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Type 2 diabetes in Australia's children and young people: a working paper

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Health and Welfare

*Authoritative information and statistics
to promote better health and wellbeing*

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Type 2 diabetes in Australia's children and young people: a working paper

Australian Institute of Health and Welfare
Canberra

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Abbreviations

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
ANDIAB	Australian National Diabetes Information Audit and Benchmarking
APC	annual percentage change
APEG	Australasian Paediatric Endocrine Group
CDE	credentialled diabetes educator
DA	Diabetes Australia
ERP	Estimated resident populations
FDS	Fremantle Diabetes Study
IDF	International Diabetes Federation
MBS	Medicare Benefits Schedule
NDDWG	National Diabetes Data Working Group
NDI	National Death Index
NDR	National (insulin-treated) Diabetes Register
NDSS	National Diabetes Services Scheme
NSW	New South Wales
NT	Northern Territory
PBS	Pharmaceutical Benefits Scheme
Qld	Queensland
SA	South Australia
Tas	Tasmania
UK	United Kingdom
US	United States
Vic	Victoria
WA	Western Australia

Symbols

—	nil or rounded to zero
. .	not applicable
n.a.	not available
n.p.	not publishable because of small numbers, confidentiality or other concerns about the quality of the data

Summary

Type 2 diabetes has typically been considered a disease of older people but reports show that it is being diagnosed at younger ages than in the past. To date, this has not been explored in Australia at the national level. This paper identifies and describes national data sources for monitoring incidence and prevalence of type 2 diabetes in children and young people and assesses their suitability for this task. This paper also presents the latest available national incidence and prevalence information from data that combined 2 national administrative data sets – the National Diabetes Services Scheme (NDSS) and the Australasian Paediatric Endocrine Group (APEG).

Data sources to monitor type 2 diabetes in children and young people

Data about type 2 diabetes in children and young people are available from a number of data sources in Australia, all of which have strengths and weaknesses. Survey data, such as the biomedical component of the Australian Bureau of Statistics' (ABS') Australian Health Survey (AHS), potentially provide an opportunity to assess the extent of undiagnosed cases of type 2 diabetes. However, the best ongoing data are from administrative databases:

- The NDSS database represents a high proportion of people in Australia with diagnosed diabetes.
- The APEG databases cover diagnosed diabetes in children and young people though, as these data are from individual state registers, each currently has a slightly different scope.

Number of children and young people with type 2 diabetes

- As of June 2012, there were around 31,000 people aged 10–39 diagnosed with type 2 diabetes; this was 0.3% of the population in this age group.
- Of these approximately 2,200 were aged 10–24 years.

New cases of type 2 diabetes in children and young people

- From 2002–03 to 2011–12, there were nearly 39,000 new cases of type 2 diabetes among those aged 10–39 – this represented around 9% of all new cases.
- Among young people, the risk of type 2 diabetes rose with increasing age – from an average annual rate of new cases of 3 per 100,000 population in 10–14 year olds, to 8 per 100,000 for those aged 15–19 and 16 per 100,000 for those aged 20–24.
- From 2002–03 to 2011–12, there were around 4,000 new cases of type 2 diabetes among those aged 10–24 – an average of nearly 400 new cases per year.
- In 2006–11, the age-specific rate of type 2 diabetes for Indigenous Australians was higher than for non-Indigenous Australians – 8 times as high among 10–14 year olds and around 4 times as high for 15–19 and 20–24 year olds.

Rate of onset of type 2 diabetes in children and young people has not risen in Australia

This study found no evidence of a rise in the rate of new cases of type 2 diabetes in young people over 2002–03 to 2011–12. The rates did not change in those aged 10–19 and 30–39, and they fell in the 20–29 year group.

1 Background

Until recently, type 2 diabetes was seldom diagnosed in children, and thus it was considered to be a disease of adulthood. Over the 2 decades ending in 2012, a rise in the prevalence of type 2 diabetes in children and adolescents has been reported (Alberti et al. 2004; Craig & Huang 2009; Pinhas-Hamiel & Zeitler 2005). This is of concern because type 2 diabetes, which is largely preventable, is a costly disease that can be burdensome to manage for individuals and their families, and it has serious health complications that can impact on quality of life and reduce life expectancy.

It is therefore important to benchmark the size of the problem in Australia, gauge if any changes have been evident in recent years and to identify sub groups of the population at higher risk. In Australia, where there are high rates of overweight and obesity in children and young people – one of the key modifiable risk factors for type 2 diabetes – the ability to monitor type 2 diabetes will contribute to understanding the epidemiology of the disease. Thus, monitoring can help in guiding preventive measures, determining clinical service provision and informing health policy and planning. As well, studies in adults have shown that diabetes complications may be prevented with appropriate and timely treatment and management; therefore early detection of any growth trends is paramount.

This paper discusses the need for monitoring type 2 diabetes in Australia's children and young people aged 10–39; it identifies and discusses the value and limitations of the national data sources currently available for undertaking such a task. The paper also presents some latest estimates of incidence and prevalence of type 2 diabetes in those aged 10–39, assessing if the rising incidence and prevalence reported in some state-based literature is evident also in data on a national scale in Australia.

Structure of the paper

This chapter provides background about type 2 diabetes in children and young people. It covers information about diabetes itself, its costs to society and health complications for individuals, as well as explaining why preventing type 2 diabetes from developing in young people is important. The chapter also includes findings about the incidence and prevalence of type 2 diabetes in young people from overseas and the results of Australian state-based studies.

Chapter 2 describes and appraises national data sources that may be used to monitor the burden of type 2 diabetes in children and young people in Australia and the issues surrounding accurately gauging disease burden from these.

Chapter 3 presents incidence and prevalence estimates for Australia, including Aboriginal and Torres Strait Islander people, providing some baseline estimates for future monitoring of type 2 diabetes in children and young people.

Chapter 4 discusses the findings and puts forward some recommendations and suggestions for improving monitoring of type 2 diabetes in Australia's children and young people.

Diabetes

Diabetes is a chronic disease in which the normal bodily processes that control a person's blood glucose (sugar) levels no longer work correctly. For the body to function effectively it needs glucose, which primarily comes from the consumption of food and drink, to go from the blood into the cells: this process needs the hormone insulin. Diabetes occurs when the body cannot produce enough insulin, cannot use insulin effectively, or both (WHO 2006). A person with uncontrolled diabetes can't convert the glucose into energy; instead it stays in the blood, causing high blood glucose levels.

Type 2 diabetes is the focus of this paper but it should be noted that type 1 diabetes, which is an unpreventable autoimmune disease, is the most common type of diabetes among children and adolescents. It is often difficult to differentiate between the types at diagnosis (see the section 'Difficulties with determining type 2 diabetes' later in this chapter for more details).

The characteristics of type 2 diabetes are the progressive failure of insulin production and resistance of body tissues to insulin action. Type 2 diabetes is most commonly diagnosed in people aged 40 and over but also occurs in younger adults, and more rarely in adolescents and children. It is the most common form of diabetes, accounting for about 85% of all cases. A combination of exercise, diet and weight loss where appropriate are the initial strategies used to manage type 2 diabetes. However, most people will eventually need medication such as oral glucose-lowering medicines or insulin treatment; young people diagnosed with type 2 diabetes are sometimes started on insulin immediately.

Risk factors for type 2 diabetes

The risk factors for type 2 diabetes in children and young people are similar to those for adults and comprise both modifiable and non-modifiable determinants. Modifiable risk factors include poor diet and physical inactivity, both of which lead to overweight and obesity, another risk factor (Alberti et al. 2007; Amed et al. 2010a).

Obesity has been labelled the most important modifiable risk factor for the development of type 2 diabetes in youth (Amed et al. 2010a), with up to 85% of affected children either overweight or obese at diagnosis (American Diabetes Association 2000). Internationally, type 2 diabetes rates are considered to have increased in line with obesity rates (Amed et al. 2010a; Flint & Arslanian 2011; Rosenbloom et al. 1999; TODAY Study Group 2012). In Australia, there are high rates of overweight and obesity in the population as a whole but also among children and young people. In 2011–12, 25% of Australian children aged 5–17 were overweight or obese (ABS 2013b).

Exposure to maternal diabetes (gestational diabetes and pre-existing type 1 and type 2 diabetes) while in the womb is also a risk factor for the development of type 2 diabetes in young people (Amed et al. 2010a). Therefore as more women develop type 2 diabetes at the ages when they are reproducing, or if the incidence of gestational diabetes (which affects about 5% of pregnancies in Australia) (AIHW 2010) increases, then this will also increase the number of children who will be at greater risk of developing type 2 diabetes.

Non-modifiable risk factors include a genetic predisposition to type 2 diabetes, as shown by family history; insulin resistance as a result of puberty; and ethnicity (Amed et al. 2010a). In particular, the highest prevalence rates of type 2 diabetes in children and young people in Australia have been reported in Indigenous Australians (Craig et al. 2007; McMahon et al. 2004; Rosenbloom et al. 2009).

Impact of type 2 diabetes in children and young people

Diabetes leads to serious health complications

Diabetes can lead to a range of serious complications involving the nerves and blood vessels. These include stroke, coronary heart disease, peripheral vascular disease, diabetic neuropathy (nerve disease), ulcers, limb amputations, kidney failure, vision impairment and blindness. Diabetes can also affect psychological wellbeing contributing to distress, anxiety and depression.

Treating diabetes is more difficult in children and young people than in adults

Diabetes complications may be prevented or minimised through the early detection and effective management of the disease and its risk factors (The ADVANCE Collaborative Group 2008; The Diabetes Control and Complications Trial Research Group 1993; UK Prospective Diabetes Study Group 1998a, 1998b). However, the most effective treatment and management strategies are not as well studied in children as they are for adults; the lack of an evidence base for management means that treatment is predominantly based on best standard practice that has been developed for adults.

Not only may the hormonal status of the prepubescent and pubescent stages affect treatment in ways that haven't been tested (Springer et al. 2013), but side effects of therapy in young people are largely unknown and may be different to those in adults.

Childhood type 2 diabetes also poses particular management issues compared with type 2 diabetes that develops in adulthood. These include: poor compliance by children and teenagers (Amschler 2002; Dart et al. 2012; Fagot-Campagna et al. 2001; Haines et al. 2007; Trissler 1999); mixed results with measures such as intensive lifestyle modification (Copeland et al. 2013; TODAY Study Group 2012); frequent comorbidities such as hypertension (Amed et al. 2010a; Pinhas-Hamiel & Zeitler 2007); and more complex psychosocial factors (Sabin 2012).

A more aggressive disease if it develops early

For most, when a person develops diabetes they have to live with the condition and self-manage the disease and its complications for the rest of their life. Thus, developing type 2 diabetes at a younger age means more years spent managing the condition.

People diagnosed at a young age face greater risk of complications due to longer exposure to the disease (Amschler 2002) and childhood type 2 diabetes is thought to be more aggressive, with an earlier onset of complications than adult-onset type 2 diabetes or childhood type 1 diabetes (Amed et al. 2010a; Constantino et al. 2013; Eppens et al. 2006a; Pinhas-Hamiel & Zeitler 2007; Ruhayel et al. 2010; Wong et al. 2008). In addition, young people with type 2 diabetes have been found to already have a high rate of comorbidities at diagnosis, such as high blood pressure (Rosenbloom et al. 2009).

Diabetes affecting more pregnancies and more babies in the womb

If more children and young people develop type 2 diabetes, there will be a growing number of women of child-bearing age with diabetes, and therefore more diabetes-affected pregnancies and more babies exposed to diabetes in the womb. Pregnant women with type 2 diabetes are at increased risk of complications throughout their pregnancy (including miscarriage, high blood pressure, pre-term birth and caesarean section) and their offspring are at higher risk of short- and long-term adverse effects (including stillbirth, congenital anomalies and malformations, high birthweight and respiratory distress) (AIHW 2010). Further, babies born to mothers with diabetes are at higher risk of metabolic disturbances in later life, such as obesity, impaired glucose tolerance and type 2 diabetes (McElduff et al. 2005; Shaw 2007).

Cost to society

In addition to the personal and community costs, diabetes and its complications already pose a considerable and costly burden on our society and the health-care system. For example, across all ages in Australia diabetes contributed to: 8% of the burden of disease in 2003 (when the greater risk of coronary heart disease and stroke that diabetes carries with it is included); 4% of hospitalisations in 2009–10; 10% of deaths in 2009 (AIHW 2012b); and is the 14th most expensive disease (AIHW 2013a).

The prevalence of diabetes has increased significantly over the 20 years to 2012 in Australia (AIHW 2012b). The growing number of Australians with diabetes means that these costs are likely to rise over time. In fact, the direct health costs due to diabetes of \$1.5 billion in 2008–09 represented an 86% increase from 2000–01 (AIHW 2013a). Another factor that may contribute to the costly burden is, if diabetes develops at a younger age than in the past, the range of complications of the disease may occur at younger ages therefore increasing the burden not only on individuals but on society.

A recent review of studies on the burden of diabetes on the ability to work concluded that diabetes is associated with productivity loss, greater absenteeism and earlier retirement (Breton et al. 2013). Developing diabetes and its comorbidities earlier in life may be detrimental to people's ability to fully participate in study and/or the workforce as they are at increased risk of complications and death during the years of peak earning and working capacity (Alberti et al. 2004; Pinhas-Hamiel & Zeitler 2007). It has also been reported that disability rates were twice as high for Australians with diabetes compared to those without diabetes and working-age people with diabetes and a disability were twice as likely to be permanently unable to work compared with people with a disability who did not have diabetes (AIHW 2013b).

