

2016

Review of diabetes among Aboriginal and Torres Strait Islander people

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Originally published as: Ride, K., & Burrow, S. (2016). *Review of diabetes among Aboriginal and Torres Strait Islander people*. Perth, WA: Edith Cowan University here

This Book is posted at Research Online.

<https://ro.ecu.edu.au/ecuworkspost2013/2226>

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1. Australian Indigenous HealthInfoNet

No.17 March, 2016

Suggested citation

Burrow S, Ride K (2016) Review of diabetes among Aboriginal and Torres Strait Islander people. Australian Indigenous HealthInfoNet.

This review – or an updated version can be viewed at:

http://www.healthinfonet.ecu.edu.au/diabetes_review

This review has been peer-reviewed

Introduction

Diabetes is the world's fastest growing chronic disease [1]. Type 2 diabetes in particular, has reached epidemic proportions globally and in Australia, and poses a challenge for public health systems everywhere [2-4]. The greatest burden tends to fall on socially disadvantaged groups and Indigenous peoples [2]. Aboriginal and Torres Strait Islander Australians experience disproportionately high levels of diabetes. They are three times more likely to have diabetes¹ than non-Indigenous Australians [5, 6] and Aboriginal and Torres Strait Islander women are almost twice as likely to develop gestational diabetes as non-Indigenous women [7]. There is also evidence that Aboriginal and Torres Strait Islander children² are eight times more likely to develop type 2 diabetes (traditionally considered an adult disorder [2]) than their non-Indigenous peers [8]. Mortality rates are correspondingly high, and Aboriginal and Torres Strait Islander people are six times more likely to die from diabetes than non-Indigenous Australians [9].

1 Based on self-reported and biomedical data from a 2012-2013 national survey measuring type 1 diabetes, type 2 diabetes, and/or high sugar levels [5, 6].

2 Aged 10-14 years [8].

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Box 1: Diabetes

Diabetes (diabetes mellitus) is a disease marked by high levels of glucose in the blood [10]. It is caused by the body's inability to produce and/or use insulin effectively. It is a complex, chronic condition that can lead to morbidity, disability, reduced quality of life and premature death [3, 10, 11]. Diabetes can affect the entire body and typically requires lifelong management [3, 11]. There is currently no known cure [3]. If undiagnosed or poorly managed, diabetes can lead to a range of complications and death [6]. Complications include diseases of the large blood vessels (macrovascular disease), such as heart disease and stroke, and diseases of the small blood vessels (microvascular disease), such as kidney disease, eye disease and nerve disease [12]. Type 2 diabetes is the most common form of diabetes, frequently affecting older people but increasingly occurring in young people and children [2, 3]. Type 1 diabetes and gestational diabetes are the other main types of diabetes [10].

The high level of diabetes among Aboriginal and Torres Strait Islander people reflects a broad range of contributing factors [13, 14]. Addressing these factors should reduce the impact of diabetes on Aboriginal and Torres Strait Islander people; but this will require a range of tailored, culturally appropriate prevention and management programs, and broader action beyond the health service sector [13, 15, 16].

About this review

The purpose of this review is to provide a comprehensive synthesis of key information on diabetes among Aboriginal and Torres Strait Islander people in Australia to: (1) inform those involved or interested in Aboriginal and Torres Strait Islander health; and (2) provide the evidence for those involved in policy, strategy and program development and delivery. The review focuses primarily on type 2 diabetes among Aboriginal and Torres Strait Islander people—which is responsible for the majority of cases of diabetes in this population—but also refers to type 1 diabetes and gestational diabetes where relevant. It provides general information on the historical, social and cultural context of diabetes, and the behavioural and biomedical factors that contribute to diabetes among Aboriginal and Torres Strait Islander people. This review provides detailed information on the extent of diabetes, and its complications and comorbidities among Aboriginal and Torres Strait Islander people, including: incidence and prevalence data; hospitalisations; mortality and burden of disease. This review discusses the issues of prevention and management of diabetes, and provides information on relevant programs, services, policies and strategies that address the health issue of diabetes among

Aboriginal and Torres Strait Islander people. This review concludes by discussing possible future directions for combatting the growing epidemic of diabetes in Australia.

This review draws mostly on journal publications, government reports, national data collections and national surveys, the majority of which can be accessed through the *HealthInfoNet's* Australian Indigenous Health *Bibliography*.

When referring to Australia's Indigenous people, the *HealthInfoNet* prefers to use the terms Aboriginal, Torres Strait Islander, or Aboriginal and Torres Strait Islander. However, when referencing information from other sources, our authors are ethically bound to utilise the terms from the original source unless they can obtain clarification from the report authors/copyright holders. As a result, readers may see these terms used interchangeably with the term 'Indigenous' in some instances. If they have any concerns they are advised to contact the *HealthInfoNet* for further information.

Acknowledgements

Special thanks are extended to:

- the anonymous reviewer whose comments greatly assisted finalisation of this review
- other staff at the Australian Indigenous Health *InfoNet*, particularly to Christine Potter, Miranda Poynton and Millie Hardford-Mills, for their assistance and support
- the Australian Government Department of Health for their ongoing support of the work of the *HealthInfoNet*.

Key facts

The context of Aboriginal and Torres Strait Islander health and diabetes

- The factors contributing to diabetes among Aboriginal and Torres Strait Islander people reflect a combination of broad historical, social and cultural factors as well as proximal health risk factors.
- In 2012-2013, after age-adjustment, Aboriginal and Torres Strait Islander people were more likely than non-Indigenous people to: be overweight or obese (1.2 times); have high blood pressure (1.2 times); have abnormal high density lipoprotein cholesterol (1.8 times) and triglycerides (1.9 times); and to smoke (2.6 times). Aboriginal and Torres Strait Islander people were less likely to meet the guidelines for daily fruit intake (0.9 times) or daily vegetable intake (0.8 times) than non-Indigenous people.
- In 2012-2013, obese Aboriginal and Torres Strait Islander people were nearly five times as likely to have diabetes than those who were of normal weight or underweight (19% compared with 4%).

- In 2012-2013, Aboriginal and Torres Strait Islander people with high blood pressure were nearly three times as likely as those without high blood pressure to have diabetes (24% compared with 9%).

The extent of diabetes among Aboriginal and Torres Strait Islander people

- Individual studies provide varying estimates of the prevalence of diabetes in specific Aboriginal and Torres Strait Islander communities—some as low as 4%, others as high as 33%.
- In 2012-2013, national estimates of the prevalence of diabetes (type 1, type 2 or high sugar levels) among Aboriginal and Torres Strait Islander people ranged from 9% (based on self-reported data) to 11% (based on biomedical data). After age-adjustment, Aboriginal and Torres Strait Islander people were more than 3 times as likely as non-Indigenous people to have diabetes.
- Between 2006 and 2011, the age-specific incidence rates of type 2 diabetes for young Aboriginal and Torres Strait Islander people were more than eight times higher than those for non-Indigenous 10-14 year olds, and almost four times higher than those for non-Indigenous 15-19 year olds.
- Between 2005 and 2007, 1.5% of Aboriginal and Torres Strait Islander women who gave birth had pre-existing diabetes and 5.1% had gestational diabetes mellitus (GDM). Aboriginal and Torres Strait Islander women who gave birth were more than three times as likely to have pre-existing diabetes and almost two times as likely to have GDM as their non-Indigenous counterparts.
- In 2012-13, after age-adjustment, Aboriginal and Torres Strait Islander people were four times more likely to be hospitalised for diabetes than non-Indigenous people. They were nearly two times more likely to be hospitalised for type 1 diabetes and GDM, and four times more likely to be hospitalised for type 2 diabetes, than their non-Indigenous counterparts.
- In 2013, diabetes (excluding GDM) was the second leading underlying cause of death among Aboriginal and Torres Strait Islander people, with an age-adjusted death rate six times higher than that for non-Indigenous people.

Complications and comorbidities associated with diabetes

- In 2012-13, age-standardised hospitalisation rates for complications of type 2 diabetes (as a principal diagnosis) were almost six times higher for Aboriginal and Torres Strait Islander people living in all jurisdictions, than those for non-Indigenous people.
- In 2012-13, hospitalisation rates for renal complications of type 2 diabetes were 10 times higher among Aboriginal and Torres Strait Islander people than those among non-Indigenous people.

- In 2012-13, Aboriginal and Torres Strait Islander people with diabetes, cardiovascular disease and chronic kidney disease (i.e. all three conditions at the same time) were seven times more likely to be hospitalised than their non-Indigenous counterparts.
- In 2005-2007, Aboriginal and Torres Strait Islander mothers who had diabetes during pregnancy were more likely than their non-Indigenous counterparts to have complications, including: pre-term delivery, pre-term induction, and a long hospital stay. Their babies were more likely than non-Indigenous babies to have a low Apgar score, high level resuscitation, and a long hospital stay.

Prevention and management of diabetes

- Evidence suggests that short-term healthy lifestyle programs designed to prevent type 2 diabetes among Aboriginal and Torres Strait Islander people, can have positive health effects for up to two years, and are more likely to be effective if they are initiated by the community.
- Evidence suggests that structured management strategies used in primary care settings can lead to sustained improvements in diabetes care and health outcomes for Aboriginal and Torres Strait Islander people.

Diabetes programs and services

- Evidence suggests that competent, culturally appropriate primary health care services can be effective in improving diabetes care and outcomes for Aboriginal and Torres Strait Islander people.
- Evidence suggests that primary health care services that apply continuous quality improvement (CQI), can experience improvements in both service delivery rates and clinical outcome measures in Aboriginal and Torres Strait Islander patients with diabetes.

Diabetes policies and strategies

- In 2013, Diabetes Australia developed the *Aboriginal and Torres Strait Islanders and diabetes action plan*. It provided to government a proposed national plan, the first of its kind, to guide future approaches in Aboriginal and Torres Strait Islander diabetes policy and program development.
- At the end of 2015, the Federal Government released the *Australian national diabetes strategy 2016-2020*. This strategy includes a specific goal to reduce the impact of diabetes among Aboriginal and Torres Strait Islander people. Many of the potential areas for action identified in the strategy are consistent with recommendations in the *Diabetes Australia Action plan*.

- The Diabetes Australia *Action plan* and the new *National diabetes strategy* highlight the need for a coordinated national approach to guide the development of holistic diabetes programs that integrate cultural values and address the health of Aboriginal and Torres Strait Islander people across their lifespan.

The context of Aboriginal and Torres Strait Islander health and diabetes

The risk of developing diabetes is influenced not only by an individual's behavior, but also by: historical, social, cultural, geographical, economic and community factors; and government health policies and services [16]. Diabetes exists alongside a broad range of historical, social and cultural determinants that influence the health of Aboriginal and Torres Strait Islander people [13, 15].

The broad health disadvantages experienced by Aboriginal and Torres Strait Islander people can be considered historical in origin [17], but they have been perpetuated by the contemporary social and cultural determinants of health that contribute to current Aboriginal and Torres Strait Islander health inequalities [18, 19]. To understand the impact of diabetes on Aboriginal and Torres Strait Islander people it is necessary to understand the historical, social and cultural context of Aboriginal and Torres Strait Islander health.

The historical, social and cultural context

Aboriginal and Torres Strait Islander people maintained a hunter-gatherer lifestyle up until the late 18th century, but the arrival of Europeans in 1788 led to major changes in lifestyle [20, 21]. Traditional activities associated with finding renewable food and resources, maintaining familial and cultural practices, and sustaining the spiritual connection to country changed over time [17, 20-23].

Adverse changes in physical activity and nutrition (key risk factors for diabetes) played an important role in the development of diabetes in Aboriginal and Torres Strait Islander people, particularly in the second half of the 20th century [20, 23]. The first case of diabetes among Aboriginal and Torres Strait Islander people was recorded in Adelaide in 1923 [24]. Records prior to this time showed that Aboriginal and Torres Strait Islander people were fit and lean, and did not suffer from the metabolic conditions characteristic of European populations [25 cited in 26]. The earliest detailed studies investigating the development of diabetes in Aboriginal and Torres Strait Islander populations were not undertaken until the early 1960s [26]. These and subsequent studies found a significant correlation between the development of a 'westernised' lifestyle and the levels of diabetes in the Aboriginal and Torres Strait Islander population [26, 27].

In contemporary society, economic opportunity, physical infrastructure and social conditions influence the health of individuals and communities [18, 28, 29]. These factors are apparent in measures of education, employment, income, housing, access to services, connection with land, racism, and incarceration. On all these measures, Aboriginal and Torres Strait Islander people suffer substantial disadvantage in comparison with their non-Indigenous counterparts.

The factors contributing to diabetes among Aboriginal and Torres Strait Islander people reflect a combination of broad historical influences, and social and cultural determinants, as well as proximal health risk factors. It is beyond the scope of this review to discuss the underlying social and cultural determinants that influence the development of diabetes; or emerging evidence regarding the role of epigenetic factors³, the intrauterine environment and other early life factors [2]; but the main health risk factors are discussed below.

Factors contributing to diabetes among Aboriginal and Torres Strait Islander people

Several behavioural and biomedical factors are known to increase the risk of developing diabetes, particularly type 2 diabetes [31]; conversely improvements in these factors can reduce the risk of diabetes and become protective in nature.

Protective factors

Beneficial changes in lifestyle, such as a reduction in obesity, increases in physical activity and improvements in diet, are critical to reducing the risk of type 2 diabetes [16, 31]. There is also evidence that breastfeeding can reduce the risk of maternal type 2 diabetes in later life [32]. An Australian study published in 2010, found an excess risk of diabetes among childbearing women who did not breastfeed, compared with women who did not have children. This risk was substantially reduced by breastfeeding, and the benefit increased with the duration of breastfeeding. Breastfeeding also reduces the risk of babies becoming overweight [13], and reduces the risk of early onset obesity and diabetes in babies born to mothers who have diabetes in pregnancy [15]. According to the 2004-2005 *National Aboriginal and Torres Strait Islander health survey*, 84% of Aboriginal and Torres Strait Islander mothers aged 18-64 years reported having breastfed their children [33]. In the 2008 *National Aboriginal and Torres Strait Islander social survey*, 76% of Aboriginal and Torres Strait children aged 0-3 years were reported to have been breastfed [34].

³ Epigenetics is the study of heritable changes in our genes that occur without altering the DNA or genetic code [30].

Risk factors

Behavioural and biomedical risk factors known to increase the risk of developing diabetes, particularly type 2 diabetes, include high blood pressure, high blood cholesterol, tobacco smoking, low levels of physical activity, poor diet, and being overweight or obese [31]. Aboriginal and Torres Strait Islander people are more likely to have these risk factors for diabetes than non-Indigenous Australians [5], and many who already have diabetes have multiple risk factors and other related health problems [35-37].

Box 2: Health risk factors for diabetes

Health risk factors refer to the behaviours, characteristics, or exposures that increase the likelihood of a person developing a disease [31]. When people have multiple risk factors, the likelihood of developing the disease is heightened. Risk factors can also increase the severity of the disease and the likelihood of developing complications or other diseases, and can compromise efforts to provide optimal care to people who already have the disease.

