framework for the National Diabetes Strategy

Goal	Some key areas for action	Some potential metrics to measure progress towards this goal
1. Reduce the number of people developing type 2 diabetes	<ul style="list-style-type: none"> ■ Reduce the prevalence of modifiable risk factors in the general population ■ Identify and provide prevention programmes to high-risk individuals 	<ul style="list-style-type: none"> ■ The number & percentage of the population developing diabetes ■ The percentage of the population that is overweight or obese & has other modifiable risk factors ■ The number of local government authorities that develop healthy community environment plans and targets
2. Promote earlier detection of type 1 & type 2 diabetes	<ul style="list-style-type: none"> ■ Increase recognition of type 1 diabetes & its presentation among health care providers and the community ■ Improve detection for type 2 diabetes in primary care 	<ul style="list-style-type: none"> ■ The percentage of people with type 1 diabetes who present with diabetic ketoacidosis on diagnosis ■ The number of people screened for risk of diabetes annually
3. Reduce the occurrence of diabetes-related complications & improve quality of life among people with diabetes	<ul style="list-style-type: none"> ■ Develop nationally agreed clinical guidelines, local care pathways & complication prevention programmes ■ Expand consumer engagement & self-management ■ Develop & implement quality improvement processes ■ Utilise information & communication technology ■ Improve affordable access to medicines & devices ■ Develop, expand & improve workforce capacity ■ Provide mental health care for people with diabetes ■ Strengthen and expand transition from child to adult services ■ Provide high-quality hospital care for people with diabetes 	<ul style="list-style-type: none"> ■ The percentage of people with diabetes who receive screening for complications & complete the Annual Cycle of Care ■ The percentage of people with diabetes who achieve target levels of HbA1c, cholesterol, albuminuria & blood pressure ■ The incidence of complications in people with diabetes ■ The number of hospitals implementing quality standards for the management of diabetes
4. Reduce the impact of diabetes among Aboriginal & Torres Strait Islander peoples	<ul style="list-style-type: none"> ■ Establish & fund pre-conception, pregnancy & early years programmes ■ Develop, fund & implement a national diabetes prevention programme designed specifically for Aboriginal & Torres Strait Islander people, including early identification ■ Develop, fund & implement community-wide interventions to increase the availability, affordability & consumption of fresh foods ■ Enhance the resourcing of primary health care services to better identify and manage diabetes (including among adolescents and children), and increase opportunities for people with diabetes to better self-manage the condition ■ Provide stimulating early years education & intervention 	<ul style="list-style-type: none"> ■ The percentage of pregnant women diagnosed with gestational diabetes ■ The number of new cases of diabetes diagnosed each year among Aboriginal & Torres Strait Islander peoples ■ The incidence of complications among people with diabetes from Aboriginal and Torres Strait Islander communities ■ The percentage of people with diabetes from Aboriginal and Torres Strait Islander communities with above-target HbA1c, albuminuria, cholesterol or blood pressure ■ The percentage of people with diabetes from Aboriginal and Torres Strait Islander communities who receive annual testing for complications ■ Rates of smoking and alcohol consumption among pregnant women with diabetes ■ The cost of a healthy food basket, monitored to assess the availability and

Goal	Some key areas for action	Some potential metrics to measure progress towards this goal
	programmes, which help to address developmental vulnerabilities & the social & environmental determinants of Aboriginal & Torres Strait Islander health	<p>affordability of foods required for a healthy diet</p> <ul style="list-style-type: none"> ■ The number of Aboriginal and Torres Strait Islander children participating in evidence-based early childhood education programmes
5. Reduce the impact of diabetes among high-risk & vulnerable groups	<ul style="list-style-type: none"> ■ Improve health literacy through the dissemination of culturally appropriate information & programmes for the management & care of diabetes ■ Develop, roll out, evaluate & adapt a culturally and linguistically appropriate diabetes education package to ensure the successful transfer of information on diabetes prevention & management ■ Promote the adoption and implementation of relevant guidelines on managing diabetes in older people to inform care and clinical decision making across health and aged care settings ■ Coordinate regional services across primary, secondary & tertiary care to ensure access to care & the necessary support services 	<ul style="list-style-type: none"> ■ The number & percentage of people in high-risk communities who develop diabetes each year ■ The percentage of people with diabetes in high-risk groups with above-target HbA1c, cholesterol, albuminuria & blood pressure ■ The percentage of people in high-risk groups who are either overweight, obese or have other modifiable risk factors ■ The number of people in these high-risk groups who receive annual testing for complications ■ Trends in hospital admissions among older people with diabetes
6. Reduce the impact of pre-existing & gestational diabetes in pregnancy	<ul style="list-style-type: none"> ■ Provide accessible prepregnancy programmes to identify & address risk factors that may result in adverse outcomes ■ Ensure that all pregnant women are appropriately screened for diabetes ■ Ensure that all women with known diabetes receive prepregnancy programmes & advice ■ Ensure that women with previous gestational diabetes receive counselling regarding their future risk of diabetes ■ Provide paediatric follow-up for at-risk children (e.g., children of mothers with GDM or obesity) 	<ul style="list-style-type: none"> ■ The percentage of pregnant women with diabetes whose HbA1c is measured in the first and third trimester ■ The percentage of mothers with gestational diabetes whose OGTT is retested at 2 years postpartum ■ Data from the NDSS National Gestational Diabetes Register ■ The perinatal and infant mortality rates of children of mothers with diabetes
7. Strengthen prevention & care through research, evidence, data & national oversight	<ul style="list-style-type: none"> ■ Develop a national research agenda ■ Improve and expand data linkage and facilitate ease of access ■ Establish a National Diabetes Commission 	<ul style="list-style-type: none"> ■ Progress against key milestones in developing a national research agenda ■ The number, completeness & coverage of national data sets documenting the burden, health system use, management & complications of diabetes ■ The estimated completeness & coverage of the NDSS database, as well as yearly registrations ■ Progress towards establishing a national diabetes database ■ Development of a mechanism for monitoring & ensuring implementation of the National Diabetes Strategy

Abbreviations

AIHW	Australian Institute of Health and Welfare
AHMAC	Australian Health Ministers' Advisory Council
ARC	Australian Research Council
AusDiab	Australian Diabetes Obesity and Lifestyle Study
CALD	Culturally and linguistically diverse
COAG	Council of Australian Governments
DKA	Diabetic ketoacidosis
eHealth	Electronic health
GDM	Gestational diabetes mellitus
GP	General practitioner
HbA1c	Glycated haemoglobin
IDF	International Diabetes Federation
IFG	Impaired fasting glucose
IGT	Impaired glucose tolerance
NDSAG	National Diabetes Strategy Advisory Group
NDSS	National Diabetes Services Scheme
NHMRC	National Health and Medical Research Council
OGTT	Oral glucose tolerance test
PBS	Pharmaceutical Benefits Scheme
PHNs	Primary Health Networks
WHO	World Health Organization

1. An urgent need for a national strategy—the challenge of diabetes

Diabetes mellitus is a chronic disorder characterised by high blood glucose (sugar) levels. The condition can lead to serious complications, including diabetes-related eye disease (leading to blindness), kidney and heart disease, stroke, and peripheral nerve and vascular damage (leading to amputations) (Figure 1).¹

There are three types of diabetes, as well as an intermediate category known as prediabetes (which exists between normal glucose tolerance and diabetes):

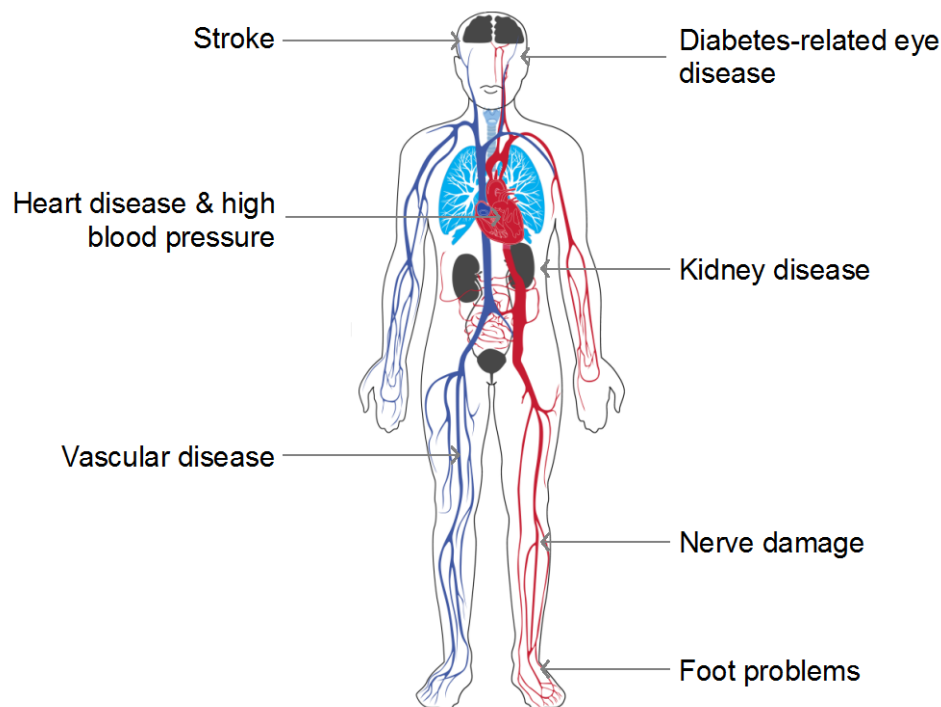
- **Type 1 diabetes.** This autoimmune condition causes the immune system to destroy cells in the pancreas that produce insulin. It is one of the most common chronic diseases in children, and most cases develop in children, teenagers and young adults (although the condition can occur at any age). There is no cure, and people with type 1 diabetes require daily treatment with insulin for survival. Approximately 120,000 Australians have been diagnosed with type 1 diabetes (approximately 10% of Australians with diabetes).² A 2014 report from the Australian Institute of Health and Welfare (AIHW) highlighted that Australia has the sixth highest incidence of type 1 diabetes in children aged 0 to 14 years (compared with other countries in the Organisation for Economic Co-operation and Development).² An average of 6 new cases of type 1 diabetes are diagnosed in Australia every day. At present, efforts to prevent and cure type 1 diabetes are hampered by a lack of understanding around its causation.
- **Type 2 diabetes.** This is the most common form of diabetes, accounting for 85% of people with diabetes.³ It is characterised by the progressive failure of insulin production in the pancreas, as well as the resistance of body tissues to insulin action. People with type 2 diabetes may not experience any symptoms for some years. Type 2 diabetes can usually be managed with diet, physical activity and oral medication, but 24% of people with type 2 diabetes require insulin therapy. In the past, type 2 diabetes was typically diagnosed after 50 years of age, but diagnosis in younger adults, adolescents and even children is becoming increasingly common.⁴ 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 research highlights that a healthy environment inside a mother's womb and during the first few years of life can decrease a child's chance of developing type 2 diabetes and obesity as an adult.⁵
- **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 subsequently remain at significant risk of developing diabetes. Approximately 13% of pregnant women will develop GDM,⁶ which equated to approximately 40,000 women in 2012.⁷ GDM requires careful control of blood glucose levels during pregnancy to avoid complications in 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.⁵
- **Prediabetes.** This condition is characterised by blood glucose levels that are higher than normal but not sufficiently high to diagnose type 2 diabetes. People with prediabetes have impaired fasting glucose (IFG) and/or impaired glucose tolerance (IGT).¹ The Australian Diabetes and Obesity Lifestyle Study (AusDiab) found that 16.4% of adults over the age of 25 have prediabetes—approximately 2.5 million people.⁸ People with prediabetes are at higher risk of developing type 2 diabetes and cardiovascular disease.¹ Between 15% and 30% of people with prediabetes are likely to develop type 2 diabetes within five years.⁹

Diabetes often occurs alongside (and shares risk factors with) other chronic diseases, including heart disease and chronic kidney disease.¹⁰ Many of the strategies for preventing diabetes and improving patient outcomes are common across chronic diseases,^{11,12} and coordination and cooperation in chronic disease management could assist in maximising the use of Australia's resources.