Increased health-care service demand

Increasing prevalence of type 2 diabetes in children and young people will mean a rising demand for health-care resources (American Diabetes Association 2000). Optimal management of type 2 diabetes needs ongoing and frequent involvement of a multidisciplinary team with specific skills in paediatrics, diabetes, nutrition, psychology, social work and diabetes education (Sabin 2012; Springer et al. 2013). In the United States (US), there are not enough paediatric endocrinologists to cope with this demand (Springer et al. 2013).

In addition to the impact on the paediatric setting, there will also be an increased need for specific transition services as more children and adolescents transition to the adult health-care system. Transitioning between the paediatric and adult health-care systems has been identified as a point where people with diabetes are at greater risk of losing contact with health-care support (AIHW 2012a). Studies have shown that clinic attendance and overall compliance with treatment is generally poor in youth with type 2 diabetes (Ruhayel et al. 2010; Sabin 2012). Therefore transitioning needs to be managed well to ensure young people with diabetes stay engaged to increase their chance of optimal management of their diabetes and reduce their risk of complications.

Estimates of the incidence and prevalence of type 2 diabetes in young people

Evidence suggests that increasingly type 2 diabetes is occurring in younger people. This could be in part a result of better diagnosis. Findings from studies presented here provide context for the results in 'Chapter 3: Type 2 diabetes – national incidence and prevalence'. It should however be noted that direct comparison between studies is difficult because of the different methods used and populations studied, and the lack of population-based data. Many of these studies focus on ethnic groups who are at a higher risk for developing type 2 diabetes and therefore results cannot be extrapolated to the general population (Amed et al. 2010a).

Incidence

Research in the United Kingdom (UK) over the 12-month period 2004–05 found the annual incidence rate of type 2 diabetes to be less than 1 per 100,000 children under the age of 17 (Haines et al. 2007). In the US in 2002–03 the incidence was 8 per 100,000 in 10–14 year olds and 12 in 15–19 year olds (SEARCH 2007). In New Zealand in 1995–07 the incidence in under 15 year olds was 1 per 100,000 (Jefferies et al. 2012). And in Canada, a 2-year national surveillance program (2006–08) found an incidence of 1.5 per 100,000 in children aged less than 18 (Amed et al. 2010b).

A study in Western Australia (WA) of type 2 diabetes in under 17 year olds in 1990–2002 reported a 27% rise in the average annual unadjusted overall incidence rate, with the overall annual incidence in 2002 being around 2 per 100,000 population (McMahon et al. 2004). A study in New South Wales (NSW) of type 2 diabetes in under 19 year olds in 2001–08 reported an annual incidence of 3 per 100,000 but found no increase in the rate over this period (M Craig 2013, pers. comm., 8 April).

Australia's Aboriginal and Torres Strait Islander children and young people are at much higher risk of type 2 diabetes than non-Indigenous children and young people (Azzopardi et al. 2012; Maple-Brown et al. 2010). Studies in WA and NSW have reported the incidence of type 2 diabetes in Indigenous children and adolescents to be more than 6 times that in the non-Indigenous population (Craig et al. 2007; McMahon et al. 2004). In WA in 2002 the incidence of type 2 diabetes among Indigenous young people aged less than 17 at diagnosis was about 16 per 100,000 population (McMahon et al. 2004). In NSW in 2001–08, the incidence of type 2 diabetes among Indigenous 10–18 year olds was 13 per 100,000 (Craig et al. 2007).

Prevalence

Internationally, high prevalence of type 2 diabetes in young people has not only been found among ethnic minority groups known to be at high risk of adult type 2 diabetes, but also in European populations with low prevalence of adult type 2 diabetes (Shaw 2007). It has been found to vary widely from less than 1% of 12–19 year olds in the US to 5% of 15–19 year-old Pima Indians of Arizona (Fagot-Campagna et al. 2001). Other groups with high prevalence include First Nation Canadians (Mendelson et al. 2011), those in the US of Hispanic origin, African-Americans (Vivian 2006), the Japanese (Kitagawa et al. 1998), Maori (McGrath et al. 1999) and Indigenous Australians (Maple-Brown et al. 2010).

In Australia, a study investigating prevalence of type 2 diabetes among 10–24 year olds in 2005–06 estimated a minimum prevalence of 18 per 100,000 (Sillars et al. 2010); these prevalence estimates rose from 7 per 100,000 in 1993–96.

The prevalence rates for the Pima Indians of Arizona also represented an increase since the 1950s, growing to 8% of people aged 20–24 and 4% of those aged 15–24. First Nation Canadians also show increases in diabetes prevalence since the 1980s (Mendelson et al. 2011). However, a number of factors may distort the true size of any rise observed in type 2 diabetes among younger people: increased awareness and detection of undiagnosed cases of type 2 diabetes, and reclassification of children previously diagnosed with type 1 diabetes (Amed et al. 2010a). These issues are discussed further in the section ‘Difficulties with determining type 2 diabetes’ below.

Age of onset of type 2 diabetes in children and young people

Globally, type 2 diabetes in very young children is extremely rare and data from both overseas and Australia suggest that it is unlikely to occur among 0–4 year olds but that some 5–9 year olds may have the condition. In the US it was found that in 2002–03 there were no children aged 4 years or less with type 2 diabetes and 19 cases in children aged 5–9 out of a population of over 1.2 million youths (SEARCH 2007).

Type 2 diabetes is extremely rare under the age of 10 (Amed et al. 2010a; Dabela et al. 2009). Some studies have indicated that 4% to 8% of children with type 2 diabetes present before the age of 10 in high-risk populations, but that the majority of cases will be in those aged 10 and over. In Australia, the youngest child with type 2 diabetes reported to date was aged 7 (Craig et al. 2007).

Countries such as Japan, UK, US, Canada and the Western Pacific region have reported an average age of diagnosis between 12 and 14 years in children and young people, aligning with the onset of puberty (Bloomgarden 2004; Eppens et al. 2006b; Fagot-Campagna et al. 2001; Haines et al. 2007).

Monitoring type 2 diabetes in children and young people

Why monitor?

Type 2 diabetes should be monitored in children and young people because it is a serious, yet in some cases a potentially preventable, disease which was previously not seen in this age group. It can reduce the quality of life of these young people and ultimately shorten their

lives. It needs ongoing and frequent involvement of a multidisciplinary health team (IDF 2008). It is a disease reported to be increasing in this age group world-wide. If this continues it will mean many more people with diabetes and associated complications than currently anticipated, thus causing a larger demand for health-care resources (American Diabetes Association 2000).

Given that type 2 diabetes is largely preventable, there is considerable potential for health, social and economic gains through diabetes monitoring (AIHW 2006).

Monitoring the prevalence of diabetes and its risk factors is important for:

- developing, implementing and evaluating effective treatment and prevention programs specifically tailored to children and young people at risk of type 2 diabetes
- planning and providing specialised management and treatment services to children and young people at risk of type 2 diabetes
- identifying specific population groups at high risk, in order to tailor preventive strategies
- monitoring the effectiveness of prevention and management programs of the disease over time
- examining the impact of diabetes on the health system (AIHW 2006, 2009a)
- working out how best to spend public health resources.

What to monitor?

Comprehensive monitoring of the information described above needs specific data (Dabelea et al. 2010) on:

- the incidence and prevalence of type 2 diabetes in all ages, by age at diagnosis (also allowing monitoring of the age of the youngest cases)
- the incidence and prevalence of risk factors for type 2 diabetes, including family history of diabetes, at all ages, by age and sex
- the average age at diagnosis and the age distribution of all people with type 2 diabetes to investigate if there has been a shift in age at onset/diagnosis
- time between diagnosis and pharmacological use including insulin use, and if this changes by age of onset/diagnosis
- the proportion of newly diagnosed cases that are type 2 in comparison to type 1, with consistent clinical and laboratory criteria to distinguish the 2 forms of diabetes
- clinical features, comorbidities, and complications: at diagnosis, by age of onset/diagnosis, and by duration of diabetes
- all of the above by various sociodemographic characteristics, including sex, socioeconomic status, Indigenous status, ethnicity and other population groups of interest.

How to monitor? Types of prevalence estimates

There are 2 main types of diabetes prevalence estimates available in Australia: total prevalence (captures diagnosed and undiagnosed cases) and diagnosed prevalence (misses the undiagnosed cases). The factors described below that determine data quality can affect the accuracy of both types of estimates. For example, a lack of clinical data that aid in

the differentiation of type 1 and type 2 diabetes limit many population-based studies, and many studies do not capture undiagnosed cases of type 2 (Amed et al. 2010a).

The optimal way at present to estimate total diabetes prevalence is a representative population survey including blood measurements, in order to identify the undiagnosed cases (see below under 'Undiagnosed diabetes' for further information).

The prevalence of diagnosed diabetes can be estimated by:

- a representative population survey including self-reported diabetes status
- counts of people using diabetes-specific services or medicines
- registers or clinical databases in which diagnostic codes are available.

Difficulties with determining type 2 diabetes

Several factors make counting the number of people who have diabetes, at any age, difficult, hindering the effective monitoring of type 2 diabetes. The following issues, which are likely to exist in any data source – undiagnosed cases of type 2 diabetes, misdiagnosis and misreporting – are outlined below.

Undiagnosed diabetes

The fact that a person can have type 2 diabetes for a long time without knowing it, and therefore remain undiagnosed, complicates the estimation of how many people have diabetes. However, greater awareness of type 2 diabetes has resulted in fewer undiagnosed cases. Just over a decade ago it was estimated that among Australian adults there was 1 undiagnosed case for every diagnosed case of type 2 diabetes (Dunstan et al. 2002). More recently state-based Australian research suggests that this has declined. Studies in Victoria (Vic) and WA estimated that for every 3 cases of type 2 diabetes, 1 was undiagnosed (Davis & Davis 2009; Department of Health 2012) and the 2011–12 AHS concluded that 1 in 4 cases remained undiagnosed (ABS 2013a).

Misdiagnosis

Distinguishing between type 1, type 2 and monogenic diabetes in children and adolescents can be difficult and misdiagnosis can occur. When managing a young patient recently diagnosed with diabetes there is no one characteristic or test that definitively identifies type 2 diabetes and its diagnosis may only become apparent over time, as the natural history of the disease is monitored (Amed et al. 2010a).

The 2013 American clinical practice guidelines for the *Management of newly diagnosed type 2 diabetes mellitus (T2DM) in children and adolescents* defined childhood type 2 diabetes as a combination of factors, including a child being overweight or obese; having a strong family history of type 2 diabetes; an insidious onset of disease; lacking clinical evidence of type 1 diabetes (the absence of autoantibodies associated with type 1 diabetes); and being insulin resistant but not depleted (Copeland et al. 2013).

However, none of these factors provide a definitive diagnosis and in children as many as one-third of those with one diabetes type have at least some features common to the other type (Copeland et al. 2005). For instance, amid a growing prevalence of overweight and obesity in the general population, obesity which is a hallmark of type 2 diabetes in children and adolescents is now common in newly diagnosed type 1 diabetes (Clarke et al. 2006,

O'Connell et al. 2007). Additionally, the presence of antibodies which are traditionally typical of type 1 diabetes may also occur in type 2 diabetes, although the existence of autoimmune type 2 diabetes is controversial. And given the increased prevalence of type 2 diabetes in the general population, a family history of type 2 diabetes (a risk factor for type 2 diabetes in the young) is more common among people with type 1 diabetes (Amed et al. 2010a; Haines et al. 2007; Rosenbloom et al. 2009). Finally, type 2 diabetes may present acutely and up to one-quarter of young people with type 2 diabetes present in diabetic ketoacidosis (a life-threatening condition caused by very high blood sugar levels), previously thought to be related to type 1 diabetes.

Misdiagnosis between type 1 and type 2 diabetes has been found in both directions. A German study that re-evaluated diagnoses of type 2 diabetes in 580 children aged less than 21 years found that 10% had been misdiagnosed, with most cases reclassified more than 2 years later as type 1 diabetes (Awa et al. 2011). A study in the UK found that, of 37 young people originally diagnosed with type 1 diabetes, 14 (38%) were later revised to type 2 diabetes (the remainder were reclassified to other forms of diabetes or could not be classified) (Haines et al. 2007).

Misreporting

Self-report

The accuracy of self-reported diabetes data first requires the correct use of diabetes classification at diagnosis (see below) and then depends on people's ability to both understand and remember their medical history (Robinson et al. 1997).

Difficulty and complexity of classification

Correctly reporting diabetes status is further complicated by the fact that over time the classifications and terminology used for the different types of diabetes have changed with increasing understanding of the disease. For example, it is now known that in a large proportion of people with type 1 diabetes the disease onset occurs in adulthood, that many people diagnosed with type 2 diabetes actually have type 1 diabetes (but a slow-onset form known as latent autoimmune diabetes (LADA) in adults), and that type 2 diabetes is appearing in younger ages than previously seen (AIHW 2001; Alberti et al. 2004). Terms such as juvenile-onset diabetes, insulin-dependent diabetes and non-insulin-dependent diabetes are no longer favoured (Daneman 2006; Gale & Gillespie 2001). This has generated some confusion in the community, including among medical professionals, about the terminology used for different types of diabetes, with many people reporting type 1 when they may have type 2, or simply not being able to report a type at all (AIHW 2001).

A common misconception is that only people with type 1 diabetes use insulin when, in fact, insulin is used to treat many people with type 2, gestational diabetes and other types of diabetes. This means that many cases are reported as having type 1 diabetes because insulin is used. This misclassification was confirmed in a small survey conducted in 2000 of certifying doctors who had registered patients with the National (insulin-treated) Diabetes Register (NDR): in 44% of replies, the doctor indicated that the reported type 1 diabetes should have been type 2 (AIHW 2001). Some doctors had changed a person's diabetes type from type 2 to type 1 once insulin use commenced (AIHW 2001).