The conventional risk factors for diabetes can be divided into two main categories: non-modifiable and modifiable [31, 38]. Non-modifiable risk factors include family history and age. Modifiable risk factors can be categorised as behavioural or biomedical and can be modified by changes in behaviour and lifestyle, or the use of medical interventions. Behavioural risk factors are health-related behaviours and include tobacco smoking, low levels of physical activity and poor nutrition. Biomedical risk factors are often influenced by behavioural risk factors, but refer to factors that are present in the body and include impaired glucose regulation, high blood pressure (hypertension), high blood cholesterol (dyslipidaemia) and obesity. When these risk factors occur together, known collectively as the metabolic syndrome, they greatly increase the risk of type 2 diabetes.

Having more than one risk factor increases the risk of diabetes and having diabetes increases the risk of some other diseases including cardiovascular disease, kidney disease and diabetic retinopathy [31, 39]. Cardiovascular disease is itself a risk factor for diabetes.

Self-reported and biomedical data regarding the prevalence of selected health risk factors among Aboriginal and Torres Strait Islander people is available from the 2012-13 *Australian Aboriginal and Torres Strait Islander health survey* (AATSIHS) [5, 6]. Although this data is from a national cross-sectional survey, and cause and effect cannot be attributed to risk factors and chronic conditions present at the time of the survey [31], the high prevalence of some risk

factors among Aboriginal and Torres Strait Islander people is likely to contribute to the high prevalence of diabetes in this population compared with the non-Indigenous population [16].

Box 3: The 2012-2013 Australian Aboriginal and Torres Strait Islander health survey (AATSIHS)

The 2012-2013 AATSIHS is the latest national Aboriginal and Torres Strait Islander health survey conducted by the Australian Bureau of Statistics (ABS). It collected information from a nationally representative sample of around 12,900 Aboriginal and Torres Strait Islander people [5, 6]. Results from the AATSIHS provide information on health risk factors, long-term health conditions (including diabetes/high sugar levels), use of health services, and biomarkers of chronic disease (including diabetes) and nutrition. The 2012-2013 AATSIHS expands on the information included in previous health surveys via two new components - the *National Aboriginal and Torres Strait Islander nutrition and physical activity survey* (NATSINPAS) and the *National Aboriginal and Torres Strait Islander health measures survey* (NATSIHMS).

Included among the health risk factors for which data has been collected in the 2012-13 AATSIHS, are several that are risk factors for diabetes, specifically: overweight and obesity; high blood pressure; abnormal cholesterol and triglycerides; smoking; and inadequate fruit and vegetable intake [5, 6].

Overweight and obesity

Sixty-six percent of Aboriginal and Torres Strait Islander people aged 15 years and over were either overweight (29%) or obese (37%) according to their body mass index (BMI) [40]. The proportion of Torres Strait Islanders⁴ who were overweight or obese was slightly higher (33% and 40% respectively) than the proportion of Aboriginal people (28% and 37% respectively). The proportion of overweight or obese children aged 2-4 years was smaller in the Aboriginal and Torres Strait Islander population than in the non-Indigenous population (17% compared with 23%) but similar among children aged 5-9 years (24% and 23% respectively) [41]. The proportion of overweight or obese people in all other age groups was significantly greater for Aboriginal and Torres Strait Islander people than for non-Indigenous people [41, 42]. After age-adjustment, Aboriginal and Torres Strait Islander people aged 15 years and over were 1.2 times as likely as non-Indigenous people to be overweight or obese [42].

4 Includes people who are of Torres Strait Islander origin only, and those who are of both Aboriginal and Torres Strait Islander origin [40]

Obese Aboriginal and Torres Strait Islander people aged 18 years and over were around five times more likely to have diabetes⁵ than those who were of normal weight or underweight (19% compared with 4%) [36].

High blood pressure

Twenty percent of Aboriginal and Torres Strait Islander adults aged 18 years and over had high blood pressure ($\geq 140/90$ mmHg or higher) [43]. After age-adjustment, Aboriginal and Torres Strait Islander adults were more likely to have high blood pressure than non-Indigenous adults (rate ratio 1.2).

Aboriginal and Torres Strait Islander people with high blood pressure were nearly three times as likely as those without high blood pressure to have diabetes (24% compared with 9%) [36].

Abnormal cholesterol and triglycerides

The proportion of Aboriginal and Torres Strait Islander adults aged 18 years and over with abnormal test results for cholesterol or triglycerides was as follows [44]:

- twenty-five percent had abnormal test results for total cholesterol (≥ 5.5 mmol/L)
- twenty-five percent had abnormal test results for low density lipoprotein (LDL) cholesterol (≥ 3.5 mmol/L)
- forty percent had abnormal test results for high density lipoprotein (HDL) cholesterol (for males < 1.0 mmol/L; for females < 1.3 mmol/L)
- twenty-five percent had abnormal test results for triglycerides (≥ 2.0 mmol/L).

After age-adjustment, Aboriginal and Torres Strait Islander adults were more likely to have abnormal HDL cholesterol and triglycerides than non-Indigenous adults (ratios of 1.8 and 1.9 respectively), but were less likely to have abnormal total cholesterol and LDL cholesterol (ratios for both were 0.8) [45].

Aboriginal and Torres Strait Islander adults with diabetes were around twice as likely to have abnormal HDL cholesterol (67% compared with 35%) and triglycerides (44% compared with 22%) than those without diabetes [37].

Smoking

Forty-two percent of Aboriginal and Torres Strait Islander people aged 15 years and over smoked on a daily basis (42% of Aboriginal people and 38% of Torres Strait Islander people) [40]. After age-adjustment, Aboriginal and Torres Strait Islander people aged 15 years and over were 2.6 times as likely as non-Indigenous people to

be current daily smokers [46]. Sixty-nine percent of Aboriginal and Torres Strait Islander adults aged 18 years and over were current or ex-smokers (47% and 22% respectively).

Among current and ex-smokers, 11% and 17% (respectively) had diabetes, compared with 12% among those who had never smoked [36].

Inadequate fruit and vegetable intake

Forty-six percent of Aboriginal and Torres Strait Islander people aged 2 years and over had inadequate daily fruit intake and 92% had inadequate daily vegetable intake based on 2013 National Health and Medical Research Council (NHMRC) guidelines [47]. Among Aboriginal and Torres Strait Islander people aged 2 years and over, 93% had inadequate fruit and/or vegetable intake, and the proportion was higher (97%) among Aboriginal and Torres Strait Islander people aged 15 years and over. Torres Strait Islander people aged 15 years and over were less likely to have inadequate daily fruit intake (52%) compared with Aboriginal people (59%), but were similarly likely to have inadequate daily vegetable intake (94% and 95% respectively) [40]. After age-adjustment, Aboriginal and Torres Strait Islander people aged 15 years and over were less likely to meet the guidelines for daily fruit intake or daily vegetable intake than non-Indigenous people (ratios were 0.9 and 0.8 respectively) [5].

Trends in chronic disease risk factors

In a study conducted between 1992 and 2006, Wang and colleagues describe trends in chronic disease risk factors over a 10 to 14-year interval in a high-risk, remote Aboriginal community in the Northern Territory (NT) [48]. Community members aged five years or older participated in two health surveys, the first performed between 1992 and 1997 and the second between 2004 and 2006. Outcomes were compared across age-matched and sex-matched pairs. Results from the two surveys suggest improvements in some risk factors for diabetes over this period, including:

- a reduction in smoking and rates of elevated blood pressure for males aged 15-24 years
- a decrease in weight, BMI, systolic blood pressure and triglycerides among males aged 15-44 years
- higher levels of HDL cholesterol among males aged 15+ years
- improvements in HDL cholesterol for women aged 15+ years and LDL cholesterol for those aged 45+.

Despite these improvements, and a decrease in the prevalence of diabetes among males aged 45-54 years, the prevalence of other risk factors for diabetes increased (particularly among women) and the prevalence of diabetes remained the same or increased across all other age groups [48]. The prevalence of diabetes was

5 Diabetes was diagnosed based on glycated haemoglobin (HbA1c) test results [36].

notably higher among males aged 55 years and over and females aged 45 years and over, compared with the same age groups in the preceding survey. Approximately 50% or more of people in these age groups had diabetes at the time of the second survey, and the prevalence of diabetes increased by more than 50% in all females aged 15 years and over. Addressing the factors that increase the risk of diabetes remains critical to the prevention and management of this condition among Aboriginal and Torres Strait Islander people [13].

Extent of diabetes among Aboriginal and Torres Strait Islander people

There are several types of diabetes, of which the most frequently occurring are type 1, type 2 and gestational diabetes (GDM) (see Box 4) [49, 50]. Type 1 diabetes is relatively uncommon in the Aboriginal and Torres Strait Islander population, but Aboriginal and Torres Strait Islander people experience disproportionately high levels of type 2 diabetes [51]. Levels of GDM are also higher among Aboriginal and Torres Strait Islander women than among non-Indigenous women [7, 52].

Box 4: Types of diabetes

Type 1 diabetes (also known as *type 1 diabetes mellitus* – T1DM) is most frequently diagnosed in childhood and adolescence [7, 35, 53]. It is an autoimmune condition that is characterised by hyperglycaemia (high blood sugar levels) resulting from the body's inability to produce insulin. Most cases are caused by the destruction of insulin-producing cells in the pancreas by the body's own immune system. People with type 1 diabetes need insulin replacement for survival.

Type 2 diabetes (also known as *type 2 diabetes mellitus* – T2DM) usually develops in adulthood, although it is increasingly reported in some child and adolescent populations [7, 53]. It is characterised by hyperglycaemia due to insulin resistance and/or a deficiency in insulin production. This form of diabetes often runs in families, and typically occurs when risk factors such as obesity, poor nutrition, and lack of physical activity are present. Type 2 diabetes can usually be controlled through lifestyle modifications, but may require insulin treatment over time.

Gestational diabetes (also known as *gestational diabetes mellitus* – GDM) is a form of diabetes that develops during pregnancy in some women [7, 35, 53]. GDM is caused by placental hormones that block the action of insulin, leading to insulin resistance and high blood sugar levels in pregnant women not previously diagnosed with other forms of diabetes [7, 35, 53, 54]. This type

of diabetes is short term and usually develops in the second or third trimester of pregnancy, with potentially adverse outcomes for both mother and baby [7, 35]. GDM usually disappears after the baby is born, although it puts the mother at increased risk of developing type 2 diabetes later in life. GDM can recur in later pregnancies.

There are various ways to measure the extent of diabetes in a given population, including prevalence, incidence, health service utilisation, mortality and burden of disease. This review focuses primarily on national data that provide an aggregate picture of the impact of diabetes on Aboriginal and Torres Strait Islander people. Much of the published data pertains to type 2 diabetes, but figures for type 1 diabetes and GDM are reported where available. Separate data for Torres Strait Islanders is limited, but is also provided where available. The various measurements used in this review are defined below (see Box 5). It should be noted however, that:

- the availability and quality of data varies
- there are data limitations associated with each of the measures of diabetes
- statistics about diabetes for Aboriginal and Torres Strait Islander people are often underestimated (Appendix 1 provides a brief discussion of limitations associated with data sources used in this review).

Box 5: Measuring diabetes

Incidence is the number of new cases of diabetes that occur during a given period [55].

Prevalence is the number or proportion of cases of diabetes in a population at a given time [55].

Age-standardised rates enable comparisons of rates of diabetes between populations that have different age structures [56]. Age standardisation is often used when comparing Aboriginal and Torres Strait Islander people and non-Indigenous people because the Aboriginal and Torres Strait Islander population has a younger age structure than the non-Indigenous population.

Rate ratio (RR) is the rate of Aboriginal and Torres Strait Islander people affected by diabetes divided by the rate of non-Indigenous people affected by diabetes [56].

Ratio (R) is the proportion of Aboriginal and Torres Strait Islander people affected by diabetes divided by the proportion of non-Indigenous people affected by diabetes.

Potentially preventable hospitalisations are hospital admissions for conditions (including diabetes) that may have been avoided through appropriate preventive measures and early disease management, usually delivered in primary care and community-based care settings [56].

Potentially avoidable deaths are deaths among people aged less than 75 years from conditions (including diabetes) considered potentially preventable and treatable [56]. Potentially avoidable deaths can be reduced through lifestyle improvements and appropriate primary prevention, early intervention and medical treatment.

Burden of disease is measured in disability-adjusted life years (DALYs). It provides a combined estimate of years of life lost due to premature mortality caused by diabetes, and years of life lost due to disability or ill health caused by diabetes [57].

Fatal burden is measured in years of life lost (YLLs) and refers to the burden of disease that is caused by premature mortality from diabetes [57].

Prevalence

A systematic review conducted in 2011—of studies published between 1997 and 2010—reported considerable variation in the prevalence of diabetes among Aboriginal and Torres Strait Islander

people [58]. Estimates of the prevalence of diabetes ranged from 4% to 33% depending on the communities or groups surveyed. According to the 2012-2013 AATSIHS, national estimates of the prevalence of diabetes (type 1, type 2 or high sugar levels) among Aboriginal and Torres Strait Islander people range from 8.6% (based on self-reported data [5]) to 11.1% (based on biomedical data [6]).

Self-reported data

According to the 2012-2013 AATSIHS, around 8.6% of Aboriginal and Torres Strait Islander people (8.8% of Aboriginal people and 7.0% of Torres Strait Islander people) aged 2 years and over reported that they had type 1 or type 2 diabetes and/or high sugar levels in their blood or urine [5, 40]. After age-adjustment, rates of diabetes and/or high sugar levels were 3.2 times higher among Aboriginal and Torres Strait Islander people than among non-Indigenous people [59]. Diabetes and/or high sugar levels were reported by a higher proportion of Aboriginal and Torres Strait Islander females (9.6%) than males (7.7%) [60].

The prevalence of diabetes and/or high sugar levels increased with age,⁶ [61] ranging from 1% for Aboriginal and Torres Strait Islander people aged 2-14 years to 40% for those aged 55 years and over (Table 1) [59]. The age-specific levels from 25 years onwards were between three and five times higher than those for non-Indigenous people.

Table 1. Proportions (%)¹ of people reporting diabetes/high sugar levels as a long-term health condition, by Indigenous status, and Indigenous:non-Indigenous ratios, Australia, 2012-2013

Age group (years)	Aboriginal and Torres Strait Islander (%)	Non-Indigenous (%)	Ratio ^{2,4}
2-14	0.5	NA ³	NA ³
15-24	1.4	NA ³	NA ³
25-34	5.3	1.1	4.8
35-44	11	2.8	4.0
45-54	23	5.6	4.2
55+	40	14	2.9

- Notes:
1. Proportions are expressed as percentages
 2. Ratio is the Indigenous proportion divided by the non-Indigenous proportion
 3. Not available
 4. Rounding may result in inconsistencies in calculated ratios

Source: ABS, 2014 (derived from Table 6.3) [59]

⁶ Data for age groups less than 25 should be used with caution due to the associated high standard error. Prevalence data for non-Indigenous people aged 2-14 and 15-24 was not reported [59].