Diabetes complications can be prevented or delayed, either by preventing people from getting diabetes in the first place, or by optimising how the health system supports people who already have diabetes.

In addition to the complications shown in Figure 1, diabetes is associated with mental health disorders,¹³ periodontal disease¹⁴ and fatty liver.¹⁵

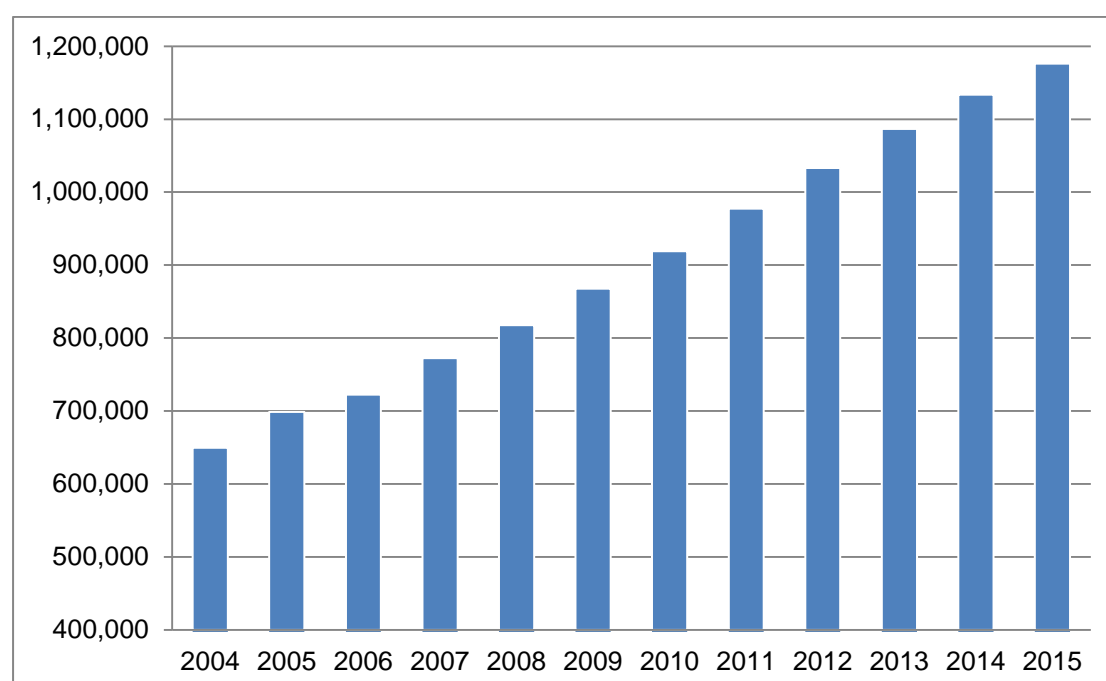
FIGURE 1. Major complications of diabetes



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 1.2 million Australians are living with the disease. At present, the best estimates come from three sources: the National Diabetes Services Scheme (NDSS);¹⁶ the Australian Health Survey (National Health Measures Survey, 2011–13);¹⁷ and the AusDiab study (1999–2000).⁸ The Australian Health Survey found that, using HbA1c (glycated haemoglobin) as the measure, 5.4% of the population over the age of 18 had diabetes, which translates to almost 1 million people.¹⁷ AusDiab used an oral glucose tolerance test (OGTT) to estimate that 7.5% of Australians over the age of 25 have diabetes, which equates to approximately 1.2 million people.⁸ A similar estimate comes from the NDSS, which has registered 1.2 million people with diabetes and gains an extra 277 people every day (Figure 2).¹⁶ However, it is likely that all three sources underestimate the total number of people affected by diabetes for the following reasons. Firstly, the AusDiab study excluded children. Secondly, registration with the NDSS is voluntary, and it is likely that a considerable number of people with diabetes are not registered. Thirdly, AusDiab was conducted 14 years ago and there has since been a considerable increase in the proportion of people who are overweight and obese and therefore at risk of diabetes.

FIGURE 2. The number of people registered with the NDSS, 2004–2015¹⁶



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

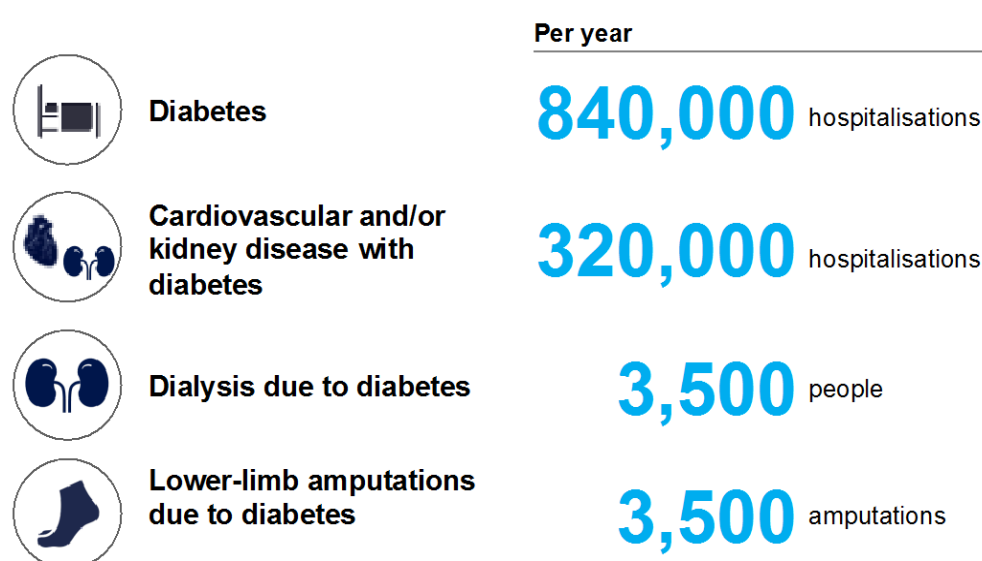
Australia has enormous cultural and social diversity, and while diabetes is increasingly common across the country, it is particularly problematic within certain communities. As with the general population, it is difficult to estimate the exact number of Aboriginal and Torres Strait Islander people with 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% to 33.1%.¹⁸ The Indigenous component of the Australian Health Survey (National Aboriginal and Torres Strait Islander Health Survey, 2012–13) found that 20.4% of Aboriginal and Torres Strait Islander people over 25 years of age have diabetes.¹⁹ This compares with rates of between 5.5% and 7.5% of the general population in the same age group, taken from the Australian Health Survey¹⁷ and AusDiab study,⁸ respectively. These figures indicate a 3-fold increase in prevalence and demonstrate that Aboriginal and Torres Strait Islander peoples experience a disproportionate share of the burden of diabetes in Australia as a result of their considerably higher diabetes rate.

There are several other groups that are also at 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.²⁰ Older Australians also have higher rates of diabetes (particularly type 2 diabetes) and experience higher rates of disability associated with the disease.²⁰ People living in rural and remote communities have more difficulty accessing health services to manage their diabetes. For example, in 2013–14, nearly 1 in 3 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 1 in 5 people who live in major cities.²¹ People who are being treated for mental health disorders such as depression, anxiety and schizophrenia may also be at higher risk of diabetes, brought about by psychotropic medications and resulting weight gain.^{20,22}

1.3 The impact of diabetes on Australia's health

Diabetes has a significant, yet potentially preventable, impact on the health and wellbeing of the Australian population. In 2011, diabetes was the underlying cause of 3% of all deaths and an underlying or associated cause of 10% of all deaths.¹⁰ In 2003, it was the fourth largest contributor to the overall disease burden in Australia.²³ There are a significant number of diabetes-related complications, including heart attacks, strokes, limb amputations, blindness, kidney failure, nerve damage and depression. Many of these complications are preventable. Figure 3 outlines the annual impact of diabetes on Australia's health, including hospitalisations and some of the major complications.

FIGURE 3. Annual impact of diabetes complications on Australia's health²⁴



People with diagnosed diabetes (approximately 5% of Australians) account for 12% of total health care costs in Australia. For type 1 diabetes, total direct costs amount to a minimum of \$570 million per annum: \$4,669 annually for a person with no complications, rising to \$16,698 per annum once complications develop.²⁵ Type 2 diabetes costs at least \$14.6 billion annually, 42% of which is attributed to direct medical costs. These costs are projected to increase to \$30 billion by 2025.²⁶ The total medication cost for treating diabetes has also been increasing in Australia over time. The cost for oral medications and insulin on the Pharmaceutical Benefits Scheme (PBS), for example, has risen from around \$540 million per year in 2000 to \$720 million per year in 2013.²⁷ Both type 1 and type 2 diabetes are chronic conditions for life, and their impact on costs reflects this.

Diabetes also has a significant social and economic impact on carers and families who support people with diabetes. Macroeconomic costs include reduced productivity, absenteeism, early retirement, premature mortality and bereavement.²⁶ Costs that contribute to the financial impact of diabetes (on both the individual and the family) include those associated with self-monitoring blood glucose, insulin needles, pump consumables, therapeutic footwear, and so on (although some of these items are subsidised by significant government funding through the NDSS).

Diabetes is also associated with a number of serious and expensive comorbidities, including obstructive sleep apnoea,²⁸ fatty liver leading to cirrhosis,¹⁵ and erectile dysfunction.²⁰ Surveys show that 22–35% of Australian adults with diabetes experience moderate to severe depressive symptoms, while 14–19% experience moderate to severe anxiety symptoms.²⁹ These comorbidities all contribute to the socio-economic cost of diabetes.

1.4 Opportunities to improve care integration and self-management

Diabetes is a complex chronic condition, and people living with the disease should be encouraged and supported to optimally manage their diabetes on a day-to-day basis. New technologies, information exchange and connectivity, and communities and workplaces can play a role in achieving this goal. It is also important to recognise the link between diabetes management and broader chronic disease management, given that many people with diabetes also live with or share risk factors for other chronic diseases such as heart disease, stroke, kidney disease, mental health, dementia and cancer.