To overcome this misclassification, many data collections (including the 1995 and 2004–05 ABS National Health Surveys, the 1983 National Heart Foundation Risk Factor Prevalence

Study, the 1999–2000 The Australian Diabetes, Obesity and Lifestyle (AusDiab) study and the NDR) have used algorithms to test the reported diabetes type against a number of criteria and reclassify it in some cases. The method of reclassification to derive diabetes type applied in the NDR is outlined in ‘Appendix C: Statistical notes and methods’.

2 National data sources for monitoring type 2 diabetes in children and young people

There are several data sources available in Australia that can be used to monitor the national incidence and prevalence of type 2 diabetes (Table 2.1). Of these, the 3 listed below could be used to monitor the national epidemiology of diagnosed type 2 diabetes among children and young people in the general population:

- the NDSS database
- the APEG state-based registers
- the National (insulin-treated) Diabetes Register (NDR), which includes data from both the NDSS and the APEG.

The strengths and limitations of each of these are described in this chapter. The following chapter presents some of the data from a data set that is produced in deriving the NDR, which combines information from the NDSS and APEG.

It is worth noting the other data sources available to the AIHW to monitor the national incidence and prevalence of diabetes and the reasons they are not considered an ideal source for monitoring type 2 diabetes in children and young people

Australian Bureau of Statistics' 2011–13 Australian Health Survey (ABS 2013b)

This is the largest and most comprehensive health survey ever conducted in Australia. It was designed to collect a range of information about health-related issues, including health status, risk factors, actions and socioeconomic circumstances. The AHS collected new information on nutrition and physical activity, as well as biomedical information.

However there are a number of limitations in using the AHS to determine prevalence of type 2 diabetes, particularly in children and young people. Mainly, the survey is based on self-reported information whereby a person reports that a doctor or nurse has told them that they had diabetes and that it was long term (that it had lasted or was expected to last, 6 months or more) or that they had diabetes but that it was not current at the time of the survey interview (ABS 2013c) (Note that the biomedical test performed cannot determine diabetes type). The ABS suppressed the prevalence estimates of type 2 diabetes among people aged 2–24 years because the survey sample was too small to give reliable estimates for this age group. The prevalence estimate for 25–34 year olds had a relative standard error of 31% and therefore results for this age group should be interpreted with caution.

Australian Diabetes, Obesity and Lifestyle Study

This study is the largest Australian longitudinal population-based study examining the natural history of diabetes, pre-diabetes (in which glucose metabolism is impaired but not to the level to cause diabetes), heart disease and kidney disease. Data for this study were not collected on people under 25 years of age.

Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) databases

The MBS relates to claims for health services and the PBS to claims for medicines that the Australian Government subsidises. The databases relating to the MBS and PBS collect

information about the consultations with doctors, the medical tests performed and the prescriptions which are filled for medications that are subsidised through the PBS.

This information could potentially provide comprehensive information about diabetes. However, the diagnosis is not recorded and therefore this can only provide information by data linkage to another collection which records diabetes type. The National Centre for Monitoring Vascular Diseases at the AIHW is currently undertaking this type of data linkage.

National Diabetes Services Scheme

The NDSS, established in 1987, is an Australian Government initiative that Diabetes Australia (DA) administers. The NDSS provides education, information and a range of diabetes-related products at subsidised prices to people with diabetes who choose to register. The subsidised products include syringes, pen-needles, blood and urine test strips and insulin pump consumables.

Registration with the NDSS is available for anyone who is a resident in Australia, has been certified as having diabetes by a doctor or credentialled diabetes educator (CDE) and holds a current Australian Medicare card or Department of Veterans' Affairs file number.

The NDSS database holds both demographic and some diagnostic information about those who have registered with the scheme.

The NDSS database has undergone 2 major structural modifications (July 2002 and November 2010) since its inception, which may have affected comparability of information over time. The system implemented in 2002 improved the data fields collected and, in 2010, there was a change to the retention of historical information so that any alteration to information was not permanently overwritten.

There are important data considerations to be aware of when using this data set to estimate the incidence or prevalence of diabetes. As with any administrative data collection, some limitations are largely a result of using an administrative data set for a task it was not designed to do. For instance, since people join the NDSS for information and purchasing products, it is a necessity to ensure that contact details are up to date, but knowing a person's type of diabetes is not essential.

Strengths and limitations of the NDSS data in examining children and young people with type 2 diabetes

Coverage of the diagnosed type 2 diabetes population

All people residing in Australia are eligible to join the NDSS if a health professional has diagnosed that they have diabetes.

However, registration with the NDSS is voluntary and motivated by the need for access to subsidised consumables and support from DA. This means some people may be less likely to register with the scheme, particularly those with non-insulin-treated diabetes for which products such as needles and pens are not essential.

Table 2.1: Summary of Australian data sources that could potentially be used for monitoring national type 2 diabetes epidemiology

Data source	Type of data source	Prevalence or incidence estimate	Type of estimate	Age covered	Ongoing or periodic	Can be used to monitor type 2 diabetes in children & young people	Notes on coverage
National Diabetes Services Scheme (NDSS)	Administrative	Both	Diagnosed diabetes (certified by a doctor or CDE)	All	Ongoing (1987–current)	Yes	Incomplete coverage for non-insulin-treated diabetes (more details below).
Australasian Paediatric Endocrine Group (APEG) state-based registers	Register	Primarily incidence (prevalence for a small age group)	Diagnosed diabetes (certified by a doctor or CDE)	Varies by state and territory (see below)	Ongoing (most started in 1999–current)	Yes	Strictly speaking this is a state-based data source but it is included here because it does have national coverage (each state and territory collect data but they are not compiled nationally). All states and territories collect data on insulin-treated diabetes in 0–14 year olds. In addition NSW, SA and WA collect data on non-insulin-treated diabetes; and WA and NSW collect data on 15–17 year olds.
National (insulin-treated) Diabetes Register (NDR)	Register	Primarily incidence (prevalence for a small age group)	Diagnosed diabetes (certified by a doctor or CDE)	All	Ongoing (1999–current)	Yes	Only insulin-treated cases.
National Health Survey (NHS)/Australian Health Survey (AHS)	Population survey	Prevalence	Diagnosed diabetes (self-reported); and total diabetes for the biomedical component	All	Periodic	No	For 2011–12 the survey sample is too small to give reliable estimates for 2–24 year olds, while the prevalence estimate for 25–34 year olds has a relative standard error of 31% and should be used with caution (ABS 2013b).
AusDiab study	Population survey	Prevalence	Total diabetes (measured and self-reported collected)	25 years and above	1999–2000	No	No data on people aged under 25 years.

(continued)

Table 2.1 (continued): Summary of Australian data sources that could potentially be used for monitoring national type 2 diabetes epidemiology

Data source	Type of data source	Prevalence or incidence estimate	Type of estimate	Age covered	Ongoing or periodic	Can be used to monitor type 2 diabetes in children & young people	Notes on coverage
Medicare Benefits Schedule (MBS)	Administrative	Prevalence	Implied diabetes status (based on annual cycle of care and/or 2 glycosylated haemoglobin (HbA1c) or fructosamine tests in a specified period (AIHW 2009a).	All	From 2001, by calendar and financial year	No (not without linking to other sources to get diabetes type)	Only a subset of diagnosed population, dependent on service use (AIHW 2009a). Diabetes type is not available.
Pharmaceutical Benefits Scheme (PBS)	Administrative	Prevalence	Implied diabetes status	All	From 2001, by calendar and financial year	No (not without linking to other sources to get diabetes type)	Only a subset of pharmacologically managed diagnosed diabetes (AIHW 2009a). Diabetes type is not available. Medications used to treat type 2 diabetes are also frequently used to treat people who do not have diabetes yet (risking over-diagnosis); and in some cases are used to treat other conditions.

Estimates of ascertainment on the NDSS for non-insulin-treated type 2 diabetes are available from the Australian National Diabetes Information Audit and Benchmarking 2 (ANDIAB2) and the Fremantle Diabetes Study (FDS) Phase II. In the ANDIAB2 studies (which surveyed diabetes centres), in 2010 and 2012: 81% and 86% respectively, of people with non-insulin-treated type 2 diabetes reported having registered with the NDSS, compared with 97% in both years for insulin-treated type 2 diabetes (J Flack, 2013, pers. comm., 5 July; Table 2.2). A similar ascertainment rate was evident in preliminary data from the FDS Phase II, which included self-report of NDSS registration for approximately 1,489 people with type 2 diabetes, suggesting 88% ascertainment for the NDSS (W Davis 2013, pers. comm., 28 June). Self-reported NDSS registration did not significantly differ by age, treatment type or Indigenous status. FDS Phase II participants were representative of residents of the study area with type 2 diabetes (any treatment type) and generalisable to the broader Australian population with type 2 diabetes (Davis et al. 2013). The ANDIAB2 study was likely to represent those with newly diagnosed diabetes or those with more complicated diabetes; that is, those with uncontrolled diabetes or with complications of the disease requiring specialist assessment and management (NADC-ANDIAB 2011).

Table 2.2: People with type 2 diabetes attending diabetes specialist centres by NDSS registration status (self-reported)

	2010				2012			
	Registered with NDSS (self-reported)							
	Yes		No		Yes		No	
	No.	%	No.	%	No.	%	No.	%
Insulin-treated	684	97.2	20	2.8	600	96.8	20	3.2
Non-insulin-treated	502	81.4	115	18.6	438	85.7	73	14.3
All ^(a)	1,189	89.7	136	10.3	1,042	91.7	94	8.3

(a) Components don't add to total because 'All' also includes those who did not have a treatment record.

Note: Data relate to those that responded to the NDSS question, 92.3% of respondents answered in 2010, and 84.7% in 2012.

Sources: ANDIAB2 2010 and ANDIAB2 2012 (J Flack, 2013, pers. comm., 5 July).

Some diabetes management products can also be purchased through the PBS. When these products are purchased through the NDSS they do not count towards the PBS safety net, designed to provide additional financial assistance once expenditure on health care has reached a certain threshold each year. Therefore, people may choose to purchase through the PBS instead in order to reach the safety net threshold earlier and receive a higher level of subsidy for other pharmaceuticals once this is reached. Once the threshold is reached, people may also decide to change their purchasing of products from the PBS to the NDSS, where they are available at a greatly reduced cost (AIHW 2009a).

Age of registrants

There are no age limitations to registering with the NDSS, therefore the database is potentially a good source for information about children and young people with diabetes.

Diagnosis certification

Because registration with the NDSS requires a doctor or CDE to certify that the person has diabetes, the diagnosis is a true reflection of their condition.

The administrative nature of this data source, however, means that it only captures people with diagnosed diabetes who are eligible and choose to register with the scheme. It will therefore underestimate the true counts of type 2 diabetes, which ideally should include those who have the disease but are not yet diagnosed. For more information about undiagnosed diabetes, see the section 'Difficulties with determining type 2 diabetes' in the previous chapter.

Type of diabetes

At the time of registration, the diabetes type recorded is that indicated by the health professional who certifies the diabetes diagnosis itself. However, diabetes type recorded in the NDSS may be incorrect due to delayed or misdiagnosis or it may be misreported.

As the characteristics of a registrant are collected at the time of registration, diabetes type may be incorrect because the diagnosis has yet to be confirmed and may not be updated in the NDSS database if it is changed at a later date. This is particularly pertinent to cases of childhood diabetes where distinguishing between type 1 and type 2 may be difficult; misdiagnosis can occur; and registration with the NDSS may occur before the diagnosis is finalised (see the section on 'Difficulties with determining type 2 diabetes' in the previous chapter for more information).

Type of diabetes may also be misreported to the NDSS database, as discussed in the previous chapter. The issue of misreporting is compounded for people registered before 2002 because before that time the NDSS registration form did not have an option for insulin-treated type 2 diabetes, reflecting diabetes classification at that time. Therefore people with insulin-treated type 2 diabetes may have been incorrectly recorded as type 1 so that their insulin using needs could be met. This issue can be addressed to some extent by testing the reported diabetes type against a number of criteria and reclassifying it in some cases. The method of reclassification to derive diabetes type applied to the NDR is outlined in 'Appendix C: Statistical notes and methods'.

Ongoing and up to date

As an administrative database, the NDSS is ongoing, meaning that at any point in time numbers used to estimate incidence and prevalence are up to date, as well as permitting comparisons over time.

Because the scheme delivers support services and/or products to people with diabetes, there is ongoing contact with individuals and therefore information can be checked and verified relatively easily (although expensive, depending on the number of people involved). DA has regularly used the ability to do this to ensure that key information about registrants is correct.

In 2012, DA implemented a data validation system to check registrations of type 2 diabetes in under 16 year olds (D Rae 2013, pers. comm., 19 April). Data validation occurs monthly and registrant records that may require validation are followed up by contacting either the parents or the relevant health professional to confirm details, such as date of birth and diabetes type, are reflected accurately in the NDSS database. It should be noted that this process usually results in a revision to date of birth rather than diabetes type; in addition where the type of diabetes needs alteration, this will only occur if a health professional certifies the change.

This validation tool has been applied retrospectively so that all records of type 2 diabetes in children aged under 16 years at the time of the checks (mostly those registered in 2012) have

undergone a review for accuracy. Applying this check more broadly in the database (that is, to all cases of type 2 diabetes aged less than 16 years at diagnosis) is not possible due to resource constraints. Therefore, the most reliable data on cases of type 2 diabetes in this age group are those collected from 2012 onwards.

Identified information

The NDSS contains personal information (name, address and date of birth) about people who have registered. This fact allows the data to potentially be used for studies where records may be linked with appropriate privacy protections and approvals to other databases containing identifiable information.