The prevalence of diabetes/high sugar levels was lower among Aboriginal and Torres Strait Islander people living in non-remote areas (7.5%) than among those living in remote areas (12.8%) [59] and varied between states and territories [45]. The prevalence among Aboriginal and Torres Strait Islander people was highest in the Northern Territory (NT) at 12%, and lowest in Tasmania (Tas) at 3.8%, with 10% in Western Australia (WA), 8.9% in South Australia (SA), 8.3% in Queensland (Qld), 8.1% in New South Wales (NSW), 7.6% in the Australian Capital Territory (ACT), and 7.1% in Victoria (Vic).

Biomedical data

Biomedical results broadly confirmed the self-reported results obtained from the AATSIHS. Biomedical data was obtained for a subset of Aboriginal and Torres Strait Islander adults (18 years and over) who provided blood and urine samples [6]. Results for fasting plasma glucose levels revealed that 11% of Aboriginal and Torres Strait Islander adults had diabetes (9.6% had known diabetes and 1.5% were newly diagnosed from their test results) [62]. A further 4.7% of Aboriginal and Torres Strait Islander adults were at high risk of diabetes. After age-adjustment, Aboriginal and Torres Strait Islander adults were 3.3 times as likely as non-Indigenous adults to have diabetes [63]. Biomedical results also revealed that:

- diabetes prevalence among Aboriginal and Torres Strait Islander adults increased with age, with particularly high rates among those aged 55 years and over (35%) [63]
- diabetes tended to occur at earlier ages among Aboriginal and Torres Strait Islander adults than among non-Indigenous adults, with Aboriginal and Torres Strait Islander people having diabetes at rates similar to those of non-Indigenous people who were 20 years older [63]
- Aboriginal and Torres Strait Islander adults in remote areas were twice as likely to have diabetes as those living in non-remote areas (20.8% compared with 9.4%) [64]
- around half of Aboriginal and Torres Strait Islander adults with diabetes also had signs of chronic kidney disease (53% compared with 11% without diabetes) [37].

Gestational diabetes mellitus

The Australian Institute of Health and Welfare (AIHW) has analysed data from the *National perinatal data collection* (NPDC) and calculated the prevalence of GDM for the period 2005-2007 [7]. In this period, 6.6% of Aboriginal and Torres Strait Islander women who gave birth in Australia had diabetes during pregnancy: 1.5% had pre-existing diabetes and 5.1% had GDM. Aboriginal and Torres Strait Islander women who gave birth were 3.2 times more likely than their non-Indigenous counterparts to have pre-existing diabetes and 1.6 times more likely to have GDM.

A systematic review investigating GDM prevalence among Aboriginal and Torres Strait Islander women was published in 2015. The meta-analysis of studies conducted between 1980 and 2013, found that the prevalence of GDM among Aboriginal and Torres Strait Islander women was 5.7% [52]. This pooled GDM prevalence is similar to that reported for 2005-2007 [7]; however GDM prevalence varied substantially between studies (1.3% to 18.5%) [52]. The researchers noted that the prevalence of GDM increased fourfold between 1985-1987 and 1989 (from 3% to 12%)—following the introduction of universal screening for Aboriginal women in Central Australia—and concluded that those studies reporting higher screening rates are more likely to reflect the true prevalence.

Incidence

Insulin-treated diabetes

National incidence data for diabetes is based on estimates for insulin-treated diabetes (type 1, type 2 and GDM) and obtained from the *National (insulin-treated) diabetes register* (NDR) [10] (Appendix 1 provides information regarding the limitations associated with this data).

In 2013, there were 70 new cases of type 1 diabetes among Aboriginal and Torres Strait Islander people, accounting for 3% of all new cases [65]. Between 2005 and 2013, 489 Aboriginal and Torres Strait Islander people were diagnosed with type 1 diabetes. The incidence rate for Aboriginal and Torres Strait Islander people in this period was lower than the rate for non-Indigenous people (7 per 100,000 population compared with 10 per 100,000 population).

In 2011, 62 Aboriginal and Torres Strait Islander people were diagnosed with type 1 diabetes⁷, 656 began using insulin to treat type 2 diabetes and 118 Aboriginal and Torres Strait Islander females began using insulin to treat GDM⁸ [10]. Of the new cases of insulin-treated diabetes identified in 2011, Aboriginal and Torres Strait Islander people accounted for 2.6% of cases of type 1 diabetes, 1.8% of cases of type 2 diabetes, and 1.9% of cases of GDM among females aged 15-49. Type 1 diabetes occurred more frequently among Aboriginal and Torres Strait Islander males (60%) than females, and type 2 diabetes (insulin-treated cases only) occurred more frequently among Aboriginal and Torres Strait Islander females (54%) than males.

Aggregated data for the years between 2006 and 2011 revealed that [10]:

- age-adjusted incidence rates of insulin-treated type 2 diabetes

7 Year of first insulin use is a proxy for year of diagnosis [10].

8 Results should be interpreted with caution as status (Indigenous/non-Indigenous) was not recorded for: 24% of cases of type 1 diabetes; 54% of cases of type 2 diabetes; and 26% of cases of GDM [10].

were almost 4 times higher for Aboriginal and Torres Strait Islander people (134 per 100,000) than non-Indigenous people (36 per 100,000)

- age-adjusted incidence rates of type 1 diabetes were lower for Aboriginal and Torres Strait Islander people (7 per 100,000) than for non-Indigenous people (10 per 100,000)
- age-adjusted incidence rates of insulin-treated GDM were similar for Aboriginal and Torres Strait Islander females (60 per 100,000) and non-Indigenous females (59 per 100,000).

Type 2 diabetes in Aboriginal and Torres Strait Islander children and adolescents

There is growing concern regarding the emergence of type 2 diabetes in Aboriginal and Torres Strait Islander children and adolescents [2]. Data is limited, but type 2 diabetes accounts for the majority of new cases of diabetes in this population [8]. It occurs more frequently among Aboriginal and Torres Strait Islander adolescents than among their non-Indigenous counterparts [66], and places them at heightened risk of comorbidities, diabetes complications and associated premature mortality [67].

Between 2006 and 2011, 252 new cases of diabetes were reported among Aboriginal and Torres Strait Islander youth aged 10-19 years at diagnosis⁹ [8]. Of these, 55% were type 2 and 43% were type 1 diabetes. The age-specific rates of type 2 diabetes for young Aboriginal and Torres Strait Islander people were much higher than for their non-Indigenous counterparts (8.3 times as high among 10-14 year olds and 3.6 times as high for 15-19 year olds). After age-adjustment, the incidence rate of type 2 diabetes for Aboriginal and Torres Strait Islander people aged 10-39 years was 3.5 times that of non-Indigenous people.

A population-based study conducted in NSW between 2001 and 2008, found that young Aboriginal and Torres Strait Islander people (aged 10-18 years) experienced a disproportionately high rate of type 2 diabetes¹⁰ [68]. The mean annual incidence of type 2 diabetes was 6.9 times higher in Aboriginal and Torres Strait Islander youth than in their non-Indigenous peers. Young Aboriginal and Torres Strait Islander females were more likely to be diagnosed with type 2 diabetes than their male counterparts (55% compared with 45%). Aboriginal and Torres Strait Islander youth were diagnosed with type 2 diabetes at an earlier average age than their non-Indigenous peers (13.5 years compared with 14.8 years) and were more likely to reside in rural areas than urban areas (71% compared with 26%).

9 Based on combined data from the *National diabetes services scheme* (NDSS) and the Australasian Paediatric Endocrine Group (APEG) [8].

10 Based on data from the APEG diabetes register and the NDR [68].

Health service utilisation

Measures of health service utilisation cannot provide information about whether the health system is meeting the needs of Aboriginal and Torres Strait Islander people, but they give some indication of the demand for, and access to, health services [69]. Included among these measures are figures for attendance at general practices and hospitals.

General practice attendances

General practitioners (GPs) are usually the initial point of contact for people with diabetes and often play a key role in coordinating the other specialised services and health professionals who are needed to manage the condition [38]. *The Bettering the evaluation and care of health* (BEACH) survey is a continuous, national, cross-sectional survey of the clinical activity of GPs [70]. The survey provides some evidence of the frequency with which GPs manage diabetes for Aboriginal and Torres Strait Islander patients.

According to survey data for the period April 2008 to March 2013, GPs were twice as likely to manage type 2 diabetes during encounters with Aboriginal and Torres Strait Islander patients compared with encounters with other patients (8.2 per 100 encounters compared with 4.0 per 100 encounters) [71].

Based on survey data for the period April 2006 to March 2011, diabetes was the most common individual problem managed by GPs during encounters with Aboriginal and Torres Strait Islander patients (7.6 per 100 encounters), due mainly to the higher management rate of type 2 diabetes (7.2 per 100 encounters) [72]. After adjusting for age, this was almost three times the rate for non-Indigenous patients. GP encounters with Aboriginal and Torres Strait Islander patients with type 1 diabetes or GDM occurred much less frequently (0.3 and 0.1 per 100 encounters respectively). After adjusting for age, these rates were higher than rates for non-Indigenous patients (1.6 times and 1.5 times respectively) but the differences were not statistically significant.

Hospitalisation

Hospital services are typically required to treat the advanced stages of complications of diabetes or acute episodes of poor glycaemic control [35]. Hospitalisation data therefore usually provides information on the more severe aspects of the disease and doesn't necessarily reflect the burden of diabetes in the community [38]. Despite these limitations (Appendix 1 provides further information regarding the limitations associated with this data), hospitalisation data remains the most comprehensive source of information about health service utilisation. The higher levels of diabetes observed among Aboriginal and Torres Strait Islander people are clearly reflected in hospitalisation figures.

In 2012-13 there were 2,749 hospital separations for diabetes (excluding GDM) for Aboriginal and Torres Strait Islander people in all Australian jurisdictions¹¹ [56]. After age-adjustment, Aboriginal and Torres Strait Islander people were four times more likely to be hospitalised for diabetes than non-Indigenous people.

There were similar numbers of hospitalisations for Aboriginal and Torres Strait Islander males and females (1,379 and 1,370 respectively). In comparison, males were 3.5 times more likely to be hospitalised, and females 4.7 times more likely to be hospitalised, than their non-Indigenous counterparts [56].

Hospitalisation rates for Aboriginal and Torres Strait Islander people with diabetes increased with increasing remoteness [56]. Age-standardised hospitalisation rates for Aboriginal and Torres Strait Islander people were highest in remote and very remote areas (11 per 1,000), followed by inner and outer regional areas (6.0 per 1,000), and major cities (4.3 per 1,000). Aboriginal and Torres Strait Islander people were 5.3 times more likely to be hospitalised for diabetes in remote and very remote areas, 3.4 times more likely to be hospitalised in inner and outer regional areas, and 2.8 times more likely to be hospitalised in major cities, than their non-Indigenous counterparts.

Further details are available for hospitalisations for diabetes as the principal and/or an additional diagnosis¹². In 2012-13, Aboriginal and Torres Strait Islander people were four times more likely to

be hospitalised for diabetes (all types¹³) as the principal and/or an additional diagnosis than non-Indigenous people [35]. Aboriginal and Torres Strait Islander males and females were both more likely to be hospitalised than their non-Indigenous counterparts (three and five times respectively).

Age-standardised hospitalisation rates for Aboriginal and Torres Strait Islander people with a principal or additional diagnosis of type 2 diabetes (5.5 and 115 per 1,000 respectively) were higher than those with a principal or additional diagnosis of type 1 diabetes (0.8 and 3.4 per 1,000 respectively) [35]. Aboriginal and Torres Strait Islander people were four times more likely to be hospitalised for type 2 diabetes, and 1.7 times more likely to be hospitalised for type 1 diabetes, than non-Indigenous people. Age-standardised hospitalisation rates for Aboriginal and Torres Strait Islander females with a principal or additional diagnosis of GDM were 1.5 and 3.9 per 1,000 respectively. Aboriginal and Torres Strait Islander females were 1.9 times more likely to be hospitalised for GDM than non-Indigenous females. Aboriginal and Torres Strait Islander males and females were more likely to be hospitalised for each type of diabetes than their non-Indigenous counterparts. When principal and additional diagnoses were analysed separately, the disparity was greatest for Aboriginal and Torres Strait Islander females with a principal diagnosis of type 2 diabetes, who were 8.1 times more likely to be hospitalised than non-Indigenous females (Tables 2 and 3).

Table 2. Diabetes hospitalisation rates, as the principal diagnosis, by Indigenous status and sex, 2012-13 (rate per 100,000 population)

Diabetes type	Males			Females		
	Indigenous	Non-Indigenous	RR	Indigenous	Non-Indigenous	RR
Type 1	88	61	1.4	78	63	1.2
Type 2	563	129	4.4	529	65	8.1
GDM				150	19	7.9

Notes: 1. 'Non-Indigenous' includes hospitalisations of those for whom Indigenous status was not stated.

2. Directly age-standardised to the 2001 Australian standard population.

Source: AIHW, 2014 (derived from Tables A6, A7 and A8) [35]

11 Data is for public and private hospitals in all jurisdictions. Data for all jurisdictions is considered to be of acceptable quality from 2010-11 onwards [56].

12 A principal diagnosis is the diagnosis considered to be chiefly responsible for the patient's hospitalisation. An additional diagnosis is recorded when another condition affects the patient's care during hospitalisation [35].

13 ICD-10-AM codes E10-E14 (type 1, type 2, other and unspecified diabetes) and O24.4 (GDM) [35].

Table 3. Diabetes hospitalisation rates, as an additional diagnosis, by Indigenous status and sex, 2012-13 (rate per 100,000 population)

Diabetes type	Males			Females		
	Indigenous	Non-Indigenous	RR	Indigenous	Non-Indigenous	RR
Type 1	328	181	1.8	344	177	1.9
Type 2	10,126	3,258	3.1	12,821	2,200	5.8
GDM				390	266	1.5

Notes: 1. 'Non-Indigenous' includes hospitalisations of those for whom Indigenous status was not stated.
 2. Directly age-standardised to the 2001 Australian standard population.

Source: AIHW, 2014 (derived from Tables A6, A7 and A8) [35]

Hospitalisation figures for 2012-13 do not provide an analysis of hospital separations for diabetes by age and Indigenous status, but these figures are available for the period July 2008 to June 2010 for Aboriginal and Torres Strait Islander people with a principal diagnosis of diabetes (all types excluding GDM) living in NSW, Vic, Qld, WA, SA and the NT¹⁴ [72]. In this period, age-specific hospitalisation rates for diabetes increased with age for both Aboriginal and Torres Strait Islander people and non-Indigenous

people, but Aboriginal and Torres Strait Islander males and females had much higher hospitalisation rates for diabetes than their non-Indigenous counterparts in all age groups from 15–24 years onwards (Table 4). The greatest rate ratio between Aboriginal and Torres Strait Islander and non-Indigenous hospitalisation rates occurred among males in the 35-44 year age group and females in the 45-54 year age group, for which Indigenous rates were 9.1 and 11.8 times greater than their non-Indigenous counterparts.