While the overall level of care provided in Australia is high by international standards, there are a number of opportunities to improve diabetes care. These include:

- **Delivering person-centred care and sharing decision making.** Optimal health and wellbeing can only be achieved and sustained when people with diabetes are involved as active and empowered partners in their own diabetes care.^{30,31}
- **Increasing the proportion of people with diabetes who receive care in accordance with the recommended clinical guidelines.** In 2009–10, only 18% of Australians with diabetes had a claim made by their general practitioner (GP) for an Annual Cycle of Care (which signifies completion of a series of up to 12 steps, including HbA1c measurement, an eye examination, blood pressure measurement and a feet check).³² It has also been estimated that the relevant clinical guidelines are not followed in 37% of diabetes-related clinical encounters.³³
- **Increasing the proportion of people with diabetes who achieve the recommended clinical targets.** In 2011–12, 45% of Australian adults with known diabetes did not achieve the recommended glycaemic targets, almost two thirds had high blood pressure, and 87% had a body mass index (BMI) above the recommended range.¹⁷
- **Improving the quality and coordination of care.** Australians with chronic disease experience gaps in care coordination: 55% have experienced gaps in hospital or surgery discharge planning, 34% reported that a pharmacist or doctor had not reviewed their medication in the past year, and 19% have seen a specialist who did not have access to their medical history, or have a regular doctor who is not adequately informed about specialist care they are receiving.³⁴

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

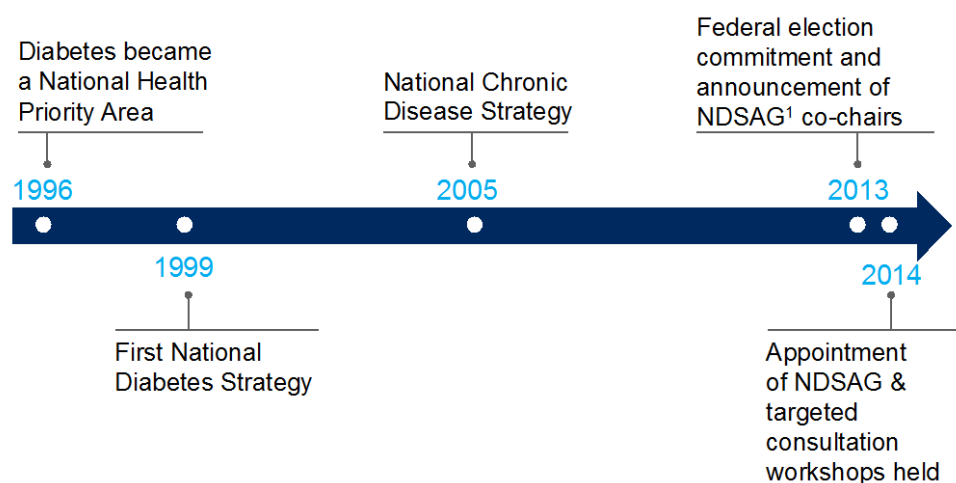
The National Diabetes Strategy seeks to prioritise Australia's response to diabetes, and to identify approaches to reducing the impact of diabetes in the community.

2.1 Key national milestones

Diabetes first became a National Health Priority Area in 1996. (Timelines for further key milestones in diabetes-related activities are shown in Figure 4.) Australia was one of the first nations to introduce universal, government-supported assistance for self-monitoring blood sugar and self-management (through the NDSS), and it remains an international leader in diabetes research and care today. 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 prevention and 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. The timeline for key national milestones in diabetes



¹ 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 health care resources

- Articulate a vision for preventing, detecting, and managing diabetes, and for guiding diabetes research efforts
- Better coordinate health resources across all levels of government and focus them where they are needed most
- Incorporate the approach adopted in the World Health Organization's 2013 Global Action Plan for the Prevention and Control of Non-Communicable Diseases¹¹ and Global Monitoring Framework for Non-Communicable Diseases¹²
- Determine how best to facilitate coordinated, integrated and multidisciplinary care; improve utilisation of primary health care services; and increase recognition of patient needs across the continuum of care.

The resulting strategy will form part of the Government's overall strategic framework for managing chronic disease, which recognises that shared health determinants, risk factors and comorbidities exist across a broad range of chronic conditions (including diabetes and heart and kidney disease).

As a first step towards developing the National Diabetes Strategy, the Minister for Health, the Hon. Peter Dutton MP, announced the formation of a National Diabetes Strategy Advisory Group at the World Diabetes Congress in December 2013. Co-chaired by the Hon. Judi Moylan and Professor Paul Zimmet AO, this Advisory Group brings together experts with a wide range of experience in diabetes-related health care, research and population health, as well as links with key stakeholders. Advisory Group members were tasked with identifying a strategic framework for action (presented in this paper) to inform and guide potential reforms in diabetes care over the coming years.

It is important to note that reforms will take place within a health care system that is undergoing change, and that 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 Primary Health Networks
- The implementation of electronic health records (My Health Record)
- A post-market review of products used in the management of diabetes and subsidised under the PBS
- The evaluation of (and any actions resulting from) the Diabetes Care Project
- The development of a new national strategic framework for chronic disease, revising the 2005 National Chronic Disease Strategy.

The progress and outcomes of these activities will remain critical to implementation of a National Diabetes Strategy.

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 health care, 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 health care 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 (e.g., kidney and heart health, eye and foot complications)
 - Focus on those most at risk (e.g., 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 the 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 NDSAG met 4 times during 2014. Between August and October 2014, 7 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.

A consultation paper was prepared to guide and inform an online public consultation process, which took place in April 2015. The NDSAG received over 400 submissions, including submissions from key stakeholders (e.g., state and territory health officials, local governments, participants in the face-to-face consultation workshops, other organisations and stakeholders who registered their interest with the secretariat). (See Appendix for a summary of key comments from those who participated in the consultation process.)

3. Key goals for a national diabetes strategy for Australia

3.1 Goal 1: Reduce the number of people developing type 2 diabetes

Rationale

Comprehensive national diabetes prevention programmes seek to reduce the number of people developing type 2 diabetes. They identify people at high risk for type 2 diabetes, including those with prediabetes, GDM³⁵ and the metabolic syndrome.³⁶ This can be achieved through screening, which has proved particularly effective among people with prediabetes.³⁷ AUSDRISK is the current recommended screening tool for identifying people at high risk of developing type 2 diabetes.³⁸ Individual risk factors can be non-modifiable, such as age or a family history of type 2 diabetes. However, once people have been identified as high risk for type 2 diabetes, steps can be taken to address modifiable risk factors (Table 2) and action taken to reduce the risk of developing type 2 diabetes.

These programmes also promote a broader healthy lifestyle approach among the general community in order to:

- Reduce the onset of type 2 diabetes and its complications and comorbidities
- Improve health outcomes in the community and reduce obesity and related risk factors.

Reducing the prevalence of diabetes requires a population-level intervention—similar to the intervention recommended for tackling obesity in *Australia: The Healthiest Country by 2020*³⁹—and programmes that target high-risk individuals must also reach into the community in order to have a meaningful overall impact. While high-risk intervention currently has a stronger evidence base, there is widespread support for whole-population programmes as a means of reducing the prevalence of diabetes across the community.^{39,40} It is therefore important that the National Diabetes Strategy adopts a community and workplace-based approach to reducing modifiable risk factors (Table 2) for the entire population, in addition to focusing on adults at high risk of diabetes, as well as adolescents and children (the age of onset for diabetes now extends to these age groups).

TABLE 2. Potentially modifiable risk factors for type 2 diabetes

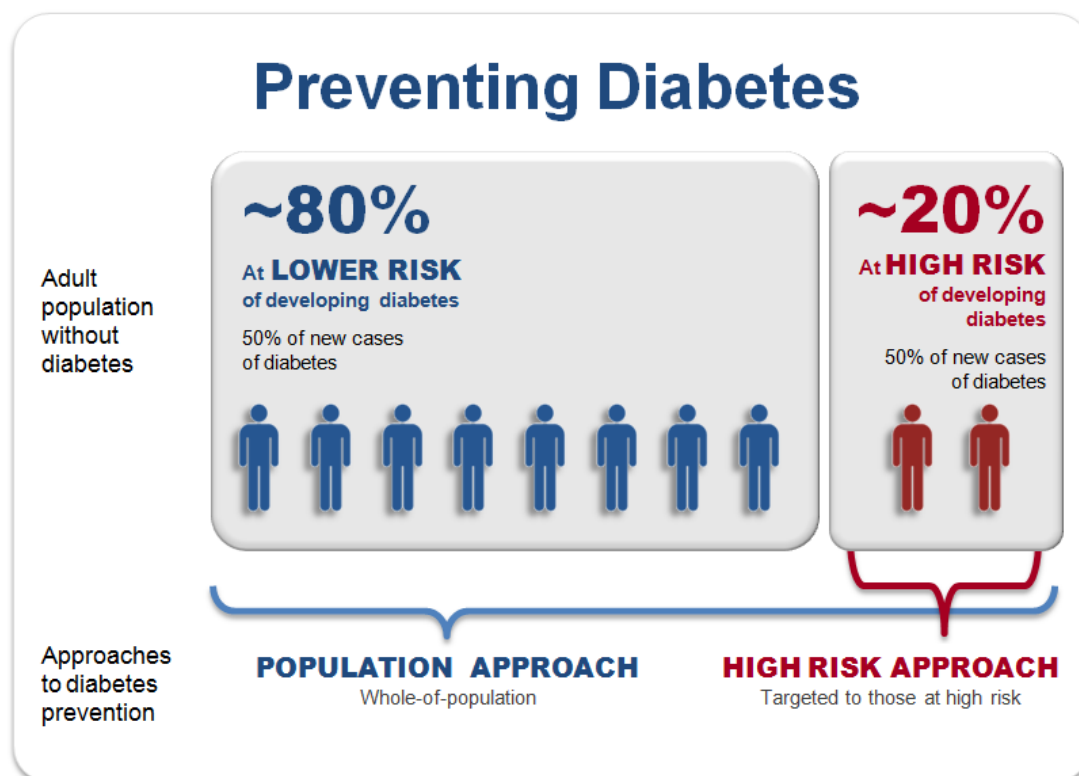
Potentially modifiable risk factors
<ul style="list-style-type: none">■ Overweight and obesity, including increased waist circumference■ Sedentary behaviour■ Physical inactivity■ Poor nutrition■ Impaired glucose tolerance (IGT) or impaired fasting glucose (IFG)■ Intrauterine environment and early life nutrition■ Smoking*■ Alcohol*

*While there is still debate on whether smoking and alcohol are modifiable risk factors, their unfavourable influence on chronic disorders, including diabetes, justifies their inclusion.

A community-based approach targets the following three groups:

- **The general population.** In order to reduce the prevalence of diabetes, Australia must focus its efforts on improving the Australian diet and encouraging Australians to undertake more physical activity and lead a less sedentary lifestyle. Reducing overweight and obesity across the general population is a high priority. A relatively small reduction in weight (approximately 5%) has been shown to successfully reduce the risk of developing diabetes in individuals who are overweight or obese.⁴¹
- **Adults at high risk of developing diabetes.** Approximately 20% of the adult population is considered to be at high risk of developing diabetes. This group is expected to account for 50% of new diabetes diagnoses over the next decade (Colagiuri S, AusDiab unpublished analysis), with the remainder of the population accounting for the remaining 50% (Figure 5). For women with a past history of GDM in Australia, the risk of developing type 2 diabetes within 15 years is 26%.⁴² People on medications such as anti-psychotics²² and steroids¹ could also be included in this category as these are considered potentially modifiable risk factors.
- **Children.** It is critical that all Australian children are given the best possible start in life. There is increasing evidence that pre-conception maternal health, the intrauterine environment and a child's first few years of life have a significant impact on the risk of developing diabetes and obesity as an adult.⁵ There is also evidence to suggest that breastfeeding reduces the risk of diabetes, overweight and obesity in people who are breastfed as babies.⁴³ 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 in Section 3.1.1.)

FIGURE 5. Approaches to type 2 diabetes prevention: Population and high-risk interventions.



3.1.1 Areas for action

Reduce the prevalence of modifiable risk factors in the general population

Reducing overweight, obesity and other modifiable risk factors across the population is a difficult task, and there is no single solution.^{40,44} The prevention of obesity and type 2 diabetes requires coordinated policy and possibly regulatory changes, including greater attention to the urban environment, transportation infrastructure, health education, and opportunities for improved nutrition and increased physical activity.^{39,40,44} A multidisciplinary, coordinated approach across health, finance, education, sport, agriculture and the food industry sectors can contribute towards reversing the underlying causes of diabetes. The National Diabetes Strategy should therefore 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.