Range of sociodemographic variables

Sex

Information about the sex of registrants is available, with few instances of missing data.

Ethnicity

The NDSS collects information on a number of parameters that provide some information about ethnic background: country of birth; Indigenous status; and main language spoken at home. However, each of these variables only captures certain facets of ethnicity. Use of country of birth alone to gauge cultural background in children and young people is particularly problematic, as an individual may have been born in Australia to immigrant parents and may have the biological and behavioural risk profile of the background of origin. In addition, the country of birth, Indigenous status and main language spoken at home fields are not mandatory for registration with NDSS and have high levels of missing data (that is, the registrant did not complete the field at registration). For example, country of birth is not known for more than one-third of registrants on the NDSS – up to 50% in earlier years – although completion rates have improved over time.

Indigenous status

Registrations occurring after a change to the Indigenous status data item in 2005 mean that data quality has improved in this area. However in spite of this, the NDSS may still underestimate the number of Aboriginal and Torres Strait Islander people with type 2 diabetes.

Before 2005, data entry of Indigenous status coded all ‘unknown’ or ‘not stated’ responses to the Indigenous status question as ‘non-Indigenous’. In 2005, the NDSS database was amended to add an extra value to the Indigenous status variable to indicate ‘inadequate/not stated’ where Indigenous status was not known. However, in spite of this improvement in recording of information, many registrants still do not complete this field – 27% of new registrants in 2011.

Aboriginal and Torres Strait Islander people may be under-represented on the NDSS either because they choose not to identify themselves when they register or because there are low rates of registration among Indigenous Australians due to the ability of Indigenous people to access diabetes supplies through other targeted programs, such as Section 100 of the *National Health Act 1953*, Aboriginal Medical Services and the National Aboriginal Community Controlled Health Organisation. NDSS Access Points are not always available in remote areas, limiting access to NDSS services. It may also be that products are shared (J Babare 2013, pers. comm., 6 May).

Strategies to enhance the NDSS' coverage of Indigenous Australians have been implemented. In 2010, DA began a program to employ Aboriginal and Torres Strait Islander health workers to engage with Aboriginal Medical Services and other health services to raise awareness of diabetes and the benefits of registering with the NDSS, and to improve the management of diabetes in Aboriginal and Torres Strait Islander people. DA reported a 29% increase in Indigenous Australian registrations nationally between 30 April 2010 and 31 July 2012, compared with a 9% increase in other registrations over this period (N Huxley 2013, pers. comm., 3 April). However, the proportion of new registrants with a 'not-stated' response to the Indigenous status question has risen in recent years, from around 12–14% in 2006–2008, to around 19–20% in 2009–2010, and further again to 27% in 2011.

Insulin use status

From information in the NDSS it is possible to determine registrants who are using insulin to treat their diabetes. This may be important for examining type 2 diabetes in children and young people where insulin is often started within a few years of diagnosis (Giampatzis & Tziomalos 2012) and in many cases, more aggressive treatment regimens result in it being prescribed as the initial and/or only therapy (Flint & Arslanian 2011).

However, it should be noted determining if someone is using insulin involves using multiple fields in the data set and there is a degree of error in this process.

Weight and height

From mid-2011 height and weight fields were added to the NDSS registration form, from which body mass index (BMI), used to measure level of overweight and obesity, can be calculated.

Data entry errors or missing data

Data entry errors can occur that may affect the monitoring of type 2 diabetes in children and young people. For example, when the same date is entered for date of birth and date of registration, an error is caused in calculations such as the age at diagnosis. Similar problems are encountered when date fields are missing. For example, date of diagnosis is missing in around 20% of cases; this creates some issue when applying the algorithm that checks the reported diabetes type. Further information about the rules used in deriving missing data is in 'Appendix C: Statistical notes and methods'.

These types of issues are less common since the 2010 upgrade of the database, which included DA implementing additional data entry checks and validations.

Australasian Paediatric Endocrine Group

The APEG is a professional body that represents health professionals involved in the management and research of children and adolescents with disorders of the endocrine system including diabetes. The APEG maintains clinic-based state and territory diabetes registers. Paediatricians, physicians, paediatric endocrinologists, endocrinologists, diabetes educators and nurses report incident cases to the registers. While each jurisdiction established its database independently, and at varying times since 1985, they have all prospectively ascertained all forms of insulin-treated diabetes in people aged less than 15 years at diagnosis and diagnosed from 1999 onwards.

Strengths and limitations of the APEG data in examining type 2 diabetes

Coverage of the diagnosed type 2 diabetes population

The APEG data are not available at a national level but do have geographic national cover of all states and territories. While the state-based registers relate to cases of diabetes for the whole of Australia, the database is not compiled at a national level.

APEG data could only provide a limited indication of the incidence or prevalence of type 2 diabetes in young Australians because the scope of the state-based registers is not consistent (Table 2.3). The registers in most states are limited to children aged 0 to 14 years at the time of diagnosis, except WA and NSW which include information up to, but not including, 18 years. In addition, 3 registers are limited to insulin-treated diabetes (Queensland (Qld)/Northern Territory (NT), Tasmania (Tas) and Vic), while the remaining 3 (NSW/Australian Capital Territory (ACT), South Australia (SA) and WA) include information for non-insulin-treated diabetes also.

Table 2.3: Summary of APEG's data holdings on type 2 diabetes in children and adolescents

State	0–14 years at diagnosis	15–17 years at diagnosis	Insulin-treated	Non insulin-treated
NSW/ACT	Yes	Yes	Yes	Yes
WA	Yes	Yes	Yes	Yes
SA	Yes	No	Yes	Yes
Qld/NT	Yes	No	Yes	No
Tas	Yes	No	Yes	No
Vic	Yes	No	Yes	No

Source: APEG state-based register data managers.

Age of registrants

APEG registers relate to information about children and young people specifically; all registers cover those aged 0–14 at diagnosis, while the WA and NSW/ACT registers also include those aged 15–17.

Type of diabetes

At the time of registration, a medical specialist certifies the diabetes type recorded in APEG records and the majority of young people have investigations to confirm the type of diabetes they have through clinical tests, including measurement of diabetes autoantibodies and c-peptide.

Records are routinely updated if diabetes type is revised after diagnosis.

Ongoing and up to date

As an administrative database, APEG records are ongoing, meaning that at any point in time numbers used to estimate incidence and prevalence are up to date, as well as permitting comparisons over time.

However, because the data are not compiled nationally, registrants who have moved interstate can appear on 2 (or even more) registers simultaneously.

Identified information

APEG records include personal information (name, address and date of birth) about young people with diabetes. This fact allows the data to potentially be used for studies where records may be linked to other databases containing identifiable information.

Range of sociodemographic variables

APEG data include a range of variables, including sex, geographic residential location at diagnosis, Indigenous status and country of birth.

National (insulin-treated) Diabetes Register

The NDR, constructed each year from the NDSS and APEG databases and held at the AIHW, relates to information about people who use insulin as treatment for diabetes. Its scope contains people who began using insulin on or after 1 January 1999.

In preparing the NDR, the AIHW uses both registrant and sales data from the NDSS, and APEG data concerning those with insulin-treated diabetes who were under 15 at the time of diagnosis.

The NDR therefore carries the same strengths and weaknesses that are applicable to the source data (see above for a discussion of these issues).

However, there are some particular points to note, which are specific to the NDR.

While both the NDSS and APEG data contain identifying information for all people whose registration records are held, the NDR does not. In the final step of its construction, the identifying information is stripped away for a portion of people who did not consent to have their information included on the NDR.

However, having all identifying information during the preparation of the NDR allows for duplicate records to be identified, as well as discrepancies between the data sources in details such as date of birth, diabetes type and diagnosis date to be checked with the data supplier; and missing data in 1 source may be available in the other source (see the section about derivation of variables in 'Appendix C: Statistical notes and methods'). This produces more robust data than those provided by NDSS data alone.

For APEG records, where a person is eligible for inclusion on the NDR (they use insulin and were aged less than 15 at diagnosis with diabetes), but did not consent to being on the NDR, there will be no record of this person on the NDR as their information will not have been forwarded to the AIHW, unless they are registered with the NDSS.

As the NDR only includes insulin-treated diabetes, it is not clear what proportion of all type 2 diabetes in children and young people would be captured. However, studies in NSW and WA have found more than 40% of young people with type 2 diabetes are insulin-treated (M Craig 2013, pers. comm., 8 April) and, as discussed previously, insulin is often started as the initial and/or only therapy in young people with type 2 diabetes.

3 Type 2 diabetes—national incidence and prevalence

This chapter examines incidence and prevalence of type 2 diabetes to determine if there is any evidence of type 2 diabetes increasing in children and young people in Australia. The figures given represent preliminary work based on the best data source available at the AIHW. The results should be interpreted in light of the discussion in Chapter 1 about difficulties in determining type 2 diabetes.

The analysis on new cases (incidence) of type 2 diabetes covers 10 years of data, from 1 July 2002 to 30 June 2012, and the results are presented by financial year. The decision to begin analysis in 2002 was based on the fact that the NDSS data set, used as one of the data sources, was considered more robust from 2002 onwards, after DA implemented changes to the database that improved the data fields.

Prevalence estimates are based on all people on the data set of analysis who were alive as of 30 June 2012 and diagnosed with type 2 diabetes.

About the data in this chapter

The results in this chapter are from a data set that the AIHW prepared in constructing the NDR; for the current purpose it provides an excellent source of data, but does have some limitations.

The data are based on NDSS registrant data (all NDSS registrants) and APEG data submitted for the purposes of the NDR (insulin-treated diabetes in those diagnosed aged 0–14). In creating the NDR, these data sets are combined, checked for duplicates, cleaned and variables derived where needed—these are the data used in the analysis. The NDR is a subset of these data, and it represents only those with insulin-treated diabetes who started insulin from 1999 onwards.

As the APEG component of the data are only those aged less than 15 with insulin-treated diabetes, any young person diagnosed with type 2 diabetes but not using insulin will not be present in the data unless they are registered with the NDSS. Of the 362 incident cases among 10–14 year olds, 12% were sourced from NDSS and APEG, 1% from APEG alone and 87% from NDSS alone (Table 3.1).

To reduce the chance of error for diabetes type (see ‘Chapter 1: Difficulties with determining type 2 diabetes’), the analysis uses derived diabetes type, whereby the reported type is tested against a number of criteria and reclassified if necessary. For detailed information about the derivation of diabetes type, as well as the derivation of other variables with missing or inconsistent information, see ‘Appendix C: Statistical notes and methods’.

Although the focus of this working paper is to examine changes in type 2 diabetes among children and young people, the analysis covers people aged 10–39 at diagnosis. Not only does this provide additional context and comparisons for the information about those in younger age groups, but it also enables changes to be detected that may, as yet, not be large enough to be apparent in children and young people. As less than 9% of the incidence of type 2 diabetes occurs in those aged less than 40, changes in the age of onset may initially be evident in this relatively young group, rather than in children.

On advice from the National Diabetes Data Working Group (NDDWG), this chapter does not include data for children aged less than 10. While there are confirmed cases in Australia in children in this age group, they are extremely rare and there were data quality concerns for the cases sourced from the NDSS.

Incidence of type 2 diabetes

From 2002–03 to 2011–12, there were approximately 460,000 new cases of type 2 diabetes (representing 250 people in every 100,000) among people aged 10 and over (Table 3.1), an average of around nearly 46,000 new cases a year. Of these new cases, there was a higher proportion of males (56% on average for the 10-year period) than females (44% on average).

The age-specific rates supported the fact that type 2 diabetes is essentially a disease that develops in middle to old age, and rises with increasing age: on average from 2002–03 to 2011–12, 3 people in every 100,000 aged 10–14 were diagnosed and 441 per 100,000 aged 40 and over (Table 3.2). The older age of onset is further highlighted by the fact that 92% of cases occurred among people aged 40 and over at diagnosis, with fewer than 9% among people aged 10–39 (derived from Table 3.1).

In order to compare rates over time, they were age-standardised to the 2001 Australian population and Joinpoint analysis was undertaken to assist in determining the existence of statistically significant trends. In this paper, a log-linear model was fitted and the results presented as an average annual percentage change (APC). For more information about Joinpoint, see 'Appendix C: Statistical notes and methods'. Over the 10-year period of analysis, the incidence of type 2 diabetes for all Australians aged over 10 fluctuated from around 200 to 264 new cases per 100,000 population each year. Joinpoint analysis confirmed that there was no overall significant trend over this time (Table 3.3).