Table 4. Age-specific hospitalisation rates for a principal diagnosis of diabetes¹, by Indigenous status and sex, NSW, Vic, Qld, WA, SA, and NT², July 2008 to June 2010 (age-standardised rate per 1,000 population)

Age group	Males			Females		
	Indigenous	Non-Indigenous	RR ^{3,5}	Indigenous	Non-Indigenous	RR ^{3,5}
0-4	0.1	0.3	0.4	0.2	0.3	0.5
5-14	1.1	0.9	1.2	1.0	1.0	1.0
15-24	1.6	0.9	1.7	1.9	1.2	1.6
25-34	3.0	0.8	4.0	4.8	0.9	5.5
35-44	11	1.2	9.1	9.8	1.1	9.2
45-54	21	2.5	8.6	20	1.7	11.8
55-64	34	6.6	5.2	36	3.9	9.1
65+	42	20	2.1	44	14	3.1
All ages ⁴	14	4.1	3.4	14	3.0	4.8

Notes: 1. Based on the ICD-10-AM sixth edition codes E10-E14 (this excludes GDM). Indigenous rates are calculated using population estimates based on the 2006 Census.
 2. Data excludes private hospitals in the NT
 3. RR is the rate ratio Indigenous: non-Indigenous people
 4. Directly age-standardised using the Australian 2001 standard population
 5. Rounding may result in inconsistencies in calculated ratios

Source: AIHW, 2013 (derived from Table 1.09.6) [72]

Age-standardised hospitalisation rates for Aboriginal and Torres Strait Islander people with diabetes were greatest in WA (21 per 1,000), followed by SA (18 per 1,000), the NT (17 per 1,000), Qld (17 per 1,000), NSW (8.7 per 1,000), and Vic (8.1 per 1,000) [72]. The

greatest disparities between Aboriginal and Torres Strait Islander and non-Indigenous hospitalisation rates were seen among females in WA and the NT (6.2 and 7.2 times higher respectively).

14 Data from the NT is for public hospitals only [72].

Potentially preventable hospitalisations

Hospitalisations for various chronic conditions, including complications of diabetes, are considered potentially preventable [56]. In 2012-13, after age-adjustment, Aboriginal and Torres Strait Islander people were hospitalised for potentially preventable chronic conditions at 4.3 times the rate for non-Indigenous people¹⁵. Diabetes complications accounted for the largest proportion (67%) of these hospitalisations, resulting in an age-adjusted rate for Aboriginal and Torres Strait Islander people that was 6.1 times greater than the rate for non-Indigenous people.

Age-adjusted hospitalisation rates for diabetes complications were greatest for Aboriginal and Torres Strait Islander people in remote and very remote areas combined, where they were 10.5 times greater than rates for their non-Indigenous counterparts [56]. In comparison, rates in major cities, and inner and outer regional areas (combined), were 5.7 and 4.5 times greater (respectively) for Aboriginal and Torres Strait Islander people.

Mortality

In 2013¹⁶, diabetes¹⁷ was the second leading underlying cause of death for Aboriginal and Torres Strait Islander people, with an age-adjusted death rate six times higher than that for non-Indigenous people [9, 73]. Diabetes was responsible for 7.6% of deaths (202 deaths) among Aboriginal and Torres Strait Islander people living in NSW, Qld, SA, WA and the NT. In comparison, diabetes was responsible for 2.7% of deaths (2,726 deaths) of non-Indigenous people in these jurisdictions.

Diabetes was the leading cause of death among Aboriginal and Torres Strait Islander females in 2013, responsible for 121 deaths (10%). In comparison, there were 81 deaths (5.7%) among Aboriginal and Torres Strait Islander males [73]. After age-standardisation, Aboriginal and Torres Strait Islander females and males were both more likely to die from diabetes than their non-Indigenous counterparts (8.1 and 4.2 times respectively).

Between 2009 and 2013, the number of Aboriginal and Torres Strait Islander females dying from diabetes increased by 15.2%, compared with a 2.1% increase in deaths among non-Indigenous females [9]. In this period, the greatest disparity in Indigenous: non-Indigenous age-specific death rates occurred in the 45-54 year age group [73]. In this age group Aboriginal and Torres Strait Islander people were 17 times more likely to die from diabetes than their non-Indigenous counterparts (rate ratios were 26.5 for females

and 12.9 for males). Age-standardised death rates for diabetes for Aboriginal and Torres Strait Islander people were greatest in the NT (180 per 100,000), followed by WA (139 per 100,000), Qld (87 per 100,000), SA (60 per 100,000) and NSW (50 per 100,000). The greatest disparity in Indigenous: non-Indigenous death rates were observed in WA (9.0 times higher among Aboriginal and Torres Strait Islander people), followed by the NT (7.9), Qld (5.6), NSW (3.5) and SA (3.3) [73].

From 2010-2012, diabetes was the underlying cause of death for 564 Aboriginal and Torres Strait Islander people (8% of all Indigenous deaths) in NSW, Qld, SA, WA and the NT [14]. Of these deaths, the underlying cause of death was recorded as: type 1 diabetes (5.0% of deaths); type 2 diabetes (46% of deaths); or the type of diabetes was unspecified (49% of deaths). In this period, diabetes was the underlying or associated cause of death for 1,474 Aboriginal and Torres Strait Islander people (21% of all Indigenous deaths).

For the period 2008-2012, diabetes was the third most common cause of avoidable mortality (after ischaemic heart disease and cancer) among Aboriginal and Torres Strait Islander people, responsible for 734 (10%) potentially avoidable deaths [56]. After age-adjustment, the potentially avoidable mortality rate from diabetes was 12.0 times greater for Aboriginal and Torres Strait Islander people than the rate for non-Indigenous people.

Burden of disease

The latest in a series of reports from the *Australian burden of disease study 2011* (ABDS) provides estimates of the fatal burden of disease and injury for Aboriginal and Torres Strait Islander people, and the 'gap' in fatal burden between Aboriginal and Torres Strait Islander people and non-Indigenous people for the 2010 reference year¹⁸ [57]. Burden of disease estimates from the ABDS 2011 provide evidence regarding the diseases and injuries currently making the greatest contribution to Aboriginal and Torres Strait Islander mortality¹⁹.

Endocrine disorders (which include diabetes) were the sixth most common contributor to fatal burden²⁰ (5%) for Aboriginal and Torres Strait Islander people and were in the top five causes of fatal burden for both Aboriginal and Torres Strait Islander men and women in all age groups from 45 years and over [57].

15 Data is from public and private hospitals in all jurisdictions [56].

16 At the time of writing, cause of death data for 2013 was preliminary and subject to a revision process [73].

17 Based on the ICD-10-AM sixth edition codes E10-E14 (this excludes GDM) [73].

18 The estimates use the average of deaths data from 2009, 2010 and 2011 [57].

19 Methodological advancements used to calculate burden of disease estimates from the ABDS 2011 preclude direct comparisons with previous burden of disease estimates for Aboriginal and Torres Strait Islander people [57].

20 The five most common contributors to fatal burden for Aboriginal and Torres Strait Islander people of all ages were: injuries, cardiovascular diseases, cancer, infant and congenital conditions and gastrointestinal diseases [57].

Endocrine disorders were the fourth most common contributor to the gap in fatal burden²¹ (10%) and had the highest relative disparity in fatal burden, with the rate for Aboriginal and Torres Strait Islander people being 7.9 times higher than the rate for non-Indigenous Australians [57]. The ABDS suggests that reducing Aboriginal and Torres Strait Islander deaths from endocrine disorders has the potential to make major inroads to ‘closing the gap’ in fatal burden between Aboriginal and Torres Strait Islander people and non-Indigenous people.

Complications and comorbidities associated with diabetes

Diabetes can cause many serious health complications [74] and is frequently accompanied by comorbidities, particularly cardiovascular disease (CVD) and chronic kidney disease (CKD) [35].

Complications

Some complications of diabetes may occur soon after diagnosis while others may develop over several years [74]. Short-term health complications include: diabetic ketoacidosis²², hypoglycaemia (low blood glucose level), increased susceptibility to infections and reduced ability to heal [10]. Over the longer term diabetes may progress to diseases of the small blood vessels (microvascular diseases) and diseases of the large blood vessels (macrovascular diseases) [74]. Diabetes can also contribute to feelings of distress, anxiety and depression [8].

Microvascular and macrovascular complications are the major causes of associated morbidity and mortality in people with diabetes [38]. Microvascular complications of diabetes include damage to the kidneys (nephropathy), nerves (neuropathy) and eyes (retinopathy) [53, 74]. Macrovascular complications include coronary heart disease, stroke and peripheral vascular disease.

Common complications of diabetes can be broadly grouped into circulatory, renal, ophthalmic and other complications²³ [56] and are described briefly in Box 6. Complications in pregnancy are discussed separately in the following section [10].

Box 6: Common complications of diabetes

Circulatory complications

Circulatory complications of diabetes affect the heart and blood vessels and include coronary heart disease (angina and heart attacks), stroke, and peripheral vascular disease [35, 38].

Angina – temporary pain or discomfort in the chest resulting from inadequate blood supply in the heart at times of extra need, such as during exercise [35].

Heart attack – a life-threatening emergency that occurs when a blood clot suddenly blocks a vessel that supplies blood to the heart muscle [35].

Stroke – a sudden blockage or bleed in an artery supplying blood to the brain. This may cause paralysis of parts of the body, speech problems, or other disabilities [35].

Peripheral vascular disease (PVD) – inadequate blood supply to the extremities, often the legs, characterised by pain in the affected areas [35]. PVD, in association with peripheral neuropathy, increases the risk of developing foot complications, specifically foot ulcers and infections, which can in turn lead to lower limb amputations [38].

Renal complications

Renal complications of diabetes affect the kidneys and include *diabetic nephropathy* and *chronic kidney failure* [38]. These occur when high blood sugar levels damage the capillaries in the kidneys, reducing their filtering efficiency. Diabetic nephropathy is often asymptomatic until the disease is well-established, by which time interventions are less effective. Severe cases of diabetic nephropathy may lead to a type of chronic kidney failure called *end-stage kidney disease (ESKD)* that, if left untreated, is fatal.

Ophthalmic complications

Ophthalmic complications of diabetes affect the eyes and include diabetic retinopathy, cataracts and glaucoma [38]. They can result in vision impairment and blindness if not identified and treated in the early stages.

Diabetic retinopathy (DR) – damage to the blood vessels of the light-sensitive tissue at the back of the eye (retina).

Cataract – clouding of the normally clear lens that leads to a reduction in light entering the eye.

Glaucoma – pressure in the eye pinches the capillaries that carry blood to the retina and optic nerve. Over time this causes damage to these parts of the eye.

21 The three most common contributors to the gap in fatal burden were: CVD, cancer and injuries [57].

22 Diabetic ketoacidosis occurs when the breakdown of fat in the body results in an accumulation of ketones, and an increased acidity in the blood. This condition can be life-threatening if not treated [10].

23 Categories are based on ICD-10-AM classification of diseases [56].

Other specified complications

Other specified complications of diabetes include damage to the nerve structure and function (neuropathy) and occur as a result of reduced blood flow to the nerves [38].

Peripheral neuropathy – occurs most frequently in the nerves of the toes, feet and legs, however the hands and arms can also be affected. Some sufferers will require amputation of the affected limbs.

Autonomic neuropathy – affects the nerves that control the heart and blood vessels, digestive system, urinary tract, sex organs, sweat glands and eyes leading to dysfunction in the major organs.

Hospitalisation figures are available for some of the conditions that can result from diabetes. These complications of diabetes are categorised according to the ICD-10-AM²⁴ classification of diseases and refer to specific peripheral circulatory complications, renal complications, ophthalmic complications and other specified complications [56].

In 2012-13, age-standardised hospitalisation rates for complications of type 2 diabetes (as a principal diagnosis) were 5.6 times higher for Aboriginal and Torres Strait Islander people living in all jurisdictions,

than those for non-Indigenous people [56]. The disparity in hospitalisation rates between Aboriginal and Torres Strait Islander people and non-Indigenous people was greatest for renal complications of type 2 diabetes (10 times higher). In comparison, hospitalisation rates for circulatory and ophthalmic complications were 2.8 and 2.7 times higher (respectively) for Aboriginal and Torres Strait Islander people than for other Australians. The hospitalisation rate for multiple complications of diabetes was 6.5 times higher for Aboriginal and Torres Strait Islander people.

In 2012-13, age-standardised hospitalisation rates for complications of type 2 diabetes were greater for Aboriginal and Torres Strait Islander people than for non-Indigenous people regardless of the areas in which they lived. Disparities in the rates of renal and circulatory complications were greatest in regional areas (10.7 and 3.5 times higher respectively); for ophthalmic complications the disparity was greatest in remote areas (3.1 times higher) (Table 5) [56]. Hospitalisations for multiple complications of type 2 diabetes were 9.7 times more likely to occur among Aboriginal and Torres Strait Islander people in remote areas than among their non-Indigenous counterparts. In comparison, the age-standardised hospitalisation rates for Aboriginal and Torres Strait Islander people with multiple complications in regional areas and major cities were 5.2 and 3.3 times greater (respectively) than for other Australians.

Table 5. Hospitalisations for type 2 diabetes as a principal diagnosis among Aboriginal and Torres Strait Islander people, by complication, by remoteness, 2012-13 (age standardised rate per 100,000 population and rate ratio)

Complication ¹	Major cities ²		Inner and outer regional combined ²		Remote and very remote combined ²		Total	
	Rate ³	Rate ratio ⁴	Rate ³	Rate ratio ⁴	Rate ³	Rate ratio ⁴	Rate ³	Rate ratio ⁴
Circulatory	34	2.8	37	3.5	23	1.3	33	2.8
Renal	15	5.3	31	10.7	52	7.7	30	10.4
Ophthalmic	26	2.8	16	3.0	29	3.1	23	2.7
Other specified	143	3.8	251	6.0	413	8.3	252	6.5
Multiple	94	3.3	153	5.2	412	9.7	192	6.7
No complications	21	4.5	13	3.3	22	4.6	18	4.1
Total⁵	334	3.5	502	5.3	951	7.3	549	5.8

Notes: 1. Categories are based on ICD-10-AM classification of diseases (International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification).

- Disaggregation by remoteness area is based on the ABS' 2011 Australian Statistical Geography Standard (ASGS) and relates to the patient's usual residence, not the location of the hospital.
- The age standardised rates per 100,000 population are calculated using the ABS Estimated 2012 Resident population by remoteness classification from the 2011 Census. Rates were directly age-standardised to the 2001 Australian population. Results for individual complications may be affected by small numbers and should be interpreted with caution.
- Rate ratio is the age standardised Aboriginal and Torres Strait Islander hospitalisation rate divided by the non-Indigenous hospitalisation rate.
- The total is not the sum of the individual conditions because diabetes complications overlap other categories.