These issues were addressed in detail in the recommendations of the 2009 Preventative Health Taskforce report—*Australia: The Healthiest Country by 2020*³⁹—and implementation of these recommendations should be prioritised. In addition, it is important that Australia evaluates the effectiveness of current initiatives in obesity and type 2 diabetes prevention, and develops a comprehensive, systems-based national diabetes prevention programme that includes and emphasises the following actions:

- Drive change to support a healthier environment, which encourages people to increase levels of physical activity and reduce sedentary activity.
- Embed physical activity and healthy eating in everyday life (e.g., workplaces, schools and communities).
- Launch education and social media campaigns to encourage people to increase their levels of physical activity and healthy eating (e.g., a campaign to educate parents about nutrition and physical activity).
- Increase the availability of and demand for healthier food, and reduce the availability of and demand for unhealthy food (including through continued implementation of targeted education, such as front-of-pack labelling and the Health Star Rating System).
- Reduce the exposure of children and others to marketing, advertising, promotion and sponsorship of energy-dense, nutrient-poor foods and beverages (e.g., through voluntary or compulsory advertising codes of conduct).
- Strengthen, upskill and support the primary health care and public health workforce to support people making healthy choices, especially in Aboriginal Community Controlled Health Services (where they exist).
- Address maternal, family and child health, enhancing early life and growth patterns.
- Identify people at high risk and provide prevention programmes.

Identify and provide prevention programmes to high-risk individuals

Evidence-based interventions exist, are effective and should be considered for high-risk groups. Interventions include structured group programmes, telephone and web-based programmes, medications and (where appropriate) bariatric surgery.³⁵

3.1.2 Potential ways to measure Australia's progress towards this goal

- **The number and percentage of the population developing diabetes.** Conduct a periodic survey of the population every 5 years along the lines of the Australian Health Survey;¹⁷ strengthen use of the NDSS database (by allowing people to decide whether

their data can be used for research purposes on an opt-out basis); and improve NDSS registration among Aboriginal and Torres Strait Islander peoples.

- **The percentage of the population that is overweight or obese or has other modifiable risk factors.** Conduct a periodic survey of the population, as suggested above.
- **The number of local government authorities that develop healthy community environment plans and targets.**

3.2 Goal 2: Promote earlier detection of type 1 and type 2 diabetes

Rationale

Type 1 diabetes: Failure to recognise the early symptoms of type 1 diabetes (such as severe fatigue and thirst) can lead to diabetic ketoacidosis (DKA).⁴⁵ This is an acute, life-threatening complication with abnormally high blood glucose levels, which often requires hospitalisation and can lead to organ damage, coma or death. The International Diabetes Federation (IDF) Life for a Child Programme has introduced a campaign to alert health professionals to the signs and symptoms of diabetes so that they can make a swift diagnosis of DKA and save lives.⁴⁶

Approximately 20–25% of people who are newly diagnosed with type 1 diabetes only learn about the diagnosis of diabetes upon presenting to hospital with unrecognised symptoms and signs of DKA. Data from Western Australia (Jones T, personal communication, 2014) and New South Wales suggest that approximately 25% of people with type 1 diabetes present with DKA.⁴⁷

Type 2 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 diabetes.^{8,17} People with undiagnosed type 2 diabetes are unaware of their condition and therefore are not receiving the necessary treatment. They may already have complications from their diabetes. This has serious health implications.

3.2.1 Areas for action

Increase recognition of type 1 and type 2 diabetes and its presentation among health care providers and the community

Type 1 diabetes

Increasing awareness and recognition of the symptoms and signs of type 1 diabetes facilitates early diagnosis. This can prevent the onset of DKA and reduce the serious consequences of undiagnosed type 1 diabetes. Actions to support early diagnosis of type 1 diabetes include:

- Educating primary health care practitioners to recognise the symptoms and signs of type 1 diabetes
- Educating the community—including parents, teachers and others involved in the care of children—to recognise the symptoms and signs of type 1 diabetes.

Type 2 diabetes

Actions to support improved early detection of type 2 diabetes include:

- Establishing a nationally coordinated detection programme for high-risk individuals, using the AUSDRISK screening tool. The programme could also include integrated social marketing initiatives.
- Establishing multiple avenues for the dissemination of AUSDRISK, including PHNs, general practice clinical care software, community health centres, community pharmacies, optometrists, dentists and online health services in state and federal health departments, relevant non-governmental organisations, health information sites such as Better Health Channel, the e-health system and phone apps.
- Promoting increased use of the AUSDRISK screening tool among all age groups. This may require further calibration of the tool for different age ranges.
- Integrating the AUSDRISK screening tool with risk assessment for other chronic conditions, including absolute cardiovascular and kidney disease risk. Attention should focus on those with a previous high AUSDRISK risk score, women who are planning a pregnancy, people from at-risk communities (including Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse communities), and those with a strong family history of type 2 diabetes.
- Educating primary health care practitioners about who should be screened.
- Establishing a national diabetes risk line (similar to Quitline for tobacco) to encourage people to access information on prevention, as well as available services, if they are at risk of developing diabetes.
- Reviewing screening methods (e.g., the use of HbA1c in the screening algorithm procedure).

3.2.2 Potential ways to measure Australia's progress towards this goal

- **The percentage of people with type 1 diabetes who present with diabetic ketoacidosis on diagnosis.** At present, there is no national tracking of the percentage of people diagnosed with type 1 diabetes who present at hospital with DKA. In the short term, data from Western Australia and New South Wales could be used to monitor progress towards this goal, but a national register should be considered.
- **The number of people screened for risk of diabetes annually.** Measuring progress on the number of people screened for risk of diabetes on an annual basis is likely to be difficult. However, potential methods include:
 - Counting the number of people who use the AUSDRISK screening tool
 - Conducting serial population surveys (as suggested in Section 3.1.2) to ascertain the ratio of diagnosed to undiagnosed diabetes
 - Counting Medicare claims data for tests in people who do not have diabetes, including OGTTs, fasting plasma glucose and diagnostic HbA1c tests
 - Assessing data from adult health checks (collecting by PHNs).

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

Rationale

Both in Australia and overseas, it has been shown that best-practice, high-quality diabetes care can only be achieved when health care professionals work seamlessly. This involves partnerships across primary health care, community care and specialist care services that deliver integrated diabetes care, with direct consumer (the person with diabetes), carer and family involvement. Establishing an effective, integrated system will require a transformation in the way care is delivered in order to make it more consumer focused, team-based and proactive. Such a system will require the application of quality standards for service delivery, as well as coordination across the relevant agencies, encompassing the whole diabetes care pathway. An excellent example of this process is outlined in the United Kingdom's NICE quality standard for people with diabetes.⁴⁸ Consumer engagement, self-management and empowerment will be major contributing factors in achieving this goal.^{30,31}

The Government is currently supporting initiatives to improve integration in primary care, including the creation of PHNs and the implementation of electronic health records. Further action is planned through the development of a strategic framework for chronic disease. Nonetheless, opportunities remain to further improve the care delivered to people with diabetes and other chronic conditions. For example, people with diabetes often have multiple comorbidities and see a number of different health professionals across primary, community and specialist care services,³⁴ and optimal care therefore requires integrated and coordinated health care services.

Although some locations in Australia have world-class, evidence-based, best-practice clinical care of diabetes, this is not uniform across the country. Major barriers to the consistent delivery of optimal care throughout the primary health care system include poor service integration, uneven distribution and activities compared to population needs, variable levels of communication, and the continued use of non-person-centred approaches to care delivery.

The most effective way to implement evidence-based guidelines for screening and managing diabetes and its complications is to integrate them into everyday clinical practice. For most medical practitioners and allied health professionals, this requires medical software that indicates the need for particular actions when a person with diabetes is in front of them. For example, the software should produce reminder notices for monitoring, assessing and managing a person's diabetes and, importantly, should include performance outcomes and metrics.

It is possible to prevent or slow the rate at which the complications of diabetes develop,⁴⁹ and the primary health care system should therefore be more strongly oriented towards prevention. This requires access to person-centred and integrated information and support services, as well as access to quality medicines and technologies. It also requires plans, programmes, monitoring and reporting across PHNs and the health system more generally for:

- Eye damage and blindness
- Cardiovascular disease and strokes
- Kidney damage and failure
- Amputations
- Mental health
- Impaired growth and development in children.

Table 3 provides an overview of key diabetes-related complications, including their assessment, frequency, diagnosis and referral pathways. It also demonstrates the wide range of components and services that are needed to deliver optimal diabetes care.

Table 3: Overview of the complexity of the management of chronic diabetes complications

	Complication	Assessment	Frequency	Means of Measuring	Referral Pathways
Eye	Retinopathy Cataract Glaucoma Visual loss Blindness	Visual acuity Fundus examination	Every 2 years (1 year for Indigenous people) More frequently if abnormalities present	Fundus examination Fundus photography	Retinopathy requires access to laser therapy and specific medications Includes access to ophthalmologists or an optometrist
Kidney	Albuminuria Chronic kidney disease	Urine examination for albuminuria Measurement of creatinine and calculation of eGFR	At least annually More frequently if abnormalities present	Urine and blood test	Access to dialysis and transplantation where indicated Access to nephrologist
Foot	Neuropathy Peripheral vascular disease Foot deformity Ulcer Amputation	Foot examination and tests of sensation and circulation	At least annually More frequently if abnormalities present	Foot inspection by doctor, podiatrist or diabetes educator	Includes access to podiatrist and multidisciplinary foot care team
Cardiovascular disease	Heart disease - Coronary artery disease - Heart failure Stroke	Blood lipids Blood pressure CVD risk assessment tool Atrial fibrillation	Annually	Clinical examination Blood test	Includes access to cardiologist and relevant tests (e.g., stress test, angiography)
Mental health	Depression Anxiety	Assessment of mental status	On diagnosis and when required	Clinical examination	Multidisciplinary team including psychologists, psychiatrists and social workers
Growth and development in children	Poor growth Delayed puberty	Growth	Annually	Clinical examination	Includes access to multidisciplinary paediatric diabetes team

Key issues

Clinical Guidelines: Diabetes management has attracted a plethora of research, and the challenge is ensuring that new clinical guidelines, medicines and therapeutic goods become available in a timely manner. It is also important that guidelines are consistent for treating diabetes, and that they are applied uniformly across the diabetes population. The current multiplicity of guidelines may reflect the fact that processes for developing high-level guidelines in Australia are slow, costly and rigid, which prompts other organisations to produce their own guidelines. There are currently over 20 different diabetes-related clinical guidelines, backed by a range of organisations (including 2 approved by the National Health and Medical Research Council [NHMRC]), which leads to confusion and unnecessary debate about standards of care.⁵⁰

Therapies and devices: New treatments are regularly released, and clear and unambiguous criteria for accessing diabetes medication are essential. At present, these do not exist. For example, PBS criteria for accessing glucose-lowering medicines for type 2 diabetes are complex, particularly specifications around combinations and sequences of medicines. Similarly, while bariatric surgery is now an accepted option for managing obese people with type 2 diabetes and significant comorbidities,³⁵ access is not always equitable. There is also a pressing need to increase the accessibility of new efficacious medicines and newer technologies, such as insulin pumps and continuous glucose monitors. For people with type 1 diabetes, insulin pump therapy can be a life-changing and potentially life-saving intervention.^{51,52}

Information technology: Electronic health has the potential to revolutionise care for people with diabetes. The Australian Government has started to build the infrastructure necessary for a fully technologically enabled system, which includes universal patient identifiers, secure messaging technologies and My Health Record.