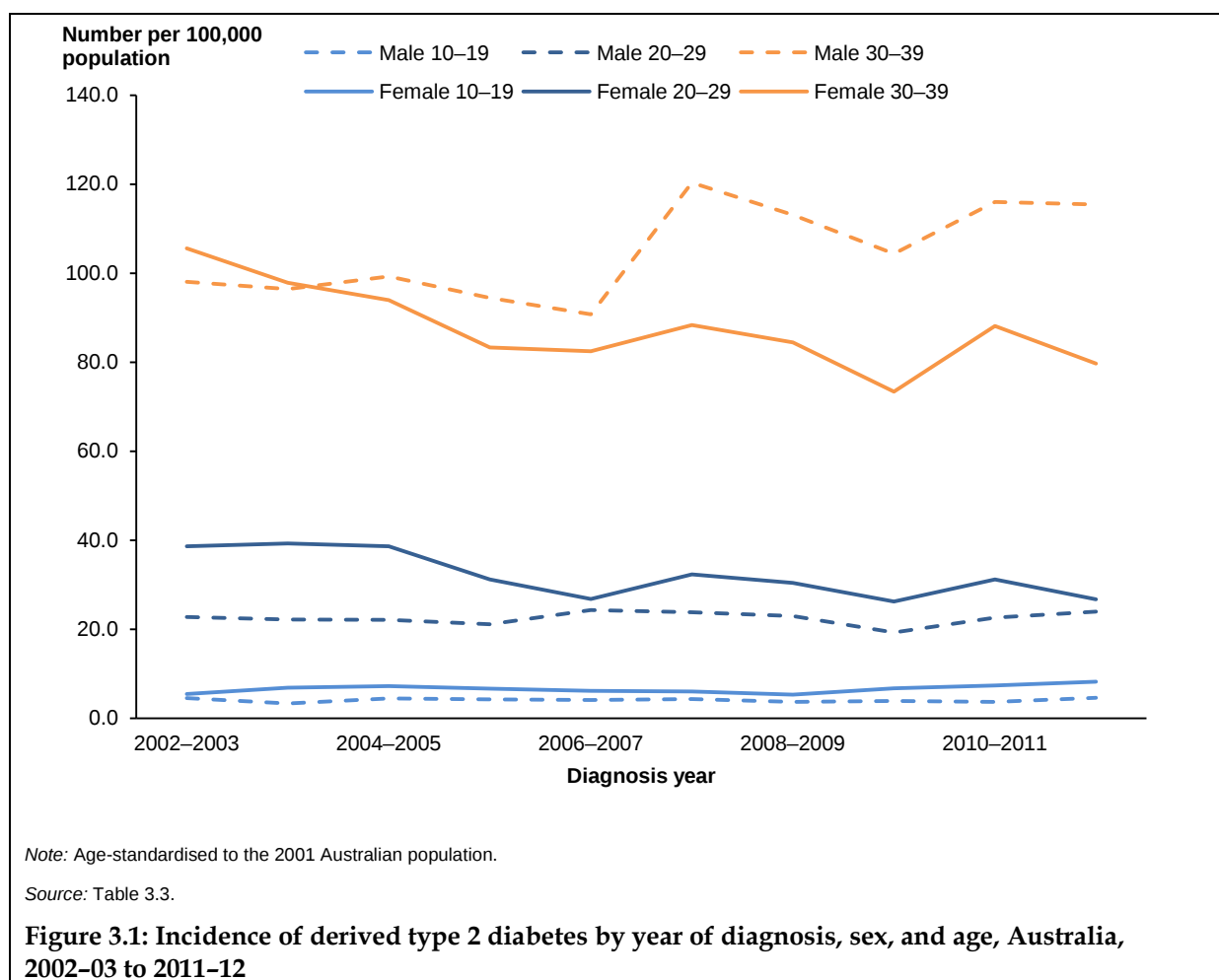
Those aged 10–39 at diagnosis

From 2002–03 to 2011–12 there were approximately 39,000 new cases of type 2 diabetes among people aged 10–39 at diagnosis (derived from Table 3.1), representing approximately 9% of all new cases over this period. The average annual rate of new cases of type 2 diabetes rose with increasing age, from 3 per 100,000 population aged 10–14 to 119 in those aged 35–39 (Table 3.2).

While males and females both showed the increasing rates of type 2 diabetes onset with age, on average from 2002–03 to 2011–12 rates among females were higher until the 30–34 age group, after which male rates were higher (Table 3.2). The approximate age at which female rates dropped below those in males appears to have fallen over the 10-year period – at the beginning of the period it was around the 35–39 year age group, moving to the early 30s and then in 2011–12 female rates dropped below male rates at around age 25–29.

Age-adjusted incidence rates from 2002–03 to 2011–12 were examined for any indication of change over this period. Figure 3.1 depicts the age-standardised rates for males and females over the period and Joinpoint analysis calculated the percentage rate of change. For 10–19 year olds, no significant change was observed. However, for those aged 20–29 there was a significant fall in incidence rate over this period of 2.4% per year ($p=0.01$), driven by a decrease in the rate for females of 4% per year, and no change for males. For those aged 30–39 there was no significant change overall but, when examined by sex, there was an

increase for males of 2.4% per year ($p=0.02$) and a decrease for females of 2.6% per year ($p=0.01$). Also see Table 3.3.



Those aged 10–24 at diagnosis

Many studies of children and young people have focused on children and adolescents (with varying upper limits of 17, 18 and 19 years), so it is worth providing some results specifically for this age group.

There were just over 1,500 new cases of type 2 diabetes diagnosed among children and adolescents aged 10–19 from 2002–03 to 2011–12, an average of approximately 150 new cases each year (Table 3.1). The incidence did not change over this 10-year period.

However, when examining young people aged 10–24 we found there were approximately 4,000 new cases of type 2 diabetes diagnosed from 2002–03 to 2011–12, an average of nearly 400 new cases each year (Table 3.1).

This indicates that there were around an additional 2,500 cases of type 2 diabetes in young people aged 20–24, which is more than in the 10–19 age group.

Table 3.1: Incidence (number of new cases) of derived type 2 diabetes, by sex, year and age at diagnosis, in Australia, 2002–2003 to 2011–2012^(a)

Age at diagnosis (years)	Diagnosis year										
	2002–03	2003–04	2004–05	2005–06	2006–07	2007–08	2008–09	2009–10	2010–11	2011–12	2002–12
Number per 100,000 people											
Males											
10–14	18	14	11	11	11	12	13	12	15	11	128
15–19	46	33	53	50	49	52	42	46	39	57	467
20–24	78	85	87	98	97	107	89	81	87	93	902
25–29	228	216	216	198	251	247	267	229	282	302	2,436
30–34	479	493	528	488	477	670	585	504	618	673	5,515
35–39	962	924	938	921	894	1,166	1,166	1,121	1,184	1,123	10,399
40+	22,660	21,420	21,417	20,739	21,777	27,011	25,472	22,113	26,350	25,927	234,886
<i>All (10+)</i>	<i>24,471</i>	<i>23,185</i>	<i>23,250</i>	<i>22,505</i>	<i>23,556</i>	<i>29,265</i>	<i>27,634</i>	<i>24,106</i>	<i>28,575</i>	<i>28,186</i>	254,733
Females											
10–14	14	19	25	28	21	20	20	27	32	28	234
15–19	59	74	73	63	64	64	55	68	71	87	678
20–24	148	165	195	136	120	146	151	138	161	152	1,512
25–29	368	361	329	293	257	322	307	271	333	277	3,118
30–34	713	664	602	503	496	569	499	449	499	462	5,456
35–39	870	805	809	755	762	792	820	701	882	783	7,979
40+	19,183	17,690	17,366	16,110	17,363	20,677	20,024	16,841	19,926	19,796	184,976
<i>All (10+)</i>	<i>21,355</i>	<i>19,778</i>	<i>19,399</i>	<i>17,888</i>	<i>19,083</i>	<i>22,590</i>	<i>21,876</i>	<i>18,495</i>	<i>21,904</i>	<i>21,585</i>	203,953
Persons											
10–14	32	33	36	39	32	32	33	39	47	39	362
15–19	105	107	126	113	113	116	97	114	110	144	1,145
20–24	226	250	282	234	217	253	240	219	248	245	2,414
25–29	596	577	545	491	508	569	574	500	615	579	5,554
30–34	1,192	1,157	1,130	991	973	1,239	1,084	953	1,117	1,135	10,971
35–39	1,832	1,729	1,747	1,676	1,656	1,958	1,986	1,822	2,066	1,906	18,378
40+	41,843	39,110	38,783	36,849	39,140	47,688	45,496	38,954	46,276	45,725	419,864
All (10+)	45,826	42,963	42,649	40,393	42,639	51,855	49,510	42,601	50,479	49,773	458,688

Note: The male and female components for 2011–12 and 2002–12 do not add to the persons total due to 2 people with a missing gender.

(a) People registered on or after 1 July 2002 and diagnosed 1 July 2002 to 30 June 2012.

Source: AIHW analyses of NDSS and APEG records (see 'Data sources' in Appendix B).

Table 3.2: Incidence (age-specific rate) of derived type 2 diabetes by sex, age and year of diagnosis, Australia, 2002–2003 to 2011–2012^(a)

Age at diagnosis (years)	Diagnosis year										
	2002–03	2003–04	2004–05	2005–06	2006–07	2007–08	2008–09	2009–10	2010–11	2011–12	2002–12
	Number per 100,000 people										
Males											
10–14	2.5	2.0	1.5	1.5	1.5	1.7	1.8	1.7	2.1	1.6	1.8
15–19	6.6	4.7	7.5	6.9	6.7	7.0	5.6	6.1	5.2	7.6	6.4
20–24	11.4	12.1	12.1	13.3	12.9	13.8	11.1	9.8	10.6	11.3	11.8
25–29	33.2	31.6	31.4	28.3	34.9	33.1	33.9	28.0	33.8	35.7	32.5
30–34	63.9	65.2	70.0	65.3	64.7	91.5	79.1	67.4	81.3	86.2	73.5
35–39	131.7	127.1	128.2	123.2	116.5	148.7	146.5	140.7	150.1	144.3	136.0
40+	538.1	497.6	487.7	462.9	477.1	581.1	537.4	457.9	535.0	515.2	509.2
All (10+)	289.0	269.9	266.8	254.3	262.0	320.0	296.1	254.2	298.0	290.1	280.3
Females											
10–14	2.1	2.8	3.7	4.1	3.1	2.9	2.8	4.0	4.7	4.2	3.5
15–19	8.8	11.0	10.7	9.2	9.2	9.1	7.3	9.5	10.0	12.3	9.7
20–24	22.3	24.3	28.1	19.1	16.5	19.7	18.8	17.8	20.5	19.3	20.6
25–29	53.7	53.1	48.4	42.5	36.4	44.0	39.0	34.1	41.1	33.7	42.3
30–34	93.4	86.4	78.6	66.5	66.8	77.3	67.5	60.1	65.7	59.4	72.2
35–39	117.5	109.2	109.1	99.8	97.9	99.3	103.0	86.5	110.2	99.6	102.8
40+	427.3	385.6	370.9	337.4	357.0	417.5	422.5	327.3	379.8	369.6	376.4
All (10+)	245.9	224.7	217.4	197.5	207.6	241.9	229.9	191.3	223.8	217.7	219.6
Persons											
10–14	2.3	2.4	2.6	2.8	2.3	2.3	2.4	2.8	3.4	2.8	2.6
15–19	7.7	7.8	9.1	8.0	7.9	8.0	6.6	7.8	7.5	9.9	8.0
20–24	16.8	18.1	19.9	16.1	14.6	16.7	15.4	13.7	15.4	15.2	16.1
25–29	43.4	42.3	39.9	35.4	35.6	38.5	37.0	31.0	37.4	34.7	37.4
30–34	78.8	75.9	74.3	65.9	65.7	84.4	73.3	63.7	73.5	72.8	72.8
35–39	124.6	118.1	118.6	111.4	107.1	123.8	123.7	113.4	130.0	121.9	119.3
40+	480.9	439.8	427.4	398.2	415.1	496.7	464.8	390.5	455.0	440.1	440.7
All (10+)	267.2	247.0	241.8	225.6	234.5	280.5	262.7	222.5	260.6	253.5	249.6

(a) People registered on or after 1 July 2002 and diagnosed 1 July 2002 to 30 June 2012.

Source: AIHW analyses of NDSS and APEG records (see 'Data sources' in Appendix B).

Table 3.3: Age-standardised incidence rate of derived type 2 diabetes by sex, age and year of diagnosis, Australia, 2002–2003 to 2011–2012^(a)

Age at Diagnosis (years)	Diagnosis year										
	2002–03	2003–04	2004–05	2005–06	2006–07	2007–08	2008–09	2009–10	2010–11	2011–12	2002–12
Age-standardised rate (number per 100,000 people) ^(a)											
Males											
10–19	4.6	3.3	4.5	4.2	4.1	4.3	3.7	3.9	3.7	4.6	4.1
20–29	22.7	22.2	22.1	21.1	24.3	23.8	23.0	19.3	22.7	24.0	22.5
30–39	98.1	96.4	99.3	94.5	90.8	120.3	113.1	104.4	116.0	115.5	105.0
40+	535.2	493.5	482.4	456.3	469.4	570.8	525.0	446.7	520.5	501.1	499.9
<i>All (10+)</i>	<i>289.8</i>	<i>268.3</i>	<i>263.5</i>	<i>249.3</i>	<i>255.7</i>	<i>311.7</i>	<i>287.2</i>	<i>245.9</i>	<i>285.4</i>	<i>276.0</i>	273.2
Females											
10–19	5.4	6.9	7.2	6.6	6.2	6.0	5.3	6.7	7.4	8.2	6.6
20–29	38.6	39.3	38.6	31.2	26.8	32.4	30.4	26.3	31.2	26.7	31.9
30–39	105.6	97.9	94.0	83.3	82.5	88.4	84.5	73.4	88.2	79.7	87.7
40+	427.5	385.5	370.0	335.7	353.8	410.4	389.2	322.1	371.5	361.1	371.8
<i>All (10+)</i>	<i>239.9</i>	<i>217.8</i>	<i>209.3</i>	<i>189.0</i>	<i>197.1</i>	<i>227.3</i>	<i>215.6</i>	<i>179.6</i>	<i>207.9</i>	<i>200.6</i>	207.9
Persons											
10–19	5.0	5.1	5.8	5.4	5.1	5.2	4.5	5.3	5.5	6.4	5.3
20–29	30.6	30.7	30.3	26.1	25.5	28.0	26.6	22.7	26.9	25.3	27.1
30–39	101.9	97.2	96.6	88.9	86.6	104.2	98.7	88.8	102.0	97.6	96.3
40+	480.0	438.3	425.0	394.8	410.4	488.7	455.5	383.0	444.2	429.4	434.4
All (10+)	264.1	242.5	235.7	218.5	225.8	268.5	250.6	212.0	245.7	237.4	239.8

(a) People registered on or after 1 July 2002 and diagnosed 1 July 2002 to 30 June 2012.