Source: Derived from Steering Committee for the Review of Government Service Provision, 2014 (based on unpublished data from the National Hospital Morbidity Database (NHMD))

24 The ICD-10-AM (International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification) is the classification system used to code diseases and health problems in Australian hospitals [56].

Complications in pregnancy

Diabetes in pregnancy refers to GDM and pre-existing diabetes, all of which can lead to a range of complications for the mother and child (see Box 7) [7].

Box 7: Complications associated with diabetes in pregnancy

Risks for the child include: miscarriage, stillbirth, congenital malformations and respiratory distress. There is also increased risk of obesity, impaired glucose tolerance and type 2 diabetes in early adulthood [7].

Risks for the mother include: miscarriage, pre-eclampsia, induced labour, pre-term birth, caesarean section, and first appearance or progression of complications including those associated with kidney, eye and cardiovascular diseases [7]. For mothers with GDM there is a risk of recurrent GDM in subsequent pregnancies and progression from GDM to type 2 diabetes.

Among Australian women who have diabetes during pregnancy, Aboriginal and Torres Strait Islander mothers and babies are more likely to experience adverse effects during pregnancy, labour and delivery than non-Indigenous mothers and babies [7]. Aboriginal and Torres Strait Islander mothers have higher rates of pre-term delivery, pre-term induction and hypertension than non-Indigenous mothers, and are more likely to have a long hospital stay. Aboriginal and Torres Strait Islander babies have higher rates of pre-term birth, low Apgar score²⁵ and high level resuscitation²⁶, and are more likely to have a long hospital stay. National figures regarding complications of diabetes in pregnancy for Aboriginal and Torres Strait Islander mothers and babies are available for the period 2005-07 (Table 6).

Table 6. Selected maternal and infant complications of diabetes among Aboriginal and Torres Strait Islander women who gave birth, by diabetes in pregnancy status, Australia, 2005-07 (percentage¹ and standardised incidence ratio²)

Complication	Pre-existing diabetes		GDM		No diabetes	
	% ¹	Ratio ³	% ¹	Ratio ³	% ¹	Ratio ³
Maternal						
Pre-term delivery ⁴	34	7.8	14	17.7	13	7.3
Pre-term induction ⁵	NA ⁶	NA ⁶	10 ⁷	2 ⁸	10 ⁷	2 ⁸
Long antenatal hospital stay ⁹	13	2.9	5.2	3.4	1.2	1.8
Long postnatal hospital stay ¹⁰	19	1.9	9.2	2.5	5.0	2.0
Infant¹¹						
Pre-term birth ¹³	34	1.4	15	1.4	13	1.7
Low Apgar score ¹⁴	4.2	1.4*	2.3	1.7	2.2	1.5
High level resuscitation ¹⁵	21	1.4	12	1.4	9.3	1.2
Long hospital stay ¹⁶	33	1.6	15	1.7	11	1.7

- Notes:
1. Not age-standardised.
 2. The standardised incidence ratio of actual cases divided by the expected number of cases among the Indigenous population based on the age-specific rate of the non-Indigenous population.
 3. Indirectly age-standardised to the 2005-07 non-Indigenous maternal population, by diabetes in pregnancy status.
 4. Duration of pregnancies from 20-36 weeks (5 pregnancies of less than 20 weeks duration also included).
 5. Labour induced at less than 37 weeks.
 6. Not available due to the small number of inductions among Indigenous women with pre-existing diabetes.
 7. Approximate figure only. Directly age-standardised to the 2005-07 population of Indigenous women with induced labour and without diabetes in pregnancy.
 8. Approximate figure only.
 9. Includes Indigenous women who gave birth in hospital (only) and were in hospital for seven or more days prior to giving birth.

25 The Apgar score is an assessment tool to test a baby's condition after delivery [7]. A score of 0-6 at 5 minutes after birth indicates the presence of complications and poor outcomes for the baby. A score of 7-10 is normal.

26 The level of resuscitation applied to a baby immediately after birth to promote normal breathing is an indication of a baby's health and expected outcome [7]. Resuscitation measures vary from none, to suction and oxygen (low level), to ventilation and external cardiac massage (high level).

10. Includes Indigenous women who gave birth in hospital and were discharged home (only) and were in hospital for seven or more days after giving birth.
11. Includes live born babies only.
12. Indirectly age-standardised to the 2005-07 population of live born babies of non-Indigenous women, by maternal diabetes in pregnancy status.
13. Gestational age of live born babies from 20-36 weeks (5 babies of less than 20 weeks gestational age were also included).
14. Apgar score (at five minutes) of 0-6.
15. High level resuscitation includes intermittent positive pressure respiration through bag and mask, endotracheal intubation and intermittent positive pressure respiration, and external cardiac massage and ventilation.
16. Includes live born babies discharged home (only) seven or more days following birth.

* Not significant

Source: Derived from AIHW, 2010 (based on data from the NHMD and NPDC)

Comorbidities

When a person has two or more health problems at the same time it is known as comorbidity [35]. Diabetes, CVD and CKD share complex causal relationships and often occur together in the same individual. The effects of comorbidity may lead to more severe illness and poorer outcomes for people with diabetes. This is apparent in hospitalisation figures for Aboriginal and Torres Strait Islander people.

The disparity in hospitalisation rates seen between Aboriginal and Torres Strait Islander people with diabetes and non-Indigenous people with diabetes, increases with greater comorbidity [35]. In 2012-13, Aboriginal and Torres Strait Islander people with diabetes, CVD and CKD were 7.3 times more likely to be hospitalised than their non-Indigenous counterparts. Aboriginal and Torres Strait Islander males and females aged 25 years and over, with all three diseases, were 5.0 and 10.7 times more likely (respectively) to be hospitalised than non-Indigenous males and females.

Prevention and management of diabetes

The prevention and management of diabetes is vital to the current and future health of Aboriginal and Torres Strait Islander people [15]. It is generally accepted that for diabetes prevention and management programs to be effective they require evidence based health promotion measures, public health interventions and clinical services. It is important that programs for Aboriginal and Torres Strait Islander people are delivered sensitively, tailored to community needs, and not perceived as being forced upon communities [13]. It is also recommended that such programs be complimented by broader action that extends beyond the health service sector, and addresses the social determinants of Aboriginal and Torres Strait Islander health such as poverty, culture, racism, employment and education [13, 15].

Formal evaluations of long-term diabetes prevention and management programs for Aboriginal and Torres Strait Islander communities are limited, but the Australian experience suggests that the current high levels of diabetes among Aboriginal and Torres Strait Islander people are potentially preventable [75].

Prevention

There is currently no known way to prevent type 1 diabetes²⁷ [76] or GDM²⁸ [77], but the prevention of type 2 diabetes in high risk individuals is a critical component of diabetes care [78]. Best practice primary prevention can prevent or delay the onset of type 2 diabetes in high risk individuals by :

- identifying those at high risk through the use of risk assessment tools
- delivering education programs
- promoting lifestyle modifications that focus on increased physical activity, dietary change and weight loss.

The *Aboriginal and Torres Strait Islanders and diabetes action plan* [13], released by Diabetes Australia in 2013, recommends implementing prevention programs that focus on Aboriginal and Torres Strait Islander people across the lifecycle. A predisposition to diabetes starts *in utero* and it is recommended that prevention programs include a focus on: women prior to and during pregnancy; pre-school and school-aged children; adolescents; and high risk people of all ages. It is also important to prevent complications in people with existing diabetes.

Risk assessment

To deliver evidence based prevention programs to high risk Aboriginal and Torres Strait Islander people they must first be identified through culturally appropriate risk assessment [13]. Systematic risk assessment of Aboriginal and Torres Strait Islander people during initial consultations with health professionals is recommended to ensure high risk individuals are identified.

The *Australian type 2 diabetes risk assessment tool* (AUSDRISK) has been developed to facilitate identification of high risk individuals. This non-invasive assessment uses basic clinical information including anthropometric measurements, family history, ethnic background, age and gender to calculate the risk of developing diabetes over a 5-year period [78-80]. The tool can be self-

27 Type 1 diabetes is an autoimmune condition that cannot currently be prevented or cured [76].

28 Although losing excess weight before pregnancy, and adopting healthy eating and exercise habits before and during pregnancy, may reduce the risk of developing GDM and subsequent type 2 diabetes [77].

administered, it is practical for use in community settings, and its utility has been recognised by all Australian governments.

It is recommended that Aboriginal and Torres Strait Islander people are screened using the AUSDRISK tool from the age of 18 years²⁹ [78]. There are however, some limitations associated with its use in this population:

- development of the AUSDRISK tool relied on an approach that may not give a true representation of the level of diabetic risk in the Aboriginal and Torres Strait Islander population [81, 82]
- use of the AUSDRISK tool to assess whether Aboriginal and Torres Strait Islander people should have a blood glucose test is considered controversial as it does not take into account the heterogeneity of this population [83].

In 2015, Adegbija and colleagues published an article describing the development of a new diabetes prediction model and tool based on long-term cohort data from a remote Aboriginal community [82]. The model predicts the 10-year absolute risk of type 2 diabetes for individuals in the community, based on waist circumference (WC) and age. To date this work has not been replicated to assess whether the findings can be generalised to other Aboriginal and Torres Strait Islander communities. The authors recommend that the prediction tool be validated with the inclusion of other risk factors such as family history of diabetes, physical activity and diet.

Education

It is recommended that education in diabetes prevention is tailored for Aboriginal and Torres Strait Islander communities, families and individuals [13]. Education should raise awareness of the risk of diabetes, and the positive steps required to lower that risk. It should also challenge the perception that diabetes is 'normal' in Aboriginal and Torres Strait Islander communities.

Early years education and intervention programs, including a systematic approach to improving nutritional status in infants and children [15], is considered critical to preventing risk factors and diabetes in later life [13]. It is suggested that children who are healthy in mind and body develop resilience and self-regulation and are more likely to make healthy choices as young adults. Programs for children and adolescents, including school-based education programs, can play an important part in providing the knowledge necessary for them to make informed decisions about their health in later life.

The *Deadly choices program* has conducted school-based chronic disease education initiatives for young Aboriginal and Torres Strait

Islander students (years 7 to 12) in Brisbane, Qld [84]. The program provided health education and opportunities for participation in physical activity, and made arrangements for health checks. A recent evaluation of the program found that participants demonstrated significant improvements over time in knowledge, attitudes and self-efficacy associated with types of chronic disease, chronic disease risk factors, prevention and health checks. The evaluation also found significant increases in breakfast frequency and physical activity per week, fruit and vegetable consumption per day, and the uptake of health checks among students who participated in the program. The students who took part in the program showed a significant improvement in their knowledge of chronic disease and associated risk factors, and a significant increase in their breakfast frequency compared with a control group.

Lifestyle modifications

Excess weight, poor nutrition and physical inactivity are risk factors that contribute to the disproportionately high levels of diabetes seen in Aboriginal and Torres Strait Islander communities [13]. Internationally, intensive lifestyle programs have reduced the incidence of diabetes among overweight people with pre-diabetes to an extent that is comparable to the use of medication [16]. Whether similar programs would be effective for Aboriginal and Torres Strait Islander people has yet to be established, but culturally appropriate, locally supported, targeted prevention programs are recommended for Aboriginal and Torres Strait Islander people with pre-diabetes [13, 16]. Such programs would provide participants with the life skills, knowledge and support needed to make sustainable lifestyle changes to prevent the onset of type 2 diabetes [13].

A recent review of healthy lifestyle programs addressing physical activity and nutrition among Aboriginal and Torres Strait Islander people found that programs can have positive health effects for up to two years, and are more likely to be effective if they are initiated by the community [16]. However, without adequate long term funding, sustaining healthy lifestyle programs in communities where multiple social and economic problems exist is particularly challenging, and very few healthy lifestyle programs have to date continued to operate beyond five years [13, 16].

The *Healthy weight program*—later renamed the *Living strong program*—was initiated in Queensland in 1997 in response to high levels of type 2 diabetes and other chronic diseases among Aboriginal and Torres Strait Islander adults [85-87]. The program offered health screenings and conducted workshops promoting healthy weight, good nutrition and physical activity. Although no longer in operation, an evaluation of the program in 2005 documented weight loss, increased fruit and vegetable intake, and modest gains in physical activity among some participants.

29 Screening for the general population is recommended from the age of 40 years [78].

A long-term program that has demonstrated considerable success is the *Looma healthy lifestyle project*. This project began in a remote WA community in 1993 and was still in operation 18 years after inception [16]. The community-directed project aimed to decrease the incidence of obesity, diabetes and coronary heart disease through strategies to increase physical activity and improve diet, such as promotion of traditional cooking methods, store management policy changes, and nutrition education. Although an initial evaluation found no significant changes in the prevalence of obesity or diabetes in the community [88] a subsequent health assessment, undertaken in 2009, found that the prevalence of diabetes in the community had not increased since 2003 [16].

A lifestyle modification program designed to help people reduce their risk of developing diabetes and cardiovascular disease, is currently funded by the Victorian Government and managed by Diabetes Australia — Victoria [89]. The *Life!* program offers a course specifically for Aboriginal people and their families called the *Road to good health* [90]. Run by Aboriginal Health Workers and other health professionals, this course supports participants to make long term, sustainable lifestyle changes, such as adopting a healthier diet and becoming more physically active [13]. A working group, that includes some Aboriginal and/or Torres Strait Islander members and organisations, has ensured that Indigenous values and health promotion practices are embedded in the course. Results suggest the course is culturally relevant and valuable to users, but published evaluations are not yet available.

Various programs have used sport to promote healthy lifestyles among Aboriginal and Torres Strait Islander children and adults, but further studies are required to establish their long-term impact [16]. Evaluation of short-term outcomes have demonstrated some positive results, such as those reported in 12-week exercise programs for Aboriginal and Torres Strait Islander men [91] and women [92].

- The men's program was conducted in a regional NSW community. The evaluation of the program found that sport and group-based physical activities reduced clinical risk factors for the development of type 2 diabetes among previously inactive, clinically obese Indigenous men [91]. The program led to improvements in various metabolic, anthropometric and fitness variables, including reduced WC, BMI and waist to hip ratio (WHR), and a decrease in insulin resistance. The observed improvements suggest there is potential for sports-based training programs to reduce the risk of developing type 2 diabetes in high risk Indigenous men.

- The women's program provided nutrition education and opportunities for physical activity to urban Aboriginal and Torres Strait Islander women in Adelaide, SA [92]. Modest reductions in weight, BMI and blood pressure were demonstrated at the completion of the program, and further improvements were observed at three-month follow-up. Changes in WC, fasting glucose and insulin, glycated haemoglobin (HbA1c), and other clinical measures were not significant. The positive intervention effects were observed despite low attendance at exercise classes and nutrition workshops. Analysis of the barriers to participation is currently underway and further follow-up is required to assess the longer-term results of the program.