Quality improvement: At present, a significant proportion of people with diabetes do not receive all the recommended checks. Approximately 50% 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.¹⁷ Ensuring that recommended care is consistently applied—as demonstrated by the work of the Primary Care Collaboratives⁵³—has the potential to slow the progress of diabetes and delay the onset of diabetes-related complications. This has positive implications for the health and wellbeing of people with diabetes.

Workforce capacity: At present, there is a shortage of appropriately qualified and certified allied health professionals across the diabetes care spectrum, particularly in rural and remote areas. Workforce capacity must be explored for a whole range of health professions involved in diabetes care, including psychologists, podiatrists, dieticians, exercise physiologists, dentists, pharmacists and care coordinators/case managers. Consistent delivery of evidence-based, best-practice diabetes care is dependent on the knowledge and skills of generalist health professionals, as well as the number and distribution of diabetes specialist health professionals in the workforce. Addressing workforce capacity is critical to supporting implementation of the National Diabetes Strategy and should be based on existing workforce data, the increasing need for services and estimates of future workforce requirements.

Mental health: Increased psychological complications are associated with poorer outcomes and higher costs.²⁹ For instance, anxiety and depression occur in over 35% of people with diabetes. As behavioural changes are generally difficult to achieve, people with type 1 and type 2 diabetes require regular support to enable change across multiple domains, including self-management, weight reduction, food regulation, exercise and mood management. At present, there is relatively little use of the existing psychology workforce, and their involvement in diabetes care plans within primary care is limited.

Transitioning: Transitioning from paediatric to mainstream adult services is described as ‘the purposeful planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult oriented health care systems.’ This is often challenging for those with type 1 diabetes.⁵⁴ Mainstream services are often poorly equipped to meet the special needs of young adults, who often struggle to cope with the demands of diabetes care. Adolescence is a time of major physiological change, and young people with type 1 diabetes who are transitioning to adult services may disengage from the health system, as well as their treatment regimes. Young adults have specific health needs relating to the physical, emotional, psychological and socio-cultural stages of adolescence, which are separate from their diabetes. Adolescents are also less likely to adhere to prescribed care, and therefore more likely to have poor glycaemic control.

3.3.1 Areas for action

Develop nationally agreed clinical guidelines, local care pathways and complication prevention programmes

This involves:

- Developing a single, nationally endorsed set of diabetes guidelines, which should be updated regularly. Support should be provided for their implementation and monitoring.
- Requiring PHNs to develop locally tailored pathways of care for people with diabetes and other chronic diseases, reflecting local service configuration and population needs. PHNs should also be required to develop and monitor key performance indicators.
- Strengthening complication prevention programmes in PHNs and across the health system more generally. These may be integrated programmes covering multiple complications or single complication prevention programmes.
- Utilising databases such as the NDSS and My Health Record to facilitate reminders and recalls.

Expand consumer engagement and self-management

There are three main ways to achieve this:

- Enhance access to structured self-management education programmes for people with diabetes, including the newly diagnosed and people starting insulin. Particular attention must be given to programmes for children with diabetes, adolescents transitioning into adult services, and older people and their carers.⁵⁵
- Ensure that peer support programmes (either face-to-face, by telephone or online) are accessible to all people with diabetes.
- Initiate education and social marketing campaigns—with a focus on people with diabetes, their carers and primary health staff—on the importance of regular diabetes-related complication screening.

Develop and implement quality improvement processes

People with diabetes and health care providers who care for people with diabetes should be involved in quality improvement processes, including the systematic collection of data on providers' adherence to clinical guidelines and clinical outcomes (e.g., screening for diabetic retinopathy, GDM and kidney disease) and peer comparison of these data (with appropriate adjustment for patient mix and risk levels). These data should be reported and reviewed nationally. PHNs should take a pivotal role in facilitating these processes, and the Australian Commission on Safety and Quality in Health Care should monitor them.

Data connectivity should be utilised to improve clinical care at the individual level, and to offer benefits at a population level by providing data to inform service delivery, health policy and research.

Utilise information and communication technology

The following actions are proposed:

- Ensure the uptake and meaningful use of My Health Record by people with diabetes and their health care providers for care planning and coordination.
- Expand access to flexible telemedicine consultations (e.g., medical consultations for diabetes, eye screening programmes and telephone-based lifestyle coaching).

- Facilitate the use and application of consumer engagement and education platforms.
- Harness emerging remote monitoring technologies.
- Ensure that upgraded, connected and consistent software programmes for diabetes management are available for GPs and allied health professionals within the primary health care system.
- Create a reminder system for screening and care planning activities, utilising the NDSS and My Health Record. This should include reminders for diabetes-related complication screening.

Measures will need to include a range of formats in order to be inclusive of people with disability.

Improve affordable access to evidence-based medicines and devices

In relation to new medicines and devices, the following actions are proposed:

- Develop and design efficient pathways for assessment, evaluation and funding that enable timely access to new diabetes treatments and devices.
- Enhance the insulin pump programme to ensure affordable access and availability on nationally agreed clinical criteria.
- Include continuous glucose monitoring in suitable access programmes.

Develop, expand and improve workforce capacity

This will require:

- Upskilling (and providing clinical support to) the existing generalist health workforce
- Upskilling (and providing clinical support to) Aboriginal and Torres Strait Islander workers and practitioners
- Significantly increasing the diabetes specialist workforce (diabetologists and credentialed diabetes educators)
- Redistributing some aspects of diabetes care to different roles (e.g., community nurses delivering beginning diabetes education; credentialed diabetes educators taking on expanded roles in diabetes management)
- Developing clear expected competencies for health professionals involved in diabetes care, based on the nationally endorsed diabetes guidelines
- Developing a culturally informed, language-appropriate trained workforce
- Training other health professionals (e.g., pharmacists, dentists, podiatrists) in diabetes care relevant to their discipline.

Improve funding mechanisms to support diabetes care

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. Options include:

- Exploring 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 and consumer-orientated care packages (e.g., for aged care)

- Considering stratifying people with diabetes based on their utilisation of health care services in order to reallocate funding to people with greater care needs
- Considering funding arrangements for allied health professionals and credentialed diabetes educators
- Reviewing funding mechanisms within Aboriginal Community Controlled Health Services to improve the delivery of diabetes care.

Provide mental health care for people with diabetes

Existing policies and services do not systematically offer routine screening for mental health issues in diabetes or effective behavioural interventions. Available mental health and behavioural support services—including technology-based services already funded by the Government—are not generally used for chronic disease management. Attending to behavioural and mental health factors is crucial for preventing complications, maximising outcomes and minimising costs in diabetes care. Possible strategies include:

- Routinely monitoring people with diabetes for mental health issues
- Performing mental health screening upon diagnosis of diabetes, and adding screening to the Annual Cycle of Care
- Ensuring more effective utilisation of mental health services within the diabetes community
- Measuring quality of life scores for people with diabetes
- Increasing psychology workforce capacity through a review of training and, where required, the development of new training opportunities, as well as the use of psychology assistants.

Strengthen and expand the transition from child to adult services

There are a number of effective transition programmes in place today to assist young people with chronic conditions (including diabetes) as they transition from paediatric to adult care.⁵⁴ These can be further improved by:

- Scaling up and strengthening programmes that assist young people with diabetes in the transition from paediatric to adult care services
- Providing access to psychological support services in the transition process.

Make pre-school, school and child care diabetes-safe environments

Supporting a child/young person with diabetes in the school environment is a challenge because best-practice clinical care for children and young people with type 1 diabetes involves multiple daily insulin injections or insulin pump therapy, together with frequent blood glucose monitoring. While some schools are receptive to teachers and support staff acquiring skills in the management of hypoglycaemia, very few are supportive of staff administering insulin injections. Strategies to improve the school environment for children and young people with diabetes include:

- Making state and territory domains responsible for ensuring that children with diabetes are in a safe and supportive environment. Education staff need to be involved in diabetes management to ensure the safety of children with diabetes in the school environment.

- Providing school systems and day care providers with the information necessary to allow children with type 1 diabetes to participate fully and safely in the school experience. This can be achieved through collaborations between parents and health care teams.

Provide high-quality hospital care for all people with diabetes

Although there are large numbers of diabetes-related hospitalisations—between 15% and 35% of public hospital admissions in Australia—diabetes care in hospitals is not universally optimal,⁵⁶ and there are insufficient numbers of trained health professionals. Specialist diabetes teams in hospitals are important, not only for patient care and safety but also as a potential means of shortening the duration of admissions (many of which are avoidable or unnecessarily long). This can be achieved by:

- Developing a clinical standard for the care of hospitalised patients with diabetes, monitored by the Australian Safety and Quality Commission
- Ensuring that all people with diabetes who are admitted to hospital receive high-quality, appropriate care for their diabetes
- Undertaking an education campaign to ensure that all hospital staff involved in the care of people with diabetes are appropriately trained to access expert help when needed
- Establishing a system of ‘Diabetes Champions’ in hospitals, where volunteers provide diabetes education to patients. In certain hospitals in the United States, this has resulted in shorter admissions, improved care and a better transition back to the home environment
- Supporting and funding hospital-based diabetes services through the National Accredited Diabetes Centres programme
- Providing patient-focused, community-directed discharge plans to GPs and allied health professionals.

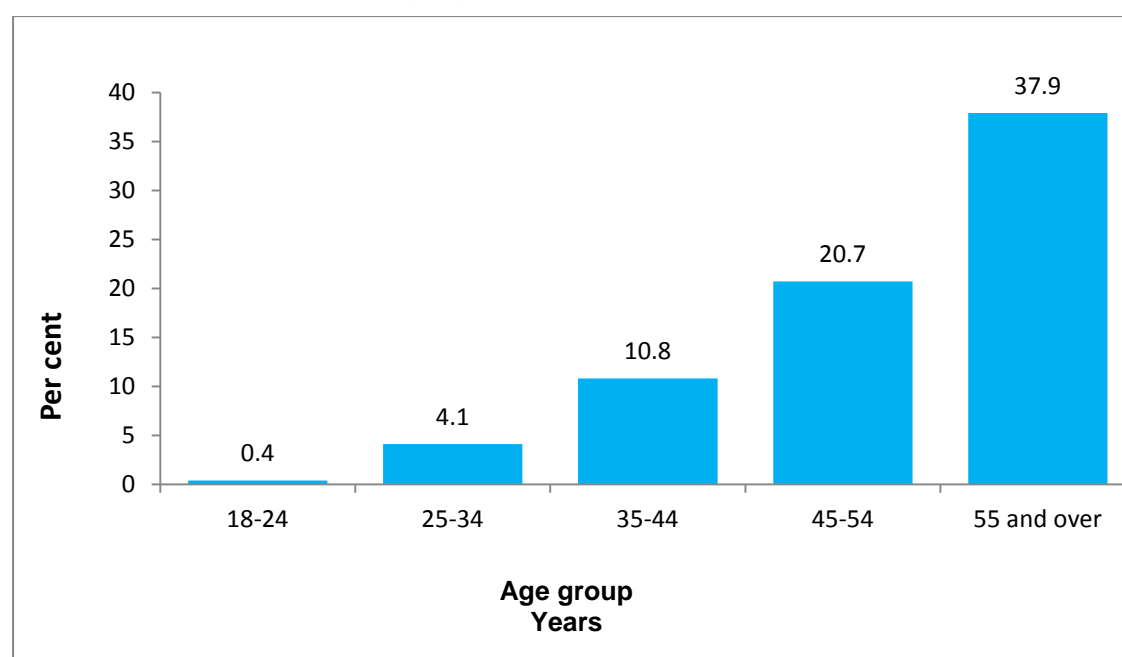
3.3.2 Potential ways to measure Australia’s progress towards this goal