Note: Age-standardised to the 2001 Australian population.

Source: AIHW analyses of NDSS and APEG records (see 'Data sources' in Appendix B).

Table 3.4: New cases of diabetes^(a) diagnosed in 10–39 year olds in 2002–03 to 2011–12^(b), by derived diabetes type – all Australians

Derived diabetes type	Age group (years)							
	10–14		15–19		20–29		30–39	
	n	%	n	%	n	%	n	%
Type 1	4,419	87.9	2,412	64.3	3,613	30.2	2,657	8.2
Type 2	362	7.2	1,145	30.5	7,968	66.6	29,349	90.3
Other	171	3.4	181	4.8	320	2.7	387	1.2
Not derived	77	1.5	11	0.3	68	0.6	126	0.4
Total	5,029	100.0	3,749	100.0	11,969	100.0	32,519	100.0

(a) Excluding gestational diabetes.

(b) People registered on or after 1 July 2002 and diagnosed 1 July 2002 to 30 June 2012.

Source: AIHW analyses of NDSS and APEG records.

Likely accuracy of these incidence figures

APEG provided additional data specifically for this project which verified that the incidence figures presented above accurately reflect the number of people aged 10 to 40 diagnosed with type 2 diabetes.

As discussed above, the data representing those less than 15 used in the above analysis comprised 2 sources: NDSS and APEG. However, where the records were obtained from APEG, they only represented insulin-treated type 2 diabetes. In order to determine how accurate the results might be, the states (NSW, WA and SA) that collect information for non-insulin-treated type 2 diabetes also provided data. The data were analysed to determine how many cases of type 2 diabetes in young people were potentially missed with the data set used in the analysis of this chapter. The results are summarised below and in Table 3.5.

- APEG NSW provided data for 2001–2008, for which there were 204 incident cases in youth aged <19 at diagnosis. The comparable figure for NDSS was 329 cases, making 125 additional cases over the 8 years, an average of 16 additional cases per year.
- APEG WA recorded 121 cases of type 2 diabetes in youth aged <19 at diagnosis over the period 1999–2011. The comparable figure for NDSS was 161 cases, 40 additional cases over 13 years, an average of just over 3 additional cases per year.
- APEG SA recorded 6 cases of type 2 diabetes in youth aged <15 at diagnosis over the period 1999–2011. The comparable figure for NDSS was 34 cases, 28 additional cases over 13 years, an average of just over 2 additional cases per year.

Table 3.5: Comparing APEG and NDSS incidence of type 2 diabetes diagnosed in children, selected states and time periods

State	Time period	Age group (years)	APEG incidence	NDSS incidence	Difference (additional cases on the NDSS)	
					Number	Cases per year
NSW	2001–2008	0–18	204	329	125	15.6
WA	1999–2011	0–18	121	161	40	3
SA	1999–2011	0–14	6	34	28	2

Source: APEG data (see Table A1) and AIHW analysis of NDSS data.

It is expected that the NDSS may capture additional cases to those that APEG registered as APEG may underestimate the incidence of type 2 diabetes ‘particularly among older adolescents or children from remote areas who may not have access to paediatric diabetes services’ (Craig et al. 2007). Last, it is also known that APEG’s coverage of insulin-treated diabetes among 0–14 year olds varies by state; for example, for insulin-treated diabetes among 0–14 year olds diagnosed in 1999–2007, APEG recorded 69% of cases listed in the NDSS in NSW, whereas in WA this figure was 104% (AIHW 2009b).

Incidence of type 2 diabetes in Aboriginal and Torres Strait Islander people

It has already been discussed that type 2 diabetes impacts some populations more than others and, in Australia, Aboriginal and Torres Strait Islander people experience a disproportionately higher rate of type 2 diabetes than non-Indigenous Australians (Azzopardi et al. 2012). While the results above do not highlight any rises in type 2 diabetes among all Australian young people, literature suggests this is not the case for Indigenous children and young people (Maple-Brown et al. 2010, Craig et al. 2007).

The data in this section cover the period from 2006 to 2011; this is because of changes made in 2005 to the way Indigenous status was coded on the NDSS database. This and other issues related to interpreting the results are discussed in the section 'Strengths and limitations of the NDSS data in examining children and young people with type 2 diabetes' of Chapter 2. These changes have also meant that the analysis is limited to incidence only as prevalence estimates were not possible.

For 2006–11, the total number of new cases among all Australians diagnosed at age 10 and over with type 2 diabetes was around 284,000 (Table 3.6). Of these approximately 5,900 (2%) were among people who identified as being of Aboriginal and/or Torres Strait Islander origin. For 14% of new cases of type 2 diabetes, Indigenous status was not stated, making direct comparisons between Indigenous and non-Indigenous Australians difficult.

Table 3.6: Number of new cases of type 2 diabetes by Indigenous status and age at diagnosis, Australia, 2006–11^(a)

Age group (years)	Indigenous	Non-Indigenous	Not stated	All Australians
10–14	58	141	17	216
15–19	81	514	88	683
20–24	157	1,071	185	1,413
25–29	292	2,563	454	3,309
30–34	458	5,129	854	6,441
35–39	661	9,118	1,542	11,321
10–39	1,707	18,536	3,140	23,383
40+	4,163	218,720	37,709	260,592
Total (10+)	5,870	237,256	40,849	283,975

(a) People registered on or after 1 January 2005 and diagnosed 1 January 2006 to 31 December 2011.

Source: AIHW analyses of NDSS and APEG records (see 'Data sources' in Appendix B).

When compared with either non-Indigenous Australians or the whole population, Indigenous Australians had much higher age-specific rates of type 2 diabetes in all age groups (Table 3.7). For example, in children and adolescents aged 10–14 and 15–19, the age-specific rate among Indigenous Australians was respectively 8 and 4 times the rate among non-Indigenous Australians.

After adjusting for age differences, the incidence rate of type 2 diabetes for Indigenous Australians aged 10–39 was 4 times that of non-Indigenous Australians – 126.7 per 100,000 population and 35.7 per 100,000, respectively (Table 3.7).

Table 3.7: Incidence rate of type 2 diabetes by Indigenous status and age at diagnosis, Australia, 2006–11^(a)

	Indigenous	Non-Indigenous	All Australians	
Age group (years)	Age-specific rate (number per 100,000 population)			Rate ratio (Indigenous: non-Indigenous)
10–14	14.9	1.8	2.6	8.3
15–19	22.2	6.2	7.8	3.6
20–24	53.3	11.9	15.2	4.5
25–29	120.5	28.5	35.8	4.2
30–34	213.2	58.7	71.9	3.6
35–39	307.4	98.4	119.4	3.1
	Age-standardised rate (number per 100,000 population)			
10–39	126.7	35.7	43.9	3.5
40+	548.9	368.1	433.6	1.5
Total (10+)	338.2	202.2	239.1	1.7

(a) People registered on or after 1 January 2005 and diagnosed 1 January 2006 to 31 December 2011.

Source: AIHW analyses of NDSS and APEG records (see 'Data sources' in Appendix B).

Notes: Directly age-standardised to the 2001 Australian population.

Type 2 and type 1 diabetes incidence compared

In contrast to the pattern seen among all Australians (albeit for a different time period), the majority of new cases of diabetes in Indigenous children and adolescents are type 2 (Table 3.8). During 2006–11, among people aged 10–19 years at diagnosis, there were around 250 new cases of diabetes. Of these, more than half (55.2%) were type 2, 43.3% were type 1, 1.2% were other types of diabetes, and 0.4% had an unknown diabetes type (that is, their diabetes type was unable to be derived). Thus, for every case of type 2 diabetes in this age group there were 0.8 cases of type 1 diabetes.

The same pattern was seen among 20–29 and 30–39 year olds where the majority of new cases were type 2, 89.1% and 96.8%, respectively (Table 3.8). Again noting the different time periods involved, the proportion of type 2 diabetes among new cases of diabetes in 20–29 year olds was much higher for Indigenous Australians than all Australians, 89.1% compared with 66.6%, respectively (Tables 3.4 and 3.8).

Table 3.8: New cases of diabetes^(a) diagnosed in 10–39 year olds in 2006 to 2011^(b), by diabetes type—Indigenous Australians

Derived diabetes type	Age group (years)							
	10–14		15–19		20–29		30–39	
	n	%	n	%	n	%	n	%
Type 1	69	53.1	40	32.8	48	9.5	32	2.8
Type 2	58	44.6	81	66.4	449	89.1	1,119	96.8
Other	2	1.5	1	0.8	5	1.0	5	0.4
Not derived	1	0.8	0	0.0	2	0.4	0	0.0
Total	130	100.0	122	100.0	504	100.0	1,156	100.0

(a) Excludes gestational diabetes.

(b) People registered on or after 1 January 2005 and diagnosed 1 January 2006 to 31 December 2011.

Source: AIHW analyses of NDSS and APEG records.

Prevalence of type 2 diabetes

At 30 June 2012 there were approximately 881, 000 Australians aged 10 years and over with type 2 diabetes – an estimated prevalence of 4.5% of Australians in this age group (Table 3.9). Among those aged 10–39, there were nearly 31,000 people (3.5% of all those over 10 with type 2 diabetes and 0.3% of this age group of the Australian population) with type 2 diabetes. Prevalence rose with increasing age, from 0.01% among 10–14 year olds to 8.1% among people aged 40 and over. Among 10–39 year olds type 2 diabetes was more common in females (4.1%) than males (3.0%).

Table 3.9: Number of people aged 10 years and over, with derived type 2 diabetes, as at 30 June 2012

Age group (years), as at 30 June 2012	Males			Females			Persons		
	Number	Per cent	Proportion with type 2 diabetes in the population (%)	Number	Per cent	Proportion with type 2 diabetes in the population (%)	Number	Per cent	Proportion with type 2 diabetes in the population (%)
10–14	35	0.01	0.00	71	0.02	0.01	106	0.01	0.01
15–19	231	0.05	0.03	363	0.09	0.05	594	0.07	0.04
20–24	592	0.13	0.07	919	0.22	0.12	1,511	0.17	0.09
25–29	1,504	0.32	0.18	2,104	0.51	0.25	3,608	0.41	0.21
30–34	3,712	0.79	0.47	4,494	1.10	0.57	8,206	0.93	0.52
35–39	7,983	1.69	1.03	8,988	2.19	1.15	16,971	1.93	1.09
10–39	14,057	2.98	0.30	16,939	4.13	0.37	30,996	3.52	0.33
40+	456,936	97.02	8.98	392,851	95.87	7.25	849,791	96.48	8.09
Total (10+)	470,993	100.00	4.81	409,790	100.00	4.10	880,787	100.00	4.45

Notes:

1. Excludes people who have been identified as deceased (unless their date of death was after 30 June 2012).
2. Excludes people who were born, diagnosed or registered after 30 June 2012.
3. Prevalence based on the ABS Australian estimated resident population at 30 June 2012 (preliminary estimates).
4. Subcomponents may not add to totals due to a small number of cases with missing gender.

Source: AIHW analyses of NDSS and APEG records (see 'Data sources' in Appendix B).

4 Discussion and recommendations

The evidence from around the world suggests that increasingly type 2 diabetes is developing in younger ages. This has been associated with greater rates of overweight and obesity, which suggests that type 2 diabetes could progressively become a major problem among children and young people. Monitoring type 2 diabetes in children and young people over time will help determine if Australia is also seeing a change in the age at which people are developing type 2 diabetes. It will also allow identification of the groups at greatest risk and has important implications for preventive efforts, clinical service provision and health sector planning.

This working paper aims to: identify and describe national data sources for monitoring incidence and prevalence of type 2 diabetes in Australia's young people, present the latest available national incidence and prevalence data and explore what is needed to improve Australia's ability to monitor this.

Type 2 diabetes in Australia's children and young people

Type 2 diabetes is present in Australia's children, adolescents, and young people. At 30 June 2012, there were nearly 31,000 people aged 10–39 with type 2 diabetes, an estimated 0.3% of Australians in that age group. For children and adolescents, the prevalence was 0.01% among 10–14 year olds, and 0.04% among 15–19 year olds. Estimates from the NDSS and the ABS 2011–12 AHS for 25–34 year olds were very similar (estimates for younger age groups were not available for comparison).

In terms of new cases, during the 10-year period from 2002–03 to 2011–12, nearly 3,900 children and young people aged 10–39 were diagnosed each year in Australia. This age group made up 8.5% of all new cases among people aged 10 or over. Among children and adolescents (10–19 year olds) there were just over 150 new cases each year, a crude average annual rate of 2.6 per 100,000 population in 10–14 year olds, and 8.0 for 15–19 year olds. On average from 2002–03 to 2011–12, less than 1% of type 2 diabetes was diagnosed among people aged 10–24, at around 400 new cases each year. Half of the new cases in 10–24 year olds occurred in those aged 20–24.

It is important to note that these incidence and prevalence figures are likely to be underestimates due to the issues described in this report (Chapter 1). It is difficult to compare these results with rates published from other studies because studies vary considerably in terms of when they were conducted, what ethnicities they targeted, and what age range they present results for. However, at a national level the Australian prevalence and incidence data seem to be similar to results in the literature from individual states in Australia, and from countries such as the UK, US and New Zealand.

Has the incidence rate changed over time?

While the evidence presented in this paper shows a level of type 2 diabetes among children and young people, the incidence rate did not rise over the 10 years studied (2002–03 to 2011–12). The rates did not change in 10–19 and 30–39 year olds, and they fell in 20–29 year olds.