Broader initiatives that extend beyond the immediate scope of the health sector have also been proposed to help reduce the incidence of type 2 diabetes in the Aboriginal and Torres Strait Islander population. They include [13]:

- increasing availability of and access to healthy foods (e.g. in stores and through community gardens and traditional food projects)
- limiting advertising and making healthy foods cheaper
- providing clearer food labelling and education regarding the nutritional value of foods
- use of taxation levers to reduce intake of sugary drinks (e.g. soft drinks)
- encouraging physical activity through partnerships with local councils
- improving housing.

Management

Providing appropriate, effective diabetes management for Aboriginal and Torres Strait Islander people depends on: access to a broad range of health services in a broad range of settings [13]; and coordinated interaction between patients, healthcare providers and the healthcare system [78]. Recent recommendations for improving diabetes management for Aboriginal and Torres Strait Islander people include:

- earlier detection of undiagnosed diabetes
- good quality primary health care
- access to medications
- self-management education
- tertiary specialist treatment when complications develop.

The following sections refer mainly to the management of type 2 diabetes for Aboriginal and Torres Strait Islander people. Some information about managing diabetes in pregnancy is also provided.

Early detection

Most primary health care services in Australia play a critical role in the early detection of diabetes [93]. Improvements in the early detection of undiagnosed diabetes in the primary health care setting are recommended to facilitate early intervention and management for Aboriginal and Torres Strait Islander people [13].

Current NHMRC guidelines for diagnosing diabetes involve a fasting plasma glucose test (FPG) or a random blood glucose test (RBG), followed by an oral glucose tolerance test if glucose results are equivocal [83]. It has been suggested that using HbA1c as a diagnostic test could be of particular benefit in rural and remote Aboriginal and Torres Strait Islander communities where the currently recommended testing is not always accepted or practical [13]. There is evidence that point-of-care (POC) capillary HbA1c testing in remote communities is an accurate alternative to laboratory testing [83] and may avoid the substantial delays that often occur when tests must be analysed in urban facilities [94]. The availability of immediate HbA1c results is likely to improve early detection and expedite the initiation of diabetes education and management. Since 1 November, 2014 a Medicare rebate (that can be claimed once every 12 months) has been available for HbA1c testing to diagnose diabetes in high risk patients [95]. It is anticipated that NHMRC guidelines may soon be changed to recommend HbA1c testing for the diagnosis of diabetes [83].

Managing diabetes in the primary health care setting

The Royal Australian College of General Practitioners (RACGP) provides clear guidelines for the management of type 2 diabetes [78], but there are often large gaps between recommended diabetes care and the care patients actually receive [96]. Access to a range of different models of culturally appropriate care [13] and involvement of an Aboriginal and Torres Strait Islander Health Worker, liaison officer, outreach worker or care coordinator [78] is recommended to address the needs of Aboriginal and Torres Strait Islander people. Other recommendations for improved diabetes management for Aboriginal and Torres Strait Islander people include up-skilling GPs to help them manage more complex patients, and providing access to local services that offer specialised treatment (such as renal dialysis for those with diabetes-related complications) [13]. It is proposed that this would reduce travel, ensure patients remain close to their support networks, and facilitate self-management.

Structured approaches to diabetes care are recommended to improve client outcomes [97, 98] and the processes of diabetes care planning, management and self-management in Aboriginal

and Torres Strait Islander communities are evolving [99, 100]. The RACGP recommends the use of written plans (see Box 8) to provide a structured approach to the management of diabetes [78].

Box 8: Written plans to manage diabetes

A *General practice management plan* (GPMP), typically developed by a GP in consultation with the patient, documents the patient's needs and goals, and the management strategies and resources used [78]. A *Team care arrangement* (TCA) is an expansion of the GPMP to include multidisciplinary, team-based care from at least two other healthcare professionals (e.g. allied health care workers).

Some chronic condition management strategies implemented in the general population have been successfully tailored to suit Aboriginal settings and clients [101]. In particular, those strategies that include structured and holistic client-centred care plans, point of care pathology testing and coordinated care arrangements—with appropriate supports and training for staff—have produced positive health outcomes.

For clients, the benefits of such strategies have included [101]:

- improved understanding of chronic conditions and their management
- greater control and active involvement in managing their own health
- ability to set and achieve realistic personal goals
- reassurance and capacity to monitor progress
- improved health and wellbeing and seeking early intervention for potential complications.

There is evidence from Aboriginal and Torres Strait Islander communities that diabetes care and outcomes can be improved and maintained over an extended period. In a pilot study in three Aboriginal communities in SA, the involvement of Aboriginal people in structured management strategies for chronic conditions led to improvements in their overall health status and health outcomes [100, 101]. In the remote Kimberley region of northern WA, an Aboriginal community controlled health service demonstrated that diabetes care and outcomes can be improved and maintained over a 10 year period [98]. This was achieved despite the challenges associated with the recruitment and retention of health care professionals that are typically experienced by remote services.

As with studies of diabetes care in Aboriginal communities, studies undertaken with Torres Strait Islanders living in remote communities in Far North Queensland (FNQ) have demonstrated improvements in clinical services and some intermediate health

outcomes [97, 102, 103]. Between 1999 and 2000, a one year trial of a simple recall system, managed by local Indigenous Health Workers and supported by a specialist outreach service achieved significant improvements in diabetes care and reductions in hospital admissions [97]. The improvements were sustained two years after the initial study [103], but weight gain and glycaemic control have remained a major challenge in the study population [102, 103].

In 2015, Gibson and colleagues published a systematic review that identified factors that support and inhibit the implementation of primary health care interventions for chronic diseases in indigenous populations from Australia, New Zealand, Canada and the United States [104]. They recommended that the following factors be considered when planning and implementing these interventions:

- intervention design - community engagement, the policy and funding environment, leadership, staff approach to change, and sufficient resourcing
- workforce issues - recruitment and retention of staff, adequate staff training, dedicated chronic disease positions with clear roles and responsibilities, employing Indigenous Health Workers, and including them in decision making
- health care provider skills and expertise - understanding, supportive and empowering attitudes towards patients, the capacity to communicate sensitively, and the willingness to allow patients to be partners in their care
- clinical care pathways - effective electronic support systems and clear referral pathways
- access issues - the provision of culturally safe, consistent services and coordinated care.

Access to primary health care services

It is generally accepted that inadequate access to primary health care services contributes to the poor health status of Aboriginal and Torres Strait Islander people [105]. Some of the barriers to accessing primary health care services that are experienced by Aboriginal and Torres Strait Islander people, include [106]:

- costs associated with consultation fees, medicines, transport, lost wages and time taken to access care
- distance and poor availability of services in remote areas
- poorer access to community controlled health organisations in metropolitan and regional areas compared to remote areas
- poor collaboration between different parts of the health system
- lack of cultural safety in mainstream services
- cultural misunderstandings, poor communication and experiences of discrimination with mainstream practitioners.

Research indicates that the current model of service delivery in remote communities in the NT has resulted in low rates of primary care use and high rates of hospitalisation for Indigenous people with diabetes [107]. The study concluded that improving access to primary health care services that provide diabetes care in remote communities would result in better health outcomes and be more cost effective.

Access to medicines

To provide the most appropriate diabetes management regime, it is recommended that Aboriginal and Torres Strait Islander people have access to the broadest range of health services and medicines, in the broadest range of settings [13]. However, many Aboriginal and Torres Strait Islander people face difficulties that impact on their capacity to access and adhere to a medication regime [108]. Potential barriers to access and use of medicines by Aboriginal and Torres Strait Islander people include:

- lack of transport and access to services
- inability to afford medication and services
- difficulty interpreting labelling and consumer medicine information
- client beliefs and behaviour about filling scripts, taking medication, sharing medication and side effects.

Suggested strategies for improving access to and use of medicines for Aboriginal and Torres Strait Islander people include:

- changes to the *Pharmaceutical benefits scheme* (PBS) to allow prescriptions to be filled and supplied in hospitals [13]
- use of *Webster packs* [109]
- home medication reviews [109]
- initiatives to heighten awareness of the subsidised products, and information and support services available through the *National diabetes services scheme* (NDSS) [110]
- cultural awareness programs for pharmacists and their staff [108, 109]
- provision of medicine education programs for Aboriginal and Torres Strait Islander Health Workers (by pharmacists) [108]
- recruitment, employment and training of Aboriginal and Torres Strait Islander pharmacy staff [108]
- improved medicine information for consumers [108].

Self-management

Self-management and support for self-management is essential to managing diabetes [78, 93]. The primary health system can support Aboriginal and Torres Strait Islander people with diabetes through improved self-management education, but the success of such programs is dependent on long term funding [13]. There

is evidence that culturally appropriate self-management support for Aboriginal and Torres Strait Islander people is most effective when led by Aboriginal and Torres Strait Islander Health Workers [93]. Examples of culturally appropriate self-management support programs include the *Aunty Jean's good health team program* [111] and the *Wurli-Wurlinjang diabetes day program* [112].

Box 9: Self-management

Self-management involves the patient (and any carers they may have) working in partnership with health professionals to [78]:

- understand diabetes and its treatment options
- be actively involved in a plan of care
- undertake activities that protect and promote health
- monitor and manage the symptoms and signs of diabetes
- manage the impact of diabetes on the patient's physical, emotional and social wellbeing.

The RACGP recommends that patients (and their carers) receive structured, evidence-based diabetes education [78]. Diabetes education can be delivered in groups or individually, but should be culturally sensitive and tailored to the needs of the recipient. Identifying barriers that impact on an individual's capacity to self-manage their diabetes is also important. Such barriers include issues around cognition, physical disability, mental health, health literacy, socioeconomic constraints, location and access to services.

Aunty Jean's good health team was a pilot project to develop a combined model of health promotion, education and self-management to support Aboriginal people with chronic and complex care needs [111]. The program was designed around a strong belief in the community's capacity to work together, and the importance given to the participation of Aboriginal Elders. It consisted of 12 modules, delivered one day per week for 12 weeks, combined with a self-managed and self-directed home program of activity. Evaluation of the program outcomes provided strong evidence of improvements in: self-management; appropriate and effective working partnerships; culturally acceptable and appropriate information-sharing; levels of physical activity; and self-management strategies. Key factors in the success of the program included: the leadership, commitment and participation of Elders; the strength of existing relationships within the community and between the community and health professionals; the input of specialist knowledge and support; a commitment to developing culturally appropriate health promotion strategies and behaviours; and location of the program within a safe community space.

The *Wurli-Wurlinjang diabetes day program*, conducted by an Aboriginal community controlled health service in Katherine in the NT [113], has been operating since 2008 [112]. The program operates once a week with the aim of providing a supportive environment and culturally appropriate, comprehensive care that fosters empowerment and promotes self-management among clients with type 2 diabetes. Evaluation of the program outcomes demonstrated: a considerable improvement in social and emotional wellbeing; an overall improvement in the proportion of clients receiving GPMPs, health checks and HbA1c testing; and a small but significant improvement in clinical outcomes, including control of blood sugar, blood pressure, cholesterol levels and weight. Certain system failures—concerning recall, medication and education—were also highlighted and subsequently addressed.

Tertiary care

Tertiary specialist services are required to treat the complications of diabetes, and many Aboriginal and Torres Strait Islander people access diabetes care in hospitals [13]. The *Aboriginal and Torres Strait Islanders and diabetes action plan* (2013), produced by Diabetes Australia, recognises that effective diabetes management requires high quality primary health care and support for self-management, but also affordable and timely access to tertiary specialist services to treat and manage complications. The *Action plan* suggests that appropriate access to tertiary and specialist services may be facilitated through investment in telehealth, and recommends models of care that promote integration between the primary and tertiary care settings. More specifically the *Action plan* recommends:

- up-skilling GPs to help them manage more complex patients
- opportunistic risk assessment in hospitals (as well as in primary care settings)
- the supply of PBS prescriptions in hospitals.

A surgical approach to diabetes management for obese Aboriginal adults has recently been trialled and evaluated in a regional community in Central Victoria [114]. Obese Aboriginal participants (26 females and 4 males) with type 2 diabetes underwent laparoscopic adjustable gastric banding (LAGB) at the regional hospital and were followed for two years. The evaluation found that LAGB led to weight loss and diabetes remission in 20 of the original 30 participants, and that the outcomes were comparable with those observed in metropolitan non-Indigenous Australians who underwent the same treatment program. Rather than having participants attend a program in a metropolitan centre, the regional model of care relied on an initial period of developing trust, sharing information, and learning. This led to close collaboration between the research team, the regional hospital, the local Aboriginal health service and the local Indigenous community. The researchers

concluded that a collaborative, regional model of care centred on the LAGB, was feasible and acceptable to obese Indigenous people in this community and an effective approach to diabetes management.

Managing diabetes in pregnancy

The early detection and management of diabetes during pregnancy³⁰ is important to reduce complications in both mothers and babies [13]. Management typically involves advice regarding diet and exercise, blood glucose monitoring, and insulin therapy as required. However, research is underway to explore the various demographic, clinical, biochemical, anthropometric and socioeconomic factors that may contribute to the high level of diabetes among Aboriginal and Torres Strait Islander women and their children [115]. The range of contributing factors suggests the need for comprehensive programs that may address:

- increasing women's access to health support before and during their pregnancy [13]
- improving control of diabetes in pregnancy [15]
- delivering healthy babies [13]
- encouraging breastfeeding (to reduce the risk of obesity and diabetes) [15]
- assisting mothers and families to establish healthy lifestyles [13].

The *Northern Territory diabetes in pregnancy partnership project* commenced in 2012 to improve the clinical care and outcomes for women with diabetes in pregnancy (including high risk Aboriginal and Torres Strait Islander women) and their babies [116]. It involves a partnership between researchers, health care providers and policy organisations in the NT, to build evidence and improve practice in relation to screening, management and post-partum follow-up [13, 115]. The project has three key elements [116]:

- a review of current models of care in the NT to improve health service delivery for women with diabetes in pregnancy
- development of a NT clinical register of referred patients for use by health professionals
- a detailed research project to assess rates and outcomes of diabetes in pregnancy in the NT (*Pregnancy and adverse neonatal outcomes in remote Australia, PANDORA*).

The project aims to contribute to the development of policy and planning for the management of diabetes in pregnancy, and the follow-up of mother and baby, in urban, rural and remote regions throughout Australia [115, 116].