- **The percentage of people with diabetes who receive screening for complications and complete the Annual Cycle of Care.** This includes eye, kidney, foot, cardiovascular disease and mental health complications. A 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).
- **The percentage of people with diabetes who achieve target levels of HbA1c, cholesterol, albuminuria and blood pressure.** These indicators are good predictors of a person’s long-term likelihood of developing diabetes-related complications. There is currently no nationally standardised way of collecting these data, and the Government should strive to identify and implement a mechanism for doing so.
- **The incidence of complications in people with diabetes.** Measured complications could include lower limb amputations, dialysis commencement, blindness, heart attacks and strokes. There is currently no standardised way of tracking all diabetes-related complications. (These specific complications have been suggested because they are easier to track. In the future, it may be possible to track earlier stages of developing complications, such as treatment for eye disease [laser surgery or intraocular injection] and early-stage kidney disease.)
- **The number of hospitals implementing quality standards for the management of diabetes.**

3.4 Goal 4: Reduce the impact of diabetes among Aboriginal and Torres Strait Islander peoples

Aboriginal and Torres Strait Islander peoples have one of the highest rates of diabetes in the world. As many as 25% of adults have type 2 diabetes,^{18,19} and the disease is increasingly diagnosed in children, adolescents and young adults,⁴ with rising rates of diabetes in pregnancy establishing intergenerational patterns of premature disease.⁵⁷ (Figure 6 shows the prevalence of type 2 diabetes by age group.) The rapid progression and severity of diabetes-related complications among Aboriginal and Torres Strait Islander peoples is a major concern.⁵⁸

FIGURE 6: Prevalence of diabetes in Australian Aboriginal and Torres Strait Islander persons (18+) by age group⁵⁹



The determinants of diabetes in Aboriginal and Torres Strait Islander populations are complex and inter-connected and have proved difficult to overcome. Any national response requires an awareness that Aboriginal and Torres Strait Islander people may experience cultural and linguistic challenges and geographic and socio-economic barriers that limit their access to diabetes-related services and education. Indigenous communities also have many unique languages and traditions, as well as varying needs and existing capacities. This cultural diversity and the varying local and regional circumstances of Indigenous communities need to be recognised and respected, and should inform the development of any strategies that seek to reduce the burden and impact of diabetes.

Policies and practices that reduce the impact of diabetes in Aboriginal and Torres Strait Islander communities offer exemplar approaches for a more coordinated and holistic national strategy, because of both the priority placed on diabetes control and the existence of a strong, community-controlled primary care sector. Aboriginal Community Controlled Health Services currently have access to electronic clinical medical record tools, collect extensive performance indicators on care provision and quality, and are well placed to integrate clinical guidelines into their activities through organisational policy and procedures.

Information sharing is vital to care coordination. This can be achieved by enabling multidisciplinary teams to work within a single primary health care service, using a unified clinical information system. While this already occurs within many Aboriginal Community Controlled Health Services, it is not the reality for most service providers in Australia, and it is

crucial that an effective, shared electronic health system is implemented to link hospital and primary care records from different disciplines. In the Northern Territory, for example, My Health Record is already supporting continuing and coordinated care for Aboriginal and Torres Strait Islander people, particularly those who move regularly between different communities and hospitals. A shared system should also enable the collection of data on the performance of all providers involved in a patient's care. The new national myHealth system will achieve this in part, but it will need to be actively shaped in this direction.

While the areas for action suggested for all Australians under earlier goals also apply to communities with a higher prevalence of diabetes, Aboriginal and Torres Strait Islander peoples warrant particular attention and, in many cases, require specific activities focused on the needs and realities of their communities (e.g., food security and affordability, maternal and child health care). This may require different policy or health system approaches.

3.4.1 Areas for action

The goals and action areas for Goals 1 to 3 are applicable to Aboriginal and Torres Strait Islander people, but additional areas of action specific to Indigenous communities include the following:

- Develop and implement community-wide, culturally relevant awareness programmes (including school education programmes) that communicate the seriousness of diabetes and its complications. Education should be provided in a culturally and linguistically appropriate manner, which includes translating materials and services.
- Develop, fund and implement a national diabetes prevention programme, designed specifically for Aboriginal and Torres Strait Islander people, which includes efforts to facilitate earlier identification of people with diabetes.
- Establish and fund pre-conception, pregnancy and early years programmes that enhance the education and health of Indigenous men and women; detect gestational and previously undiagnosed diabetes and manage it through pregnancy; and coordinate follow-up and postnatal care for mothers and babies.
- Enhance the pre-conception education and health of Indigenous women. This includes targeted efforts to reduce the use of alcohol, tobacco and other drugs, and to promote a healthy diet.
- Develop, fund and implement community-wide interventions to increase the availability, affordability and consumption of fresh foods, and to reduce the consumption of sugar-sweetened beverages, as well as high-fat, high-sugar, high-salt and highly processed foods (including price signalling to disincentivise the consumption of unhealthy foods).
- Ensure access to necessary specialist support through strategically located regional networks of care and linked facilities for the treatment of serious diabetes complications, particularly kidney and eye disease.
- Enhance the resourcing of primary health care services to better identify and manage diabetes (including among adolescents and children), incorporate risk calculators and electronic decision-support mechanisms, and increase opportunities for people with diabetes to better self-manage the condition.
- Streamline and reduce the complexity of MBS reimbursement options to maximise access to multidisciplinary care.
- Increase the number of diabetes educators working in Aboriginal and Torres Strait Islander primary care settings.
- Provide stimulating early years education and intervention programmes that address developmental vulnerabilities and the social and environmental determinants of Aboriginal

and Torres Strait Islander health, including the Nurse Home Visitation programme (which targets mothers) and the Abecedarian Educational Day Care Programme (which targets the child).

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

- **The number of new cases of diabetes diagnosed each year among Aboriginal and Torres Strait Islander peoples.** There is currently no definitive way of counting the number of people with diabetes in Australia. Although the NDSS register may be used in the short term, many people with diabetes from Aboriginal and Torres Strait Islander communities are not currently registered. Increasing the number of people who register with the NDSS needs to be encouraged and facilitated.
- **The incidence of complications among people with diabetes from Aboriginal and Torres Strait Islander communities.** As with the general population, measured complications could include treatment for eye disease (e.g., laser or intra-vitreous injection), lower limb amputations, use of dialysis, heart attacks and strokes. 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 percentage of pregnant women diagnosed with gestational diabetes.**
- **The percentage of people with diabetes from Aboriginal and Torres Strait Islander communities with above-target HbA1c, albuminuria, cholesterol or blood pressure.**
- **The percentage of people with diabetes from Aboriginal and Torres Strait Islander communities who receive annual testing for complications.**
- **Rates of smoking and alcohol consumption among pregnant women with diabetes.**
- **The cost of a healthy food basket, monitored to assess the availability and affordability of foods required for a healthy diet.**
- **The number of Aboriginal and Torres Strait Islander children participating in evidence-based early childhood education programmes.**

3.5 Goal 5: Reduce the impact of diabetes among high-risk and vulnerable groups

Rationale

Australia is socially and culturally diverse, which has important implications for the development of a National Diabetes Strategy. The areas for action suggested for all Australians under Goals 1 to 3 apply equally to socially and culturally diverse communities, including culturally and linguistically diverse (CALD) communities, older Australians, and rural and remote communities. Each group warrants particular attention and may require different policy or health system approaches.

In order to develop a comprehensive and culturally responsive national approach to diabetes, the National Diabetes Strategy must engage with those at higher risk of developing diabetes or its complications in a culturally appropriate and relevant way. It must also devote specific attention to high-risk and vulnerable groups when identifying actions for the prevention, diagnosis and management of diabetes and its complications. Health care for these high-risk and vulnerable groups can be greatly improved 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 through additional training
- Collaboratively planning and implementing integrated, multidisciplinary care.

Culturally and linguistically diverse people

This strategic framework recognises the ethnic diversity of the Australian population, approximately 30% of whom were born overseas. People from some CALD backgrounds are at higher risk of developing type 2 diabetes, most notably Pacific Islanders, people from the Indian subcontinent, and people of Chinese and Vietnamese origin.²⁰

People from these backgrounds who have diabetes may also experience cultural and linguistic barriers that limit their access to diabetes-related services and education. In Australia, 1 in 5 people speak a language other than English at home. Health literacy is a major issue for over 60% of Australians, but for people in high-risk or vulnerable groups—and particularly those who speak a language other than English—lower health literacy can impede informed decision making around health care and result in poorer health outcomes. For this reason, implementing and evaluating culturally appropriate prevention and management programmes, which focus on the specific needs of these groups, remains essential. This is particularly true for people with diabetes, which imposes ongoing lifestyle modification and self-care requirements on the individual.

Strategies for preventing and managing diabetes must be tailored to the specific needs of CALD communities. Programmes must be person-centred and culturally safe, and they must respect the many diverse languages, religious beliefs and cultural practices in the community.

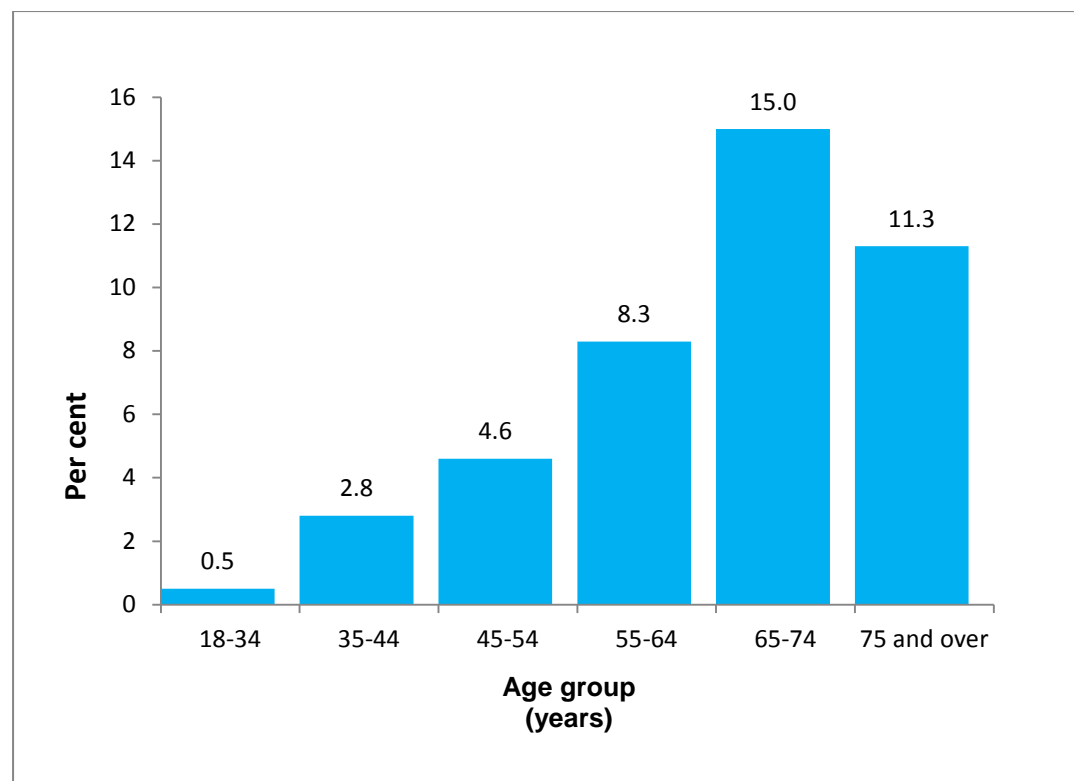
Older Australians

Diabetes (especially type 2 diabetes) is more prevalent among older Australians (Figure 7),^{8,17} and older people with diabetes experience higher rates of comorbidity and disability. In particular, they experience functional decline and frailty earlier,⁶¹ as well as an increased risk of hospitalisation and longer hospital stays.