Data from this paper also suggest differences between males and females. Among those aged 20–29, the statistically significant fall in incidence of 2.4% per year was driven by a decrease in the rate for females of 4% per year, with no change for males. For those aged 30–39, there was no significant change overall but when examined by sex there was a significant rise for males of 2.4% per year and a drop for females of 2.6% per year.

There are several important points to keep in mind when considering if the incidence of type 2 diabetes has changed in this population during this period.

First, it may be that an increase in incidence occurred in Australia before the 10-year period studied here (2002–03 to 2011–12). Results from 2 studies in WA showed rises: in a study conducted during 1990–2002 in people aged 17 or under the rate increased by 27%, while another study found an increase in incidence comparing the rates of type 2 diabetes in 2005–2006 to 1993–1996 in 10–24 year olds (McMahon et al. 2004; Sillars et al. 2010). However, a study conducted in NSW in 2001–2008 in under 19 year olds did not find an increase (M Craig 2013, pers. comm., 8 April).

In addition, assignment of diabetes type has varied over time (the proportion of type 2 diabetes cases misclassified as type 1 may have decreased over time) and it is possible that the level of undiagnosed cases has fallen due to greater awareness and surveillance (Shaw 2007).

Increases in prevalence of type 2 in Australia may indicate that treatment for diabetes is getting better and people are living longer with the disease. However, the lack of change in incidence still warrants further exploration in relation to the observed rise in the prevalence of type 2 diabetes in Australia and accompanying risk factor trends.

Young females at higher risk than males

Young females have a higher risk of type 2 diabetes than males. Many studies have found a female excess in cases of type 2 diabetes among the young. After adjusting for age, the average annual rate of new cases was higher for females than males aged 10–19 and 20–29 but the opposite was observed for the 30–39 age group. This is similar to findings from the UK during 2006–2010, where females had a higher incidence than males among those aged 10–39 but the opposite for people aged 40 and over (Holden et al. 2013).

How do Indigenous Australians fare?

Young Indigenous Australians experience a much greater risk than their non-Indigenous counterparts – after adjusting for age, Indigenous Australians aged 10–39 had incidence rates (during 2006–2011) that were 4 times those of non-Indigenous Australians (127 per 100,000 and 36 per 100,000 population, respectively).

This finding is in line with those of earlier state-based studies in Australia that reported much higher incidence rates among Indigenous than non-Indigenous youth (Craig et al. 2007; McMahon et al. 2004), and with high rates of type 2 diabetes observed in Indigenous populations around the world.

Compared with non-Indigenous Australians, the type 1 to type 2 ratio is strikingly different among Indigenous Australians aged 10–19 where more than half (55%) of new diabetes cases were type 2 in 2006–2011.

Type 1 and type 2 diabetes incidence compared

Type 1 diabetes is still by far the most common form of diabetes diagnosed in children and adolescents (aged 10–19). However, type 2 diabetes makes up 17% of new cases among those aged 10–19 (7% among 10–14 year olds, and 31% among 15–19 year olds). This is higher than the previously reported proportion of 11% of those aged 10–18 in NSW for 2001–2006, and around 10% in under 15 year olds in the Auckland region of New Zealand over 1995–2007 (Craig et al. 2007; Jefferies et al. 2012).

Does Australia have an appropriate data source to monitor type 2 diabetes in children and young people?

The analyses in this paper used a data set which combined NDSS and APEG data and was derived during the processing to compile the National (insulin-treated) Diabetes Register. This is considered to be the best available source to monitor type 2 diabetes in children and young people in Australia. The strengths of the data set include that it has national coverage of all ages and contains diabetes type as certified by a health professional. In addition, it is ongoing, allowing for monitoring of trends over time; current, allowing for up-to-date information to inform health policy and planning; and it has ongoing contact with registrants allowing for data queries to be checked.

However, Australia's ability to effectively monitor type 2 diabetes in children and young people with this data source has several important limitations.

- Counts of people registered with the NDSS will underestimate the true incidence and prevalence of diabetes because undiagnosed cases are not captured and because coverage of the diagnosed population is incomplete. That said, data from the FDS Phase II and ANDIAB2 indicate very good ascertainment for the NDSS, 81–86% for non-insulin-treated diabetes and 97% for insulin treated diabetes.
- The counts of people with type 2 diabetes may be inaccurate due to the wrong type of diabetes being recorded in the database. This is particularly pertinent to cases of childhood diabetes where distinguishing between type 1, type 2, and monogenic diabetes may be difficult. Misdiagnosis can occur, and registration with the NDSS may happen before the diagnosis is finalised. In addition, due to the administrative nature of the NDSS database, diagnostic details such as test results for diabetes-associated autoantibodies are not available. However, use of an algorithm to derive diabetes type goes some way to improve the accuracy of the estimates (see 'Appendix C: Algorithm for deriving diabetes type').
- Of particular importance in the Australian setting is our inability to monitor the incidence and prevalence of type 2 diabetes in the migrant and ethnic populations known to be at an increased risk of type 2 diabetes. Poor data on Indigenous Australians and inadequate information on ethnic background hinder monitoring. For example, Indigenous Australians may not register with the NDSS for a variety of reasons and, if they do register, they may not identify themselves as Indigenous. Despite these issues, young Indigenous Australians were still found to have incidence rates 4 times those of their non-Indigenous counterparts.

Discussion points for consideration

As stated above, Australia already has a good data source for monitoring type 2 diabetes in children and young people, the combination of NDSS, NDR and APEG data. However, the following initiatives would enhance monitoring of type 2 diabetes in younger populations.

Existing data sets

Considerations for the NDSS

1. Linking the NDSS and PBS databases to assist in finding further cases of insulin-treated diabetes not counted in the NDSS data (AIHW 2009a) and to allow confirmation of insulin using status for NDSS registrants would improve the accuracy of the derived diabetes type.

This linking could potentially provide comprehensive information about diabetes; the AIHW is piloting the linkage of the NDSS and PBS data for this purpose. Linking the NDSS to existing cohorts where diabetes type has been confirmed would provide an indication of the actual level of accuracy of diabetes type on the NDSS. Potential cohorts to be used for this purpose include the FDS, APEG or the cohort used in a recent NSW study on the long-term complications and mortality in young-onset diabetes (which included 354 with type 2 diabetes, with age of onset between 15 and 30) (Constantino et al. 2013).

2. Introducing a mechanism to update the data recorded on diabetes type; this would require health professionals to notify NDSS of a change in type of diabetes.
3. Adding a field to the NDSS database to record that the type 2 case has been confirmed following the completion of validation checks on cases of type 2 diabetes in under 16 year olds; in the future this might allow reporting of cases aged less than 10.
4. Working to reduce the proportion of not-stated responses to the Indigenous status question for new registrants to the NDSS. For instance, by linking the NDSS to studies, such as the FDS, with known Indigenous status, to provide an indication of the accuracy/coverage of the Indigenous population.
5. Improving data on ethnicity by:
 - working to reduce the proportion of missing data for country of birth (parents or grandparents) and main language spoken at home for new registrants to the NDSS.
 - increasing NDSS registration in *Remote* and *Very remote* areas. This is a focus of ongoing work that the NDSS is carrying out through the employment of Aboriginal Health Workers and Liaison Officers for example, and has been successful to date in raising registrations among Indigenous Australians.

Considerations for the APEG and NDR

1. Expanding the scope of Australia's NDR from insulin-treated diabetes to include those with non-insulin-treated diabetes, in line with a recommendation from the International Diabetes Federation that 'existing registers for type 1 diabetes in children should be expanded to include those with type 2 diabetes' (Alberti et al. 2004).
2. Extending the scope of data that the APEG provides to the NDR. The APEG currently only supply cases to the NDR for insulin-treated children aged 0–14. This could be

expanded to cover those aged 0–18 with both insulin- and non-insulin-treated diabetes so that the NDR has dual ascertainment for a broader age range and diabetes type.

Other options to fill data gaps

Another option is to explore the possibility of accessing information collected on care provided to Indigenous Australians with type 2 diabetes in general practice and Aboriginal Medical Services.

At present there is incomplete information about type 2 diabetes in Indigenous people from the data sources included in this paper (NDSS and APEG). With specific regard to monitoring type 2 diabetes in young Indigenous Australians, Azzopardi and colleagues recently recommended that improved systems for monitoring the evolution of type 2 diabetes in Indigenous children and adolescents be established (Azzopardi et al. 2012).

Conclusion

This working paper presents, for the first time, national incidence and prevalence estimates of type 2 diabetes in Australia's children and young people. It is thought that the increased rates of obesity in young people will impact on type 2 diabetes, with greater numbers developing the disease at younger ages.

It is clear that type 2 diabetes is now affecting children and young people in Australia, but the numbers are small. This study found no evidence of a rise in the rate of new cases of type 2 diabetes in children and young people over the decade 2002–03 to 2011–12.

However, it is important to monitor type 2 diabetes in young people because it already accounts for 17% of new diabetes cases in 10–19 year olds in Australia, and it appears to have a more aggressive nature than type 1 diabetes or type 2 diabetes that develops later in life, leading to higher rates of comorbidities and complications and earlier death.

The incidence and prevalence data presented here are likely to underestimate the true situation given the limitations of the data sources as described above. Nevertheless, these data provide a baseline against which future monitoring efforts can be compared. There is scope to improve Australia's ability to monitor type 2 diabetes in children and young people, and to prevent this serious disease and its complications among young people.

Further improvements to data would enable more accurate counts of the number of children and young people with type 2 diabetes and give better identification of diabetes type in this group.

Appendix A: Additional data

Table A1: Incidence/prevalence data supplied by APEG state and territory registers

State	Incidence/prevalence	Age at diagnosis mean (S.D.)	Gender	Insulin-treated status
NSW only (i.e. not including ACT)	In youth aged <19 years from 2001 to 2008 there were 204 incident cases of type 2 diabetes. The mean annual incidence of type 2 diabetes was 3.0 per 100 000 per year (95% CI 2.6 to 3.4) in 10–18 year olds, and did not change over time ($p=0.36$).	14.6 + 2.5 years	96 boys, 47%	not provided
WA	Over the period 1999 to 2011, there were 121 cases of type 2 diabetes ascertained in youth aged <15 years by the APEG Diabetes Register.	13.9 (+ 2.2) years and only 6 cases were aged <10 years at diagnosis	59% female	43% were insulin treated at diagnosis
SA	Six cases reported 1999 to 2012.	not provided	not provided	not provided
Vic (<i>Royal Children's Hospital, Melbourne</i>)	33/1574 (2.1%) of prevalent cases of diabetes in children and adolescents had type 2 diabetes (Ruhayel et al. 2010).	not provided	not provided	not provided
Vic (<i>Monash Medical Centre, Melbourne</i>)	There were 44 prevalent cases with type 2 diabetes (as of March 2013), which represents <10% of the clinic population.	14.4 (+ 3.1) years	not provided	41% were treated with insulin
Qld	24 cases reported since 1999 (approximately 2 cases per year). However, these data are likely to under-represent rates of type 2 diabetes, because they may not be seen in tertiary diabetes centres or by paediatric endocrinologists/paediatric diabetes educators, who report the majority of diabetes cases to the Queensland APEG Diabetes Register.	not provided	not provided	not provided
Tas	2 cases reported to the APEG database 1999 to 2012.	not provided	not provided	not provided

Source: M Craig 2013, pers. comm., 8 April.

Appendix B: Data sources

Australasian Paediatric Endocrine Group

The APEG state-based registers are described in detail in Chapter 2.

Estimated resident populations

Throughout this report, population data were used to derive rates of diabetes incidence and prevalence. Population data that the AIHW holds are sourced from the ABS and are updated as revised or new estimates become available. All population estimates that the ABS currently produces are based on a usual residence concept; that is, where people usually reside. These Estimated Resident Populations (ERPs) are derived from the ABS Census of Population and Housing and adjusted for deaths, births and net migration. The ERPs used in this report are based on the 2006 Census and include final estimates for 2002–2006 and preliminary revised estimates for 2007 to 2012.

Where a rate is calculated for a calendar year, the population used is the ERP as reported at 30 June of that year. Where a rate is calculated for a financial year, the population used is the ERP for 31 December of that year. The prevalence estimate presented in Table 3.3 was based on ERP data for 30 June 2012.

Australia's Indigenous population is calculated from the census. However, because of the smaller Indigenous population, it is difficult to accurately measure population changes between census years using the method described above. Therefore, the ABS developed experimental estimates and projections based on the 2006 Census. All calculations of Indigenous rates in this report use the Series B projected populations for 2006 to 2011.

National Death Index

The National Death Index (NDI) is a database housed at the AIHW that contains records of all deaths occurring in Australia since 1980. The data are obtained from the Registrars of Births, Deaths and Marriages in each state and territory. The data set used in this report was linked to the NDI to determine which registrants may have been deceased. This information was used in calculating the prevalence estimates presented in Chapter 3.

National Diabetes Services Scheme

The NDSS database is described in detail in Chapter 2.

National (insulin-treated) Diabetes Register

The NDR is described in detail in Chapter 2.

Appendix C: Statistical notes and methods

The Data Quality Statement

Information about limitations and issues regarding the data set used in this report are found in the *Data Quality Statement: National Diabetes Services Scheme–Australian Paediatric Endocrine Group dataset*, which is located at:

<<http://meteor.aihw.gov.au/content/index.phtml/itemId/556451>>.

Algorithm for deriving diabetes type

The following algorithm (method of calculation) assesses and re-classifies reported diabetes type for some registrants. The algorithm is based on age at diagnosis and the period between diagnosis and first insulin use because of the correlation with diabetes type. The algorithm has been updated several times over the years in consultation and agreement with the NDDWG. The current algorithm is shown in Box C1. Note that with or without the algorithm, there will always be some level of misclassification as the algorithm cannot reclassify all records that have been misreported.