Programs and services

A range of Australian Government Department of Health programs contribute to the prevention and management of diabetes and other chronic conditions among Aboriginal and Torres Strait Islander people at a national level [117, 118]. These programs include:

- the *Medicare benefits schedule (MBS)* - provides subsidies for patient care and includes Medicare items for the planning and management of chronic conditions. GP health assessments are available for Aboriginal and Torres Strait Islander patients (*MBS Aboriginal and Torres Strait Islander health assessments*), along with follow on care and incentive payments for GPs (*Practice incentive payment - Indigenous health incentive*). Eligible patients can also be referred by a GP for up to five Medicare subsidised allied health services that are directly related to the treatment of their chronic condition, including diabetes
- the *Pharmaceutical benefits scheme (PBS)* - provides subsidies for medicines used in the treatment of diabetes (*PBS medicine co-payments*)
- the *National diabetes services scheme (NDSS)* - provides subsidised diabetes products and services to persons with diagnosed diabetes who are registered with the scheme
- healthy lifestyle promotion programs including those that tackle smoking
- a care coordination, outreach and support workforce based in Medicare Locals (Medicare Locals were replaced by Primary Health Networks in 2015) and Aboriginal community controlled health organisations (ACCHOs)
- GP, specialist and allied health outreach services
- funding for research into diabetes conditions through the NHMRC
- funding for AIHW to support national surveillance and monitoring of vascular diseases including diabetes.

Despite government investment in these programs, and broader initiatives such as *Closing the gap*, disproportionately high levels of diabetes persist in Aboriginal and Torres Strait Islander communities [13]. Diabetes experts are calling for a nationwide, large scale, sustained effort to prevent type 2 diabetes, and the Australian Government's recent release of a new national diabetes strategy is considered an encouraging development [119].

Primary health care services

At a local level, most mainstream and community controlled primary health care services in Australia play a critical role in the delivery of diabetes care [93]. To meet the needs of Aboriginal and Torres Strait Islander people, primary health care services need to

30 Diabetes in pregnancy refers to pre-existing diabetes and GDM.

deliver both competent and culturally appropriate chronic disease care [120].

Culturally appropriate primary health care services

Culture and identity are central to Aboriginal and Torres Strait Islander perceptions of health, which encompass both the physical wellbeing of the individual, and the social, emotional and cultural wellbeing of the community [120]. It is important that services that deliver primary health care to Aboriginal and Torres Strait Islander people are culturally appropriate and recognise the importance of community values such as connection to culture, family and land, and opportunities for self-determination [107].

Culturally appropriate chronic disease services are typically characterised by [120]:

- a high level of Aboriginal and Torres Strait Islander community engagement and effective communication at all levels
- local knowledge about what works and what is acceptable
- strong Aboriginal and Torres Strait Islander leadership
- partnerships and community engagement that foster shared responsibilities
- sufficient sustainable resources and effective financial and project management
- integrated data and information systems to monitor the impacts of the intervention.

The involvement of Aboriginal and Torres Strait Islander Health Workers has been identified by health professionals and patients as an important factor in the delivery of good diabetes care to Aboriginal and Torres Strait Islander people [93, 121]. Aboriginal and Torres Strait Islander Health Workers have been shown to help patients feel comfortable, help break down communication and cultural barriers that may exist between patients and non-Indigenous health staff [93], and provide culturally appropriate self-management support [121].

A cluster randomised controlled trial, conducted between 2011 and 2013, found that an Indigenous Health Worker led case management approach to diabetes care (supported by an Indigenous clinical outreach team) was effective in improving diabetes care and control among Aboriginal and Torres Strait Islander adults in remote FNQ communities [121]. The health workers helped patients make and keep appointments, understand their medications, and learn about nutrition and the effects of smoking. Where appropriate, they also helped families to support the patient in self-management. Home visits and out of clinic care were provided, according to the patients' preferences.

However, there can be barriers to the involvement of Aboriginal and Torres Strait Islander Health Workers in diabetes care such as: inadequate training; lack of clear role divisions among health care professionals; lack of stable relationships with non-Indigenous staff; and high demands for acute care [122]. Workforce initiatives that have been implemented to address some of the training needs of Aboriginal and Torres Strait Islander Health Workers include: the development of the diabetes education tool 'Feltman' (a life-sized felt body showing relevant organs and body parts) [123]; and the delivery of accredited postgraduate diabetes educator courses [124]. However, primary health care services need more Aboriginal and Torres Strait Islander Health Workers (including males) [122] and more diabetes-trained Aboriginal and Torres Strait Islander staff at all levels (health and allied health professionals, and support workers) [13]. This will require greater access to training and mentoring [13], clarification and support for the role of the Health Worker [122], and the identification and promotion of structured career pathways in Aboriginal and Torres Strait Islander chronic disease management [13].

Aboriginal and Torres Strait Islander community controlled primary health care services

Aboriginal and Torres Strait Islander community controlled primary health care services play a major role in delivering essential primary health care services to Aboriginal and Torres Strait Islander people in a culturally secure manner [125]. Health services run by Aboriginal and Torres Strait Islander communities provide holistic care that is relevant to the local community and addresses the physical, social, spiritual and emotional health of the clients [13]. Such services can deliver effective prevention and management programs that enable lifestyle changes that are maintained and supported by the community. In 2011-12, 80% of Aboriginal and Torres Strait Islander primary health care services that received funding from the Federal Government provided early detection activities for diabetes [126].

Box 10: Aboriginal and Torres Strait Islander community controlled primary health care services

Aboriginal and Torres Strait Islander community controlled primary health care services are located in all jurisdictions and funded by the federal, state and territory governments and other sources [126]. They are planned and governed by local Aboriginal and Torres Strait Islander communities and aim to deliver holistic and culturally appropriate health and health-related services. Aboriginal and Torres Strait Islander community controlled primary health care services vary in the primary health care activities they offer. Possible activities include: diagnosis and treatment of illness or disease; management of chronic illness; transportation to medical appointments; outreach clinic services; immunisations; dental services; and dialysis services.

National initiatives to improve diabetes care in Aboriginal and Torres Strait Islander primary care settings

The disproportionately high level of diabetes experienced by Aboriginal and Torres Strait Islander people necessitates an understanding of how primary care services are organised to deliver diabetes care, monitor the quality of diabetes care, and improve systems for better diabetes care [127]. Continuous quality improvement (CQI)³¹ can assist health services to identify and address poor quality of care [93].

Health services that deliver primary care to Aboriginal and Torres Strait Islander people are at the forefront of applying CQI [129]. In Aboriginal and Torres Strait Islander primary care settings CQI has been shown to improve service delivery rates and clinical outcome measures in patients with diabetes [93].

Over the past decade, the *Audit and best practice for chronic disease project* (ABCD) (and the subsequent extension project) has operated a wide-scale CQI program in Aboriginal and Torres Strait Islander community controlled and government health centres [130]. The project has, from its inception, included a focus on type 2 diabetes. Health centres participating in the project have shown substantial variations in the delivery of guidelines-scheduled services, medication management, and intermediate health outcomes associated with diabetes care [96]. However, Improvements in systems and processes of care have been demonstrated [127, 130], as have some improvements in intermediate health outcomes [127].

Adding to the body of knowledge regarding CQI and diabetes care, a recent study—conducted in 2011-12 with four Aboriginal community controlled health services in remote northern Western Australia—found that good diabetes care was facilitated by [93]:

- clearly defined staff roles for diabetes management
- support and involvement of Aboriginal Health Workers
- efficient recall systems
- well-coordinated allied health services.

The *Healthy for life program* (HfL) is funded by the Federal Government and includes a focus on early detection and management of chronic disease among Aboriginal and Torres Strait Islander people. It commenced data collection and reporting in 2007 and has a strong focus on CQI [131]. The program is available to Aboriginal community controlled health services and other primary health care services that provide health care to Aboriginal

and Torres Strait Islander people. Services participating in the program are located in every state and territory, and across urban and remote areas of Australia. The program collects and reports on service activity and health outcome data, including clinical outcomes for diabetes. HfL program data collected from most participating services has been reported for the period between July 2007 and June 2011. In this period there were improvements in various service activities, including:

- an increase in the proportion of clients who had a health assessment from 12% to 15% for those aged 15-54 years, and from 15% to 21% for those aged 55 and over³²
- an increase in the proportion of clients with type 2 diabetes who had a GPMP from 25% to 32%
- an increase in the proportion of clients with type 2 diabetes who had a TCA from 16% to 22%
- an increase in the proportion of clients with type 2 diabetes who had a HbA1c test in the previous 6 months from 46% to 56%
- an increase in the proportion of clients with type 2 diabetes who had a blood pressure test in the last 6 months from 53% to 62%.

However clinical outcomes for diabetes have not yet shown an improvement [131]:

- the proportion of clients with type 2 diabetes whose HbA1c was less than or equal to 7% decreased from 34% to 30%
- the proportion of clients with type 2 diabetes who had a blood pressure result less than or equal to 130/80mmHg remained about the same at 41% and 42% respectively.

As a result of the generally positive findings from the HfL program the Australian Government has recently committed funding to expand the program into an additional 32 Aboriginal and Torres Strait Islander community controlled health services [132].

Policies and strategies

There are few national policies and strategies that focus specifically on diabetes in the Aboriginal and Torres Strait Islander population. However, there are relevant policy developments that pertain to diabetes in the general population, chronic diseases in general, or broader aspects of Aboriginal and Torres Strait Islander health.

The recent national emphasis on addressing diabetes within broader chronic disease policies and strategies reflects the common risk factors and co-existence of chronic diseases (particularly cardiovascular disease, diabetes and kidney disease)

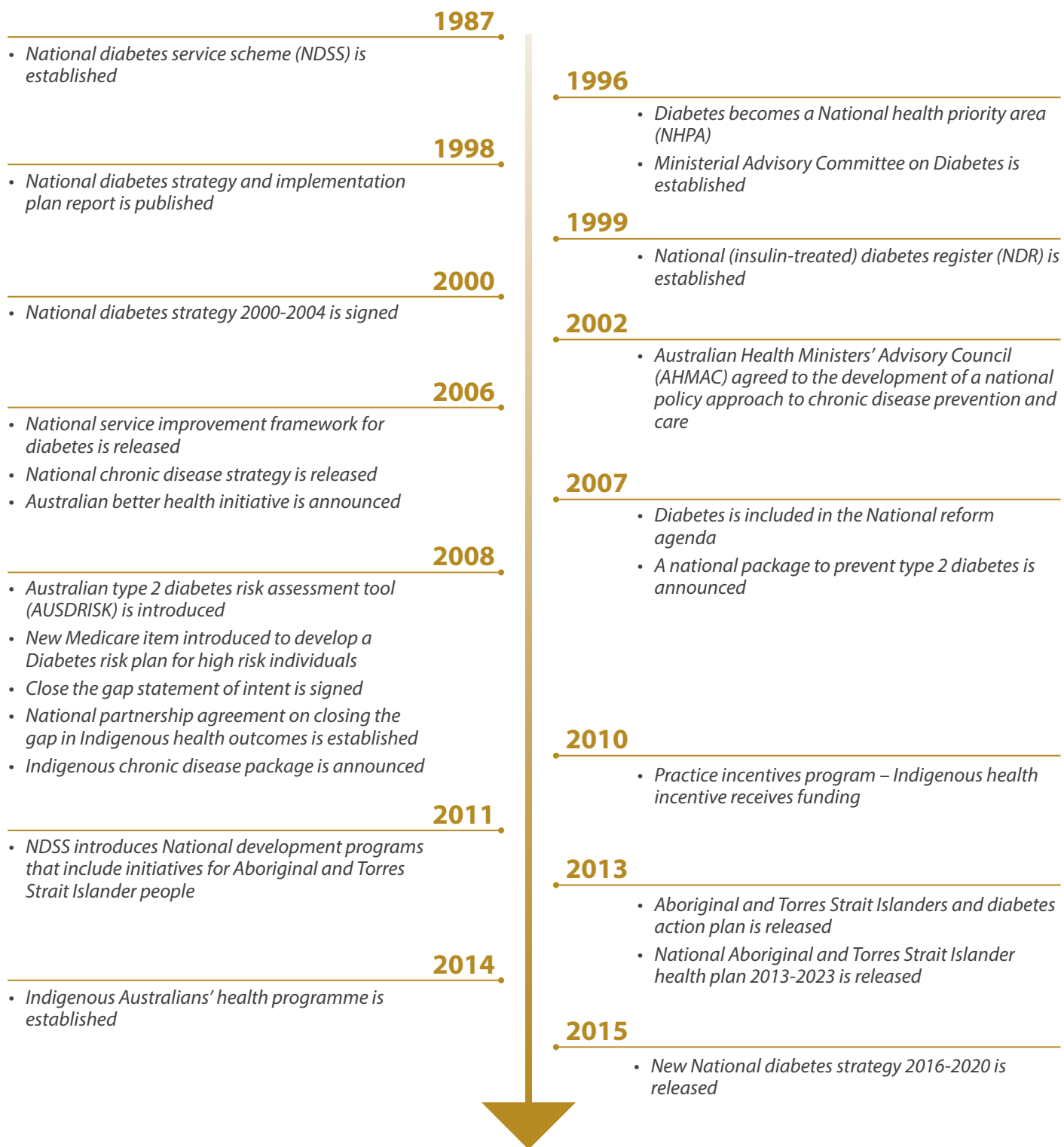
31 CQI is a structured, ongoing process of improvement and evaluation. It involves a systematic approach to collecting and reviewing data to identify opportunities for improving the quality of services [128].

32 There was a slight decrease in the proportion of clients aged 0-14 years who had a health assessment (from 16% to 14%) [131].

[55, 133]. However, diabetes experts are concerned that without a specific emphasis on diabetes prevention and management the seriousness, complexity and challenge of diabetes will be underestimated [133]. Diabetes Australia released the *Aboriginal*

and Torres Strait Islanders and diabetes action plan in 2013 [13], and the Federal Government's recent release of a new *National diabetes strategy* is considered an encouraging development by diabetes experts [119].

Figure 1. Selected national policy developments relevant to addressing diabetes among Aboriginal and Torres Strait Islander people



Diabetes first became a *National health priority area* (NHPA) in 1996 [134], however, some national developments addressing diabetes were implemented prior to this. Selected national policy developments relevant to addressing diabetes among Aboriginal and Torres Strait Islander people are described briefly below.