Spending on health and aged care is expected to rise rapidly over the next few decades as Australia manages changing community needs, including an estimated 7-fold increase in health care expenditure for those aged over 65 years.

Potential actions for older Australians include ensuring that the relevant guidelines inform care and clinical decision making across health and aged care settings,^{61,62} as well as linking services that provide diabetes care and support to older Australians through implementation of My Health Records and the creation of PHNs. Steps should also be taken to facilitate early discharge planning and communication with the outpatient diabetes care team and/or treating GP. Transitioning care between services is a key area of vulnerability in the management of diabetes among older Australians, and there is a high risk of medication mismanagement and increased hypoglycaemia or hyperglycaemia.^{61,62}

FIGURE 7: Prevalence of diabetes in Australian adults (18+) by age group⁶⁰



In order to efficiently provide best-practice care, maintain good quality of life and reduce future costs, it is essential that the health and aged care systems have a coordinated and complementary approach to diabetes care during ageing. The role of informal carers for older people with diabetes should be supported through information, education and links to services, including culturally appropriate local support groups. Consideration of care context, assessment, care planning and diabetes-specific risk assessments are required to enable a proactive and preventative care approach.

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, CALD communities and older Australians 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.²¹

3.5.1 Areas for action

Culturally and linguistically diverse people

Actions for the prevention and management of diabetes need to be tailored to the specific needs of CALD communities to ensure that person-centred, culturally safe care respects diverse languages, religious beliefs and cultural practices.

Actions to remove barriers that limit access to services and education include:

- Translating all consumer resources into the appropriate languages
- Ensuring that appropriate translation services are available during health care encounters

- Investigating the potential for NDSS registration, and developing a communication strategy to overcome barriers and promote the NDSS to these communities through nationally consistent messages
- Improving health literacy through the dissemination of culturally appropriate information and programmes for the management and care of diabetes
- Developing, rolling out, evaluating and (where necessary) adapting a culturally and linguistically appropriate diabetes education package to ensure the successful transfer of information on diabetes prevention and management.

Older Australians

In order to efficiently provide best-practice care, maintain good quality of life and reduce future costs, health and aged care systems must have a coordinated and complementary approach to diabetes care during ageing. This can be assisted by:

- Promoting the adoption and implementation of relevant guidelines on managing diabetes in older people to inform care and clinical decision making across health and aged care settings
- Ensuring that staff in aged care settings are trained in managing diabetes, given the high risk of medication mismanagement and increased risk of hypoglycaemia or hyperglycaemia (which may result in hospitalisation)
- Ensuring appropriate care transitions between services
- Facilitating early discharge planning and communication with the diabetes care team and/or treating GP
- Supporting the role of carers for older people with diabetes through information, education and links to services, including culturally appropriate local support groups
- Ensuring consideration of care contexts, care planning and diabetes-specific risk assessments to enable proactive and preventative care approaches.

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. This can be addressed by:

- Coordinating regional services across primary, secondary and tertiary care to ensure access to care and the necessary support services
- Supporting community-based health workers through training and education
- Expanding telehealth and internet medical services, and ensuring equitable access to other technologies and services
- Examining the possible benefits of empowering community pharmacies and other health professionals (such as dentists) to provide advice and care when other primary health care access is limited
- Developing partnerships and linkages between local clinicians and health professionals and major specialist diabetes centres.

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

- The number and percentage of people in high-risk communities developing diabetes each year.
- The percentage of people with diabetes in high-risk groups with above-target HbA1c, cholesterol, albuminuria and blood pressure.
- The percentage of people in high-risk groups who are overweight, obese or have other modifiable risk factors.
- The number of people in these high-risk groups who receive annual testing for complications.
- The incidence of complications in people with diabetes in high-risk groups.
- Trends in hospital admissions among older people with diabetes.

3.6 Goal 6: Reduce the impact of pre-existing and gestational diabetes in pregnancy

Rationale

Rates of type 2 diabetes in pregnancy are increasing among both Aboriginal and Torres Strait Islander women and non-Indigenous women. Compared to other Australian women, Aboriginal and Torres Strait Islander women who gave birth between 2005–06 and 2007–08 were 10.4 times more likely to have pre-existing type 2 diabetes in pregnancy, and 1.5 times more likely to have GDM.⁶² Diabetes during pregnancy places women and their children at significant risk during and after pregnancy, and fetal and infant death is 4 times more likely among women who have diabetes prior to pregnancy.⁶³ It is important that steps are taken to mitigate this risk prior to pregnancy (e.g., through pre-conception care for both men and women), during pregnancy and following delivery.

While all women should be included in general preventative care, women with GDM in previous pregnancies are at high risk of developing diabetes in the future and therefore warrant particular focus, in terms of both health and lifestyle. The provision of ongoing support and care after pregnancy is essential to help prevent the development of type 2 diabetes. In the long term, 50% of women who develop GDM will also develop type 2 diabetes. In addition, their children are at increased risk of developing obesity and type 2 diabetes,⁶⁴ hence the saying 'Diabetes begets Diabetes.' Identifying and normalising maternal hyperglycaemia provides an opportunity to minimise the short-term complications and reduce the later development of diabetes, obesity and their associated complications. In addition, evidence suggests that breastfeeding reduces the risk of diabetes in both mother and baby.⁴³

3.6.2 Areas for action

Diabetes during pregnancy places women and their children at significant risk during and after the pregnancy. Actions to optimise pregnancy outcomes include:

- Providing accessible prepregnancy programmes to identify and address risk factors that may result in adverse outcomes
- Ensuring that all women with known diabetes receive prepregnancy programmes and advice
- Ensuring that all pregnant women are appropriately screened for diabetes
- Ensuring that women with diabetes in pregnancy have access to a credentialed diabetes educator and expert advice on diet and physical activity

- Providing post-pregnancy programmes for all women with diabetes in pregnancy
- Ensuring that women with previous GDM receive counselling regarding the future risk of diabetes
- Providing paediatric follow-up for at-risk children (e.g., children of mothers with GDM or obesity).

3.6.2 Potential ways to measure Australia's progress towards this goal

- **The percentage of pregnant women with diabetes whose HbA1c is measured in the first and third trimester.**
- **The perinatal and infant mortality rates of children of mothers with diabetes.**
- **The percentage of mothers with GDM whose postnatal OGTT is retested at 2 years postpartum.**
- **Use data from the NDSS National Gestational Diabetes Register (collected on an opt-out basis).**

3.7 Goal 7: Strengthen prevention and care through research, evidence, data and national oversight

Rationale

Strengthening research

Diabetes is the fastest growing chronic disease in Australia, and it is predicted that diabetes will become the leading burden of disease in Australia by 2017.⁶⁵ Diabetes already has a significant impact on Australia's health and productivity,²⁶ and research into the condition has therefore been prioritised. This includes research on the basic science of the disease and its socio-economic, environmental and behavioural impacts; translational research; and research on appropriate clinical outcomes.

Australia has a long history of conducting high-quality diabetes research and contributing to international research efforts. However, while research funded through the NHMRC likely falls within the research priorities suggested in previous national diabetes strategies, it has not been officially allocated to those research priorities. In order to progress research into evidence-based best practice for the prevention of diabetes and its complications, as well as a cure for diabetes, a national research agenda needs to be multidisciplinary, complementary and collaborative, and research priorities need to be clearly defined.

At present, a number of organisations fund diabetes research, including government bodies such as the Australian Research Council and the NHMRC; non-governmental organisations including 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 should be taken to better coordinate their efforts.

While Australia currently has multiple diabetes research funding streams, research efforts need to be more closely focused on:

- Strengthening evidence-based practice for the prevention of diabetes and its complications

- Identifying a cure for diabetes
- Developing new data sets (and enabling connectivity between existing data sets) that can inform population-based health decisions
- Informing health policy decisions
- Evaluating newer and improved medications and technologies.

To achieve this, an internationally relevant and nationally coordinated Australian diabetes research agenda should be developed to focus, coordinate and translate research into clinical practice. Appointing a custodian or existing body to effectively coordinate diabetes research in Australia, including the management of existing and new data sets, will help to prioritise and leverage research outcomes.

Strengthening data linkage and connectivity

While best practices for diabetes care are well documented, health care policies for 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 medication has contributed to recorded health data. As a result, there are a number of existing data sets and databases, including the NDSS (incorporating the National Gestational Diabetes Register), the National Insulin Treated Diabetes Register, the PBS, Medicare records, the AIHW, My Health Record, hospital records, and birth and death registries.

Hospitalisation and birth/death records, along with Medicare and PBS data and other health programme data, are state and national assets. They are immeasurably valuable for research purposes, but they could also play a critical role in strengthening chronic disease prevention and management if they were better linked. These data have already been recorded and are ready to be analysed and used, and many questions can be answered using these data (rather than performing long-term and expensive clinical trials). At present, however, it is difficult to access and link these data sources in an effective and time-efficient manner, primarily because of administrative requirements and concerns about data security and individual privacy. In many cases, individual consent is required from each person whose data will be accessed.

3.7.1 Areas for action

Develop a national research agenda

A nationally coordinated research agenda, designed specifically to coordinate diabetes research across multiple funding streams, should be developed. This agenda should guide research on a range of relevant topics, including the basic science of diabetes, clinical practice, prevention, complications, implementation and translation of research, health service delivery, lifestyle changes, and the social, economic, demographic and environmental impacts of the disease. In collaboration with the NHMRC and the Australian Research Council (ARC), as well as other funders and organisations, research efforts should be supported in the following areas:

- Examining the barriers to best practice and the availability of (and access to) appropriate health services in order to develop specific strategies to address and overcome these barriers.
- Identifying the cause(s) of type 1 diabetes and how to prevent, cure and treat the condition (including research into the potential benefits of stem cell technology and islet cell transplantation).
- Identifying 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 others, and how best to identify which people will respond favourably to these medicines).

- Translating research into improved therapies for the optimal management of diabetes.
- Preventing and managing type 2 diabetes in Aboriginal and Torres Strait Islander peoples, including children, adolescents and other high-risk and vulnerable groups.
- Using de-identified aggregate data (provided by linking existing data sets) to understand how people develop diseases, including diabetes; how diseases progress under different preventative and treatment strategies; and how health dollars can be more efficiently and effectively focused.
- Collating and widely disseminating research findings.

Improve and expand data linkage and facilitate ease of access

This can be achieved by:

- Providing clear pathways and criteria for accessing existing data sets for research purposes—including NDSS data, the National Diabetes Register, the National Gestational Diabetes Register, PBS records, MBS records, My Health Record, hospital records, and birth and death registries—as well as a means of assessing applications to access these data sets
- Facilitating and improving the connectivity of key data systems between different levels of the health care system to optimise diabetes care
- Undertaking a regular national biomedical health survey (which includes diabetes, chronic disease and Aboriginal and Torres Strait Islander components) every 5 years to collect additional and prospective data that can inform and underpin health policy.