- The NDSS was established in 1987 [135]. The NDSS is an initiative of the Federal Government administered by Diabetes Australia. It provides diabetes-related products at subsidised prices and offers information and support services to people with diabetes. The latest five year agreement (2011-2016) between the Federal Government and Diabetes Australia provides for the introduction of *National development programs* that place particular emphasis on increasing access and support for various population groups including Aboriginal and Torres Strait Islander communities [110].
- In mid-1996, Australian health ministers agreed to the inclusion of diabetes as the fifth NHPA [134]. In doing so they formally recognised the health burden imposed by diabetes, and the significant health gains that can be achieved through appropriate prevention and management [136]. Later that year, a report to the ministers outlined a future work program which included consideration of a national register of insulin-treated diabetes [134].
- In the same year the Federal Minister for Health and Family Services announced the establishment of the Ministerial Advisory Committee on Diabetes to provide the Government with independent advice on the management of diabetes in Australia [137]. The *National diabetes strategy and implementation plan*, published in 1998, was an initiative of this committee. It made recommendations for reducing the burden of diabetes in Australia. Aboriginal and Torres Strait Islander people were highlighted among the groups within the Australian population who would require special consideration in the planning, delivery and coordination of diabetes prevention and care services.
- In 1999, the NDR was established. The NDR aims to record all new cases of people who use insulin to treat diabetes, including type 1, type 2, GDM and other forms of diabetes [10]. While there are various reasons why the NDR may underestimate the number of Aboriginal and Torres Strait Islander people with insulin-treated diabetes (see Appendix 1), it remains one of the main sources of information on the incidence of insulin-treated diabetes in the Aboriginal and Torres Strait Islander population.
- In the year 2000, all Australian health ministers signed the *National diabetes strategy 2000-2004* [133]. It aimed to help reduce the personal and public burden of diabetes in Australia [138]. The *Strategy* identified five goals and a framework for action. Aboriginal and Torres Strait Islander people were identified as a high-risk population who would require specific attention.
- In 2002, the Australian Health Ministers' Advisory Council (AHMAC) agreed to the development of a national policy approach to chronic disease prevention and care [139]. This led to the development of the *National service improvement frameworks* (one of which is for diabetes) [140], followed by the *National chronic disease strategy* in 2006 [139]. A blueprint for a national surveillance system was also developed [141]. There was an emphasis on improving access to services for Aboriginal and Torres Strait Islander people in each of these initiatives.
- In 2007, the Council of Australian Governments (COAG) announced that it would add diabetes to the 'human capital' stream of the *National reform agenda* and the Federal Government provided funding over four years for a national package to prevent type 2 diabetes [142]. This led to the introduction of a new Medicare item for GPs to develop a diabetes risk plan for high risk individuals aged 40-49 years. It also led to the development of a risk assessment tool (the AUSDRISK tool) that predicts the five year risk of type 2 diabetes [143]. Aboriginal and Torres Strait Islander people aged 15-54 years (inclusive) who receive a 'high' score on the AUSDRISK tool are eligible for a MBS health assessment [80].
- In 2007, COAG also agreed to a partnership between all levels of government to work with Aboriginal and Torres Strait Islander communities to 'close the gap' in Indigenous disadvantage [144]. COAG set targets to address the disadvantage faced by Aboriginal and Torres Strait Islander people : life expectancy, child mortality, education and employment [145]. In 2008, the Government and Opposition signed the *Close the gap statement of intent* [146], committing to closing the health and life expectancy gap between Aboriginal and Torres Strait Islander people and other Australians by 2030. By the end of 2010, most state and territory governments and oppositions had also signed the *Statement* [147].
- In 2009, all Australian governments committed to achieving the *Closing the gap* targets in the *National Indigenous reform agreement (Closing the gap)* [148]. COAG also agreed to the *National partnership agreement on closing the gap in Indigenous health outcomes* [149] which included a commitment to expanded primary health care and targeted prevention activities to reduce the burden of chronic disease. As part of this Agreement, the Federal Government committed funding to the *Indigenous chronic disease package* (ICDP) [144]. The ICPD aimed to reduce the burden of chronic diseases by: reducing chronic disease risk factors; improving chronic disease management and follow-up care; and increasing the capacity of the primary care workforce through expansion and

support [144, 150]. The Federal Government's *Implementation plan* [151] was subsequently endorsed by the Australian Health Ministers' Conference [152].

- The *Practice incentives program – Indigenous health incentive* commenced in 2010 [153]. Funding was allocated over four years to support primary health care services to provide better health care for Aboriginal and Torres Strait Islander people, including best practice management of chronic disease [150, 153]. The program offers incentives to: identify Aboriginal and Torres Strait Islander patients with chronic disease; undertake and review chronic disease management plans; and provide a targeted level of care.
- In 2013, Diabetes Australia developed the first national policy document specific to diabetes in the Aboriginal and Torres Strait Islander population. Titled the *Aboriginal and Torres Strait Islanders and diabetes action plan* [13], it seeks to address the disproportionate burden of mortality and morbidity that Aboriginal and Torres Strait Islander people experience due to diabetes.
- The *National Aboriginal and Torres Strait Islander health plan 2013-2023* (the *Health plan*) was also released in 2013 [147]. It is the latest evidence-based policy framework developed to guide policies and programs to improve Aboriginal and Torres Strait Islander health [154]. The *Health plan* [155] makes specific reference to the impact of chronic diseases, including diabetes, on the health of Aboriginal and Torres Strait Islander adults. Recommendations include strategies to review and improve the implementation of the ICDP, and to ensure best practice primary health care services are focused on chronic disease prevention and treatment. In mid-2014, the Federal Government announced it was beginning work on the *Implementation plan* [147].
- The *Indigenous Australians' health programme* was established in 2014, consolidating four existing Aboriginal and Torres Strait Islander health funding streams including the Aboriginal and Torres Strait Islander chronic disease fund (which replaced the ICDP) [156]. The majority of the original ICDP measures continue to be funded under the new program.
- The *Australian national diabetes strategy 2016-2020* was released at the end of 2015 [157]. It outlines a national response to diabetes that includes a specific goal to reduce the impact of diabetes among Aboriginal and Torres Strait Islander people. The strategy identifies potential areas for action and measures of progress, but notes that further work is required to develop policy options to implement the strategy. Collaboration across all levels of government, the health sector and relevant organisations will be required to develop an implementation plan.

Future directions

In 2013, Diabetes Australia consulted with Aboriginal and Torres Strait Islander community groups, clinicians, peak health organisations and researchers to develop the *Aboriginal and Torres Strait Islanders and diabetes action plan* for submission to the Federal Government [13]. The *Action plan* outlined a series of principles to guide future diabetes policy and program development for Aboriginal and Torres Strait Islander people. The principles were:

- prioritising children, family and community to address health across the lifespan
- engaging with Aboriginal and Torres Strait Islander communities and building trust
- improving health outcomes by focusing on diabetes as an intergenerational issue
- providing long term funding for interventions
- building on the effective and innovative Aboriginal and Torres Strait Islander programs that already exist
- addressing the broader determinants of Aboriginal and Torres Strait Islander health
- integrating cultural values into policy and program design and implementation.

The *Action plan* recommended that Australian governments address diabetes in the Aboriginal and Torres Strait Islander population by [13]:

- broadening access to clinical screening for diabetes and diabetes complications
- funding a national, high risk prevention program to address pre-diabetes
- funding a national diabetes self-management program
- allowing PBS prescriptions to be supplied in hospitals
- developing the Aboriginal and Torres Strait Islander health workforce
- funding programs that
 - enhance pre-conception and antenatal health
 - optimise early detection and management of diabetes in pregnancy
 - provide early years education and intervention
 - promote awareness about the seriousness of diabetes and its complications
 - enable early identification of risk factors and high risk individuals
 - improve access to healthy foods
 - offer clearer food labelling and better pricing mechanisms.

Many of the recommendations in the *Action plan* have been identified as potential areas for action in the recently released

Australian national diabetes strategy 2016-2020 [157]. This new strategy prioritises a national response to diabetes and outlines seven high-level goals, one of which is to reduce the impact of diabetes among Aboriginal and Torres Strait Islander people.

Recommendations for specific actions associated with this goal include:

- developing and implementing community-wide, culturally relevant awareness programs
- promoting pre-conception, pregnancy and early years programs
- providing early years education and intervention programs that address the social and environmental determinants of Aboriginal and Torres Strait Islander health
- developing and implementing community-wide healthy eating interventions
- promoting access to specialist support services
- encouraging better identification and management of diabetes in primary care settings
- supporting diabetes workforce development in primary care settings
- encouraging use of the *My health record* among rural and remote health care providers.

Both the *Action plan* and the *National diabetes strategy* have identified the need for holistic, culturally appropriate diabetes programs that integrate cultural values and address the health of Aboriginal and Torres Strait Islander people across their lifespan [13]. A study undertaken in 2013 and 2014 has contributed to our understanding of how this can be achieved by investigating ways to deliver culturally appropriate chronic care to Aboriginal and Torres Strait Islander people. The study has developed a *Wellbeing framework* that seeks to incorporate not just the physical aspects of health and wellbeing, but also the social, emotional, cultural and spiritual aspects [158, 159]. The *Framework* consists of two core values considered fundamental to the provision of care for Aboriginal and Torres Strait Islander people, and four essential elements that can assist primary health care services to support the wellbeing of Aboriginal and Torres Strait Islander people living with chronic disease.

The core values highlight that wellbeing is supported by [158, 159]:

- upholding peoples' identities in connection to culture, spirituality, families, communities and country
- culturally safe primary health care services.

The four elements recommend that wellbeing be supported by [158, 159]:

- locally defined, culturally safe primary health care services
- appropriately skilled and culturally competent health care teams
- holistic care throughout the lifespan
- best practice care that addresses the particular needs of a community.

It is anticipated that primary health care services, in consultation with the communities they serve, may be able to use the *Wellbeing framework* to more effectively address the particular chronic care needs of their communities [158, 159].

Concluding comments

Aboriginal and Torres Strait Islander people are disproportionately affected by the diabetes epidemic [5, 6, 9] and face particular challenges accessing effective chronic care [96, 107]. The high levels of diabetes in many Aboriginal and Torres Strait Islander communities reflect a broad range of historical, social and cultural determinants, and the contribution of lifestyle and other health risk factors [13, 15, 16]. The prevention and management of diabetes is vital for the current and future health of Aboriginal and Torres Strait Islander people, and will require programs that are tailored to community needs and are culturally appropriate [13, 15]. Action beyond the health service sector that addresses the broader historical, social and cultural determinants of health will also be required.

The importance of mitigating the impact of the diabetes epidemic is recognised by experts and Australian governments alike [119], but the high prevalence of type 2 diabetes, and the associated burden of early deaths and serious complications experienced by Aboriginal and Torres Strait Islander people persists [13]. Providing effective diabetes prevention and management for Aboriginal and Torres Strait Islander people will require improved access to both high quality primary health care services and tertiary specialist services. Effective and innovative programs for the prevention and management of diabetes among Aboriginal and Torres Strait Islander people do exist at the local level [16, 101], and much can be learned from the ways in which Aboriginal and Torres Strait Islander community controlled health services provide culturally appropriate care [125], but a coordinated national approach is also required [75, 133]. The release of the new *Australian national diabetes strategy 2016-2020* [157] may be an important first step toward this goal. Without a long term commitment to culturally appropriate prevention and management interventions that address diabetes across the lifespan, Aboriginal and Torres Strait Islander people will continue to suffer unacceptably high levels of diabetes.

Appendix 1: data sources, limitations and methods

The statistical information provided in this review draws on data from a number of sources. The various limitations associated with the data are discussed briefly below:

Defining diabetes

Reported statistics on diabetes prevalence, incidence, health service utilisation, mortality and burden of disease may not clearly define which type (or combination of types) of diabetes is being analysed. Care should be taken to avoid assumptions and generalisations.

Prevalence

People who develop diabetes are often unaware they have the condition, and surveys that do not medically verify self-reported data may underestimate the true prevalence of diabetes [160].

Incidence

The *National (insulin-treated) diabetes register* (NDR) is a database established in 1999 to collect information on new cases of insulin-treated diabetes [10, 161, 162]. The register is operated by the Australian Institute of Health and Welfare (AIHW), using data from the *National diabetes service scheme* (NDSS) and the Australasian Paediatric Endocrine Group (APEG). Information is only held for individuals who consent to be included. Cases of type 2 diabetes and GDM that do not require insulin treatment are not included in the register.

The NDR may underestimate the number of Aboriginal and Torres Strait Islander people with insulin-treated diabetes and incidence data should be interpreted with caution. Underestimates may result from non-identification of people of Aboriginal or Torres Strait Islander origin. Underestimates may also be due to low levels of registration with the NDSS, as Aboriginal and Torres Strait Islander people can access diabetes services and products through other programs (this is particularly true in rural and remote areas) [10].

The incidence of type 2 diabetes not requiring insulin treatment cannot be estimated with accuracy due to gaps in currently available data [162].

Hospitalisations

Hospitalisation figures can provide information about the impact of chronic diseases (such as diabetes) on a population, but should be interpreted with caution. Hospitalisation figures are for 'separations', and as there can be multiple separations for the

same individual, hospital records do not necessarily reflect the prevalence of a disease in the population [56].

The overall quality of data provided for Indigenous status varies between states and territories [163]. For analysis and reporting purposes, Indigenous identification in hospital statistics has been considered adequate in all jurisdictions since 2010-11 [56, 164]. Between 2004-05 and 2009-10, Indigenous identification in hospital statistics was considered adequate for NSW, Vic, Qld, WA, SA and public hospitals in the NT [56].

Mortality

Indigenous status may be under-identified in death data. Death data for Aboriginal and Torres Strait Islander people is typically only available for NSW, Qld, WA, SA and the NT, as these jurisdictions have sufficient levels of identification and sufficient numbers of deaths to support analysis [56, 165].

Death data probably underestimates deaths due to diabetes as the condition is frequently under-reported on death certificates or not recorded as the underlying cause of death [166]. Death data may be aggregated over five year periods to account for the volatility associated with small numbers of deaths [56].

Burden of disease

The *Australian burden of disease study* uses the underlying cause of death to calculate estimates of fatal burden [57]. Use of the underlying cause of death alone (without consideration of associated causes) cannot reflect more complex situations where more than one disease contributes to death. Diabetes is often associated with other diseases and listed as an associated cause of death; therefore burden of disease estimates may not reflect the total fatal burden of diabetes.

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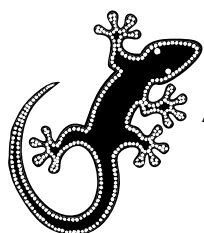
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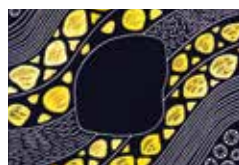
Australian Indigenous HealthInfoNet

The Australian Indigenous HealthInfoNet's mission is to contribute to improvements in Aboriginal and Torres Strait Islander health by making relevant, high quality knowledge and information easily accessible to policy makers, health service providers, program managers, clinicians, researchers and the general community. We are helping to 'close the gap' by providing the evidence base to inform practice and policy in Aboriginal and Torres Strait Islander health.

The HealthInfoNet addresses this mission by undertaking research into various aspects of Aboriginal and Torres Strait Islander health and disseminates the results (and other relevant knowledge and information) mainly via its Internet site (www.healthinonet.ecu.edu.au). The HealthInfoNet's research mainly involves analysis and synthesis of data and other information obtained from academic, professional, government and other sources, but it also undertakes some primary data collection and analysis.

The HealthInfoNet is a leader in knowledge transfer, the area of research which aims at transferring the results of pure and applied research into practice. In this research, the HealthInfoNet addresses the knowledge needs of a wide range of potential users. These include policy makers, health service providers, program managers, clinicians and other health professionals (including Aboriginal and Torres Strait Islander health workers), and researchers. The HealthInfoNet also provides easy-to-read and summarised material for students and the general community.

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ISBN 978-0-7298-0741-X

Core funding
is provided by the
Australian Government
Department of Health