National oversight

The National Diabetes Strategy Advisory Group strongly recommends that the Federal Government establish a National Diabetes Commission in recognition of the significant impact of diabetes on the Australian community. This would have the capacity to successfully transform systems, promote change and ensure that Australians with or at risk of diabetes receive optimal care. The commission could be modelled on Australia's National Mental Health Commission and the United States' National Commission on Diabetes. A National Diabetes Commission would provide leadership, oversee reporting and facilitate the integration of national diabetes activities by:

- Developing a National Diabetes Strategy implementation plan, agreed to by the states and territories (AHMAC/COAG endorsement)
- Establishing a mechanism for monitoring and ensuring implementation of the National Diabetes Strategy.

3.7.2 Potential ways to measure Australia's progress towards this goal

- **Progress against key milestones in developing a national research agenda.** A series of milestones could be created to monitor progress towards meeting national data set needs. A regular national health survey that collects biomedical data (including diabetes data) should be undertaken every 5 years. While potential milestones are yet to be determined, they may include the number of research studies accessing the data sets and should encompass evidence of progress towards implementing the National Diabetes Strategy.

- The number, completeness and coverage of national data sets documenting the burden, health system use, management and complications of diabetes.
- The estimated completeness and coverage of the NDSS database, as well as yearly registrations.
- Progress towards establishing a national diabetes database.
- Development of a mechanism for monitoring and ensuring implementation of the National Diabetes Strategy.

Next steps

Australia has an opportunity to further enhance its already excellent health care 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 Strategic Framework for Action provides a useful foundation for Australia's National Diabetes Strategy. The NDSAG will submit this paper to the Minister for Health for consideration, and the Australian Government will then prepare a draft National Diabetes Strategy for review by the AHMAC and the COAG Health Council. The final National Diabetes Strategy is anticipated in late 2015.

Looking to the future, the NDSAG have provided (below) a short commentary on the potential impact of emerging technology on the prevention and management of diabetes.

Emerging technologies for the future management of diabetes

Background

A National Diabetes Strategy for Australia will be delivered in the context of a rapidly changing health care system. The role of technology, patient engagement, the connectivity and utilisation of data from a variety of sources, and the emergence of new entrants in the health system will all influence change.

One of the challenges identified in this strategic framework is the need to improve the integration and coordination of care. Emerging technology is one of the few ways in which solutions can be scaled fast enough to respond to a health problem growing as rapidly as diabetes. As a result, technology will play an increasingly important role in preventing and managing diabetes effectively in the health system of the future.

Technology is already actively used in the health system. At present, over 95% of GPs and GP practices use computers during patient consultations, and systems that connect healthcare providers and support longitudinal and collaborative care (such as cdmNet) are now being adopted. A range of targeted online educational materials, resources, videos and games are available to patients, who also have access to chat rooms and social media to share knowledge and experiences, and to seek and provide peer support. In addition, a wave of new, non-traditional providers of health care devices and applications—including consumer technology and telecommunication companies—are offering mobile and wearable devices, software and phone apps.

Despite these advances, many systems in the health sector are disconnected. For example, while My Health Record connects information from a range of databases (including the MBS, PBS, and organ donor registries), it is not connected with the NDSS.

Emerging trends

A number of influential trends will define the health system of the future and drive further changes, providing improved health outcomes for people with or at risk of developing diabetes. These are outlined in Figure 8.

FIGURE 8. Influential trends that will drive further changes

Trend	Opportunity
1 Technology led patient-centric care	<ul style="list-style-type: none"> • Online consumer engagement platforms for self-management – better empowering, informing, and supporting patients to more actively manage their own care
2 Connectivity and care coordination	<ul style="list-style-type: none"> • Technologies to improve the sharing of patient data, increasing connectivity and coordination among care providers – improving health outcomes, reducing adverse events and complications, decreasing hospital admissions, improving efficiency and reducing cost
3 Increased remote & self management	<ul style="list-style-type: none"> • Remote patient monitoring – integration of home tracking and monitoring devices and in-home care into daily regime • Telemedicine – definitive treatment online, videoconference e-consults, and e-prescription of routine medications
4 Big data consumer analytics	<ul style="list-style-type: none"> • Analysing complex de-identified data and data linked across current datasets to better understand management outcomes and improve service delivery and inform health policy
5 New funding & investment models	<ul style="list-style-type: none"> • Potential for increased incentives and investment from new corporate players, reducing the need for investment by Governments • Focus on value to health system and improved health outcomes

Relevance to the future management and care of people with diabetes

These trends in health care are particularly relevant to the future management of people with diabetes or diabetes-related illnesses for a number of reasons, including the following:

- **Technology can help improve the delivery, integration and coordination of diabetes care.** Technologies and systems that better connect and share information across the diabetes' care team improve longitudinal care management and care coordination, help deliver evidence-based care plans and guidelines at the point of care, support regular follow up and review, and reduce the administrative burden on practices and patients. This may include:
 - **Personal data capture and usage**—from the collation of data from home-monitoring devices to the future use of a comprehensive personal electronic health record that draws on My Health Record and adds patient-generated content or patient-collected data.
 - **Information to support health-related decisions**—the provision of general educational information and resources (e.g., on diabetes and pregnancy) through to telephone coaching, online forums, and potential future incentives and rewards. This is described as the 'gamification' of health, where game thinking and game mechanics are used to engage users in problem solving and increase users' self-contributions.
 - **Conducting health-related transactions**—the emergence of online consultations and treatments and the potential for pre- and post-appointment support (such as appointment booking, follow up, and medication compliance surveys).

In the future, these activities, services, data sources and transactions will be increasingly connected and together can facilitate increased levels of care coordination and integration between health care players, increased patient engagement in the management of diabetes, and improved overall care outcomes.

- **The nature of diabetes merits increased patient engagement.** Diabetes is the most self-managed of all the chronic diseases, and people with diabetes spend very little time with a health professional or engaging directly with the health system. People with diabetes often make the decisions that most affect their health and wellbeing themselves, outside hospitals or clinics and often in their home or workplace.

This provides an opportunity to make significant changes to management activities and improve health outcomes by better empowering, informing and supporting people with type 1 diabetes, type 2 diabetes and prediabetes to play a more active role in self-management. Patient engagement (supported by technology platforms) is already proving successful, beginning with initiatives as simple as SMS-based reminders for appointments and periodic checks. Patient engagement platforms can build on existing policy initiatives (such as My Health Record) and are often developed with private funding and investment (if an environment supporting such investment is provided).

- **The scale of the challenge suits cost-effective, scalable e-Health interventions.** Section 1.3 outlines the projected increase in the prevalence of diabetes in Australia and its resulting cost impact on the health system. A national response needs to address the scale of this challenge, including the likely pace of growth and the cost of interventions and/or new initiatives. Technology-supported e-Health interventions can be scaled up, at a relatively low marginal cost, to meet the growing demand for diabetes management in the future. The impact of e-Health is likely to dramatically increase across data, information and functions.

National Diabetes Strategy Advisory Group

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 Aylen – 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 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
- 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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Appendix: Overview of consultation feedback

Online public consultation on the strategy ran for 47 days (from 15 April, 2015, to 31 May, 2015).

Although originally intended to be open for 4 weeks, the online consultation was extended so that participants could consider the findings of two reports released during the consultation period: the evaluation of the Diabetes Care Project and the Australian Institute of Health and Welfare's report on the *Incidence of type 1 diabetes in Australia 2000–2013*. The two-week extension resulted in an additional 148 submissions.

In total, 423 submissions were received: 106 official submissions were received on behalf of an organisation, and 317 submissions were received from individuals and/or health professionals (note that some reported being an individual *and* a health professional). Organisations that made submissions included a number of non-governmental health organisations, peak bodies, professional associations, health care businesses and state and local governments.

The majority of submissions were received from individuals. Of the individual respondents:

- 37% are caring for someone with diabetes
- 36% are living with type 1 diabetes
- 21% are living with type 2 diabetes
- 6% are at risk of diabetes.

Around one quarter of the total submissions were received from health professionals.

Most respondents (77%) were from urban areas; 23% of respondents were from rural and remote areas.

Nearly 10% of the submissions were received from respondents from culturally and linguistically diverse backgrounds.

Themes arising from the public consultation included:

- Supporting a healthier environment that encourages people to increase their levels of physical activity (for example, through urban redesign).
- Dealing with misconceptions around type 1 and type 2 diabetes (e.g., the need for a community awareness campaign on the differences between the different forms of the disease in order to reduce the stigma around diabetes and discrimination against people with diabetes in the community).
- Providing consumer education (in particular, healthy lifestyle initiatives that focus on young people within the school environment).
- Reducing children's exposure to marketing, advertising, and the promotion of unhealthy foods.
- Providing workforce education, particularly within the primary care setting, on the early warning signs and symptoms of type 1 diabetes. Education needs to be extended to parents, teachers and carers of children.
- Ensuring that early learning centres and schools have type 1 diabetes information and education so that they can support students with diabetes (and their parents).
- Providing more opportunistic testing for the detection of type 2 diabetes, such as at pharmacies, shopping centres, sporting events and in workplaces.

- Raising awareness about testing tools in preventative health.
- Recognising the importance of diabetes self-management products and services in improving quality of life for people with diabetes. Good glucose control will reduce future complications and greatly improve quality of life.
- Sharing decision making and improving health literacy to support and empower the consumer.
- Addressing the issues surrounding the transition from paediatric to adult care for youth diagnosed with type 1 diabetes, including access to government assistance (for example, criteria for the health care card change at 16 years of age, leading to greater health expenses for people with type 1 diabetes).
- Increasing access and government subsidies for the type 1 Insulin Pump Program.
- Reviewing chronic disease management GP services on the Medicare Benefits Schedule to provide better planning and coordination of multidisciplinary health care and include prediabetes.
- Increasing the frequency of testing for eye health and kidney checks and potentially incorporating them into GP management plans; increasing the use of prompts (e.g., via My Health Record or the National Diabetes Services Scheme).
- Providing an opportunity to work with existing health reforms through the new Primary Health Networks (PHNs), including setting performance indicators, targets, incentives and reporting requirements.
- Recognising that PHNs have an important role to play in providing collaborative health care planning and case management.
- Examining the role of PHNs in the supporting workforce within Indigenous communities.
- Increasing workforce capacity, particularly in relation to Indigenous communities.
- Addressing the role of the GP in care pathways, in particular helping to connect patients with appropriate specialist services. There is a need for increased GP awareness and education.
- Addressing the social determinants of health.
- Ensuring food security and access (e.g., through price signalling and rates of food inflation).
- Better managing comorbidities, especially psychosocial issues, anxiety and depression.
- Ensuring mental health care for people with diabetes, especially upon diagnosis but also in adolescence (when transitioning from child to adult services).
- Providing more support for dementia and ageing as multi-morbidities. There are significant issues to address.
- Developing a set of nationally consistent guidelines, rationalising the number of current guidelines, and removing barriers to implementation.
- Supporting a national research agenda and equitable research funding.
- Improving availability and cost of access for new and emerging technologies.
- Realising the benefits of My Health Record and GP/medical software systems to improve patient care.
- Making My Health Record an 'opt-out' system.

- Implementing data linkage, with suggestions for a data repository to improve research translation.
- Supporting the regularity of the Australian Health Survey to monitor population-level indicators of diabetes and other risk factors and trends.
- Providing separate research funding for type 1 and type 2 diabetes.
- Further exploring the benefits of bariatric surgery for diabetes.
- Addressing workforce issues, including the variability of care across health professionals and lack of access to (and use of) guidelines. It was also suggested that practice nurses could become more involved in prediabetes care.
- Considering early life influences, including nutrition in pregnancy, infant nutrition and breastfeeding, early childhood, maternal and child health, and the impact of smoking and alcohol.
- Integrating care across all levels of government.