Of particular note for this report is that children aged under 10 with reported type 2 diabetes are reclassified as not derivable when they are sourced solely from NDSS.

Also, in preparing the data for this report, 532 cases of type 2 diabetes in children diagnosed before 1990 were identified. The NDDWG advised that in Australia type 2 diabetes was unlikely to have been diagnosed in children before 1990. Thus, in order to ensure that data entry errors didn't affect the figures presented in this paper, an additional data cleaning step was added before the application of the algorithm shown in Box C1. The NDDWG advised that if the reported diabetes type is type 2 and the age at diagnosis is less than 15 for anyone diagnosed before 1990, then the derived diabetes type is unable to be derived. Note this step has no impact on the incidence figures presented in this paper.

Tables C1 and C2 show the diabetes type before (reported) and after (derived) the algorithm was applied for the 594,177 people registered after 1 July 2002 and diagnosed between 1 July 2002 to 30 June 2012. Tables in this report are based on derived type of diabetes.

Reported versus derived type of diabetes

Of people who registered after 1 July 2002 and were diagnosed between 1 July 2002 and 30 June 2012, there were 458,688 cases of derived type 2 diabetes compared with 457,461 cases of reported diabetes (Table C2). That is, using derived diabetes type yields 1,227 more cases of type 2 diabetes overall. When looking at these additional cases as a proportion of the total in each age group, they make the most difference in 15–24 year olds (see Table C2).

In Chapter 3 there is an analysis of whether the incidence of type 2 diabetes changed over the 10 years 2002–03 to 2011–12, based on derived type of diabetes. This analysis was performed for reported and derived type of diabetes and the results were the same with 2 exceptions. For 10–19 year olds where the derived type showed no change in incidence (APC=1.01, $p=0.35$) the reported type showed a significant increase of 2.5% per year (APC=2.48, $p=0.02$). For the 20–29 year age group where the derived type showed a significant drop in incidence

(APC=-2.36, $p=0.01$), the reported type, while showing the same pattern, did not reach significance (APC=-1.68, $p=0.06$).

Table C1: Reported and derived diabetes type, Australia, 2002–2003 to 2011–2012^(a)

Reported diabetes type	Derived diabetes type					Total
	Type 1	Type 2	Gestational	Other	Not derived	
Type 1	16,740	981	..	..	260	17,981
Type 2	..	457,461	..	..	..	457,461
Gestational	..	246	114,420	..	1	114,667
Other	..	..	..	3,895	..	3,895
Missing	..	..	..	..	173	173
Total	16,740	458,688	114,420	3,895	434	594,177

(a) People registered on or after 1 July 2002 and diagnosed 1 July 2002 to 30 June 2012.

Source: AIHW analyses of NDSS and APEG records (see 'Data sources' in Appendix B).

Table C2: Reported and derived diabetes type, by age, Australia, 2002–2003 to 2011–2012^(a)

Age at diagnosis (years)	Reported diabetes type					Derived diabetes type						Difference: derived type 2 minus reported type 2	Proportion of type 2 diabetes extra cases after deriving diabetes type
	Missing	Type 1	Type 2	Gestational	Other	Type 1	Type 2	Gestational	Other	Not derived	Total		
10–14	..	4,495	362	11	171	4,419	362	10	171	77	5,039	0	0.0
15–19	2	2,517	1,049	1,346	181	2,412	1,145	1,346	181	11	5,095	96	8.4
20–24	5	2,002	2,295	8,504	161	1,870	2,414	8,504	161	18	12,967	119	4.9
25–29	43	1,896	5,408	26,960	159	1,743	5,554	26,960	159	50	34,466	146	2.6
30–34	55	1,648	10,815	40,469	156	1,478	10,971	40,469	156	69	53,143	156	1.4
35–39	43	1,288	18,283	28,871	231	1,179	18,378	28,871	231	57	48,716	95	0.5
40+	25	4,135	419,249	8,506	2,836	3,639	419,864	8,260	2,836	152	434,751	615	0.1
Total	173	17,981	457,461	114,667	3,895	16,740	458,688	114,420	3,895	434	594,177	1,227	0.3

(a) People registered on or after 1 July 2002 and diagnosed 1 July 2002 to 30 June 2012.

Source: AIHW analyses of NDSS and APEG records (see 'Data sources' in Appendix B).

Box C1: Algorithm to derive diabetes type

APEG only or APEG and NDSS records

If the record is sourced from APEG only, or from both APEG and NDSS, then the derived diabetes type is equal to the reported diabetes type.

NDSS only records

If the record is sourced from NDSS only, if:

- the reported diabetes type is type 1 and the age at diagnosis is missing, then the derived diabetes type is unable to be derived
- the reported diabetes type is type 1 and the age at diagnosis is less than 15 years:
 - if the time between diagnosis and first insulin use is missing, then the derived diabetes type is unable to be derived
 - if the time between diagnosis and first insulin use is more than 1 year, then the derived diabetes type is unable to be derived
 - if the time between diagnosis and first insulin use is less than or equal to 1 year, then the derived diabetes type equals type 1, that is, the reported diabetes type
- the reported diabetes type is type 1 and the age at diagnosis is greater than or equal to 15 years:
 - if the time between diagnosis and first insulin use is missing, then the derived diabetes type is unable to be derived
 - if the time between diagnosis and first insulin use is more than 1 year, then the derived diabetes type equals type 2
 - if the time between diagnosis and first insulin use is less than or equal to 1 year, then the derived diabetes type equals type 1, that is, the reported diabetes type
- the reported diabetes type is type 2:
 - if age at diagnosis is less than 10 years, then the derived diabetes type is unable to be derived
 - if the age at diagnosis is greater than or equal to 10 years, then the derived diabetes type equals type 2, that is, the reported diabetes type
- the reported diabetes type is gestational diabetes:
 - if the age at diagnosis is less than 14 years, then the derived diabetes type is unable to be derived
 - if the age at diagnosis is greater than or equal to 14 and less than 50 years, then the derived diabetes type equals gestational diabetes, that is, the reported diabetes type
 - if the age at diagnosis is greater than or equal to 50 years, then the derived diabetes type equals type 2
- the reported diabetes type is other diabetes, then the derived diabetes type equals other diabetes, that is, the reported diabetes type.

Derivation of variables

When data were missing, inconsistent or illogical in the NDSS and APEG data sets, variables were derived using the following rules.

Box C2: Derivation of variables

Date of first insulin injection

To derive a single date of first insulin injection using the APEG date of first insulin injection and the NDSS date of first insulin injection:

- use APEG date of first insulin injection, or
- if APEG date of first insulin injection is missing, use NDSS date of first insulin injection, or
- if both dates are missing, then date is missing.

Date of registration

To derive a single date of registration using the APEG date of registration and the NDSS date of registration:

- if 2 dates are the same, use either date, or
- if 1 date is missing, use the other date, or
- if 2 dates differ by less than 1 year, use the earlier date, or
- if 2 dates differ by more than 1 year but 1 date of registration is within 1 year of the date of first insulin injection, use that date of registration, or
- if 2 dates differ by more than 1 year and neither date is within 1 year of the date of first insulin injection, then date is missing.

Date of first insulin use

To derive a date of first insulin use for all people identified as insulin users using the derived date of first insulin injection and the date of first insulin purchase from the NDSS sales data:

- if 2 dates are the same, use either date, or
- if 1 date is missing, use the other date, or
- if 2 dates are different, use the earlier date, or
- if 2 dates are missing, then date is missing.

Date of diagnosis

To derive a single date of diagnosis using the derived date of first insulin use, derived date of registration and NDSS date of diagnosis:

APEG only or APEG and NDSS records

- use date of first insulin injection, or
- if date of first insulin injection is missing, use date of registration, or
- if date of registration is missing, use NDSS date of diagnosis, or
- if NDSS date of diagnosis is missing, then date is missing.

NDSS only records

- use NDSS date of diagnosis, or
- if NDSS date of diagnosis is missing and reported diabetes type is gestational diabetes, use date of registration, or
- if NDSS date of diagnosis is missing, then date is missing.

Age at diagnosis

To calculate age at diagnosis using the derived date of birth and derived date of diagnosis:

- if date of birth is not missing and date of diagnosis is not missing, and date of birth is earlier than or equal to date of diagnosis, then age at diagnosis is calculated as the number of years between date of birth and date of diagnosis
- otherwise, if date of diagnosis is earlier than date of birth by less than 1 month, then age at diagnosis is zero
- otherwise, if date of diagnosis is earlier than date of birth by greater than equal to 1 month, or either date is missing, age at diagnosis is unable to be calculated.

Time between diagnosis and first insulin use

To calculate the time, in years, between the derived date of diagnosis and derived date of first insulin use:

- if date of diagnosis is not missing and date of first insulin use is not missing, and date of diagnosis is earlier than or equal to date of first insulin use, then time between diagnosis and first insulin use is calculated as the number of years between date of diagnosis and date of first insulin use
- otherwise, if date of first insulin use is earlier than date of diagnosis by less than 1 month, then time between diagnosis and first insulin use is 0
- otherwise, if date of first insulin use is earlier than date of diagnosis by greater than equal to 1 month, or either date is missing, time between diagnosis and first insulin use is unable to be calculated.

Age-specific rates

Age-specific rates provide information on the occurrence of a particular event in an age group relative to the total number of people at risk of that event in the same age group. It is calculated by dividing the number of events occurring in each specified age group by the corresponding 'at risk' population in the same age group, and then multiplying the result by a constant (for instance, 100,000) to derive the rate.

In this report, age-specific rates are expressed as number per 100,000 population.

Age-standardised rates

Age-standardisation is a technique used to eliminate the effect of differences in population age structures when comparing rates across different population groups.

This report uses the direct method of standardisation, whereby standardised rates are derived by applying the specific rates observed in the study population to a single standard population. The ERP as at 30 June 2001 was the standard population used in all analyses in this report. Five-year age groups were used for all age-standardisation analyses, with an

upper age group of 85 years and over. For analyses by Indigenous status, the upper age group was 75 years and over.

The calculation of direct age-standardised rates consists of three steps:

- Calculate the age-specific rate for each age group.
- Calculate the expected number of cases in each age group by multiplying the age-specific rates by the corresponding standard population for each age group.
- Sum the expected number of cases in each age group and divide this sum by the total of the standard population to give the age-standardised rate.

Joinpoint analyses

The software used to perform Joinpoint analysis was Joinpoint Version 3.4.3, developed by the Statistical Research and Applications Branch of the National Cancer Institute in the US (NCI 2013). This software has been used frequently to examine mortality and morbidity trends, both internationally (Cancer Care Ontario 2006; Yang et al. 2009), and within Australia (Baade & Coory 2005; Tracey et al. 2009).

A Joinpoint regression model describes changing trends over successive segments of time and the amount of change within each segment. Trends are characterised by joined linear segments; a Joinpoint is created where 2 segments meet, thus representing a statistically significant change in the trend. It is important to note that while the Joinpoint analysis identifies a particular point in time where a trend changes, in reality changes in trends are not usually abrupt, depending on the underlying cause of the change.

The Joinpoint software takes trend data in the form of age-standardised rates and fits the simplest Joinpoint model possible, where there is a minimum number of segments necessary to characterise a trend. The software begins with a model with zero Joinpoints (that is, no changes in trend) and incrementally tests whether more Joinpoints are statistically significant. The number of significant Joinpoints is identified through performing several permutation tests and each *p*-value is found using Monte Carlo methods.

Annual percentage change

When fitting a log-linear model using Joinpoint, the slope of the line represents the annual percentage change (APC) attributable to each Joinpoint segment.

A negative APC indicates a decreasing trend whereas a positive APC indicates an increasing trend.

Glossary

autoimmune disease: Occurs when a person's immune system mistakenly attacks their own body tissues.

body mass index: The most commonly used method of assessing if a person is of normal weight, underweight, overweight or obese. It is calculated by dividing the person's weight (in kilograms) by their height (in metres) squared; that is, kg/m².

chronic diseases: Term applied to a diverse group of diseases, such as diabetes, heart disease and arthritis, which tend to be long-lasting and persistent in their symptoms and development.

complications: A secondary problem that arises from a disease, injury or treatment (such as surgery) that makes a condition worse.

comorbidity: When a person has 2 or more health conditions at the same time.

c-peptide: A c-peptide test measures the level of this peptide in the blood. It is generally found in amounts equal to insulin. A c-peptide test can be done when diabetes has just been found and it is not clear if type 1 diabetes or type 2 diabetes is present. A person whose pancreas does not make any insulin (type 1 diabetes) has a low level of insulin and c-peptide. A person with type 2 diabetes has a normal or high level of c-peptide.

diabetes (diabetes mellitus): A chronic condition in which the body cannot properly use its main energy source, the sugar glucose. This is due to a relative or absolute deficiency in insulin, a hormone that is produced in the pancreas and helps glucose enter the body's cells from the bloodstream and then be processed by them. Diabetes is marked by an abnormal build-up of glucose in the blood, and it can have serious short- and long-term effects. The 3 main types of diabetes are type 1 diabetes, type 2 diabetes and gestational diabetes. See *type 1 diabetes*, *type 2 diabetes*.

gestational diabetes: Diabetes that is first diagnosed during pregnancy (gestation). It may disappear after pregnancy but signals a high risk of diabetes occurring later on.

glucose: The main sugar that the body uses for energy. Glucose is a simple sugar that comes from the breakdown of carbohydrates in the diet, as well as from the breakdown of glycogen (the storage form of glucose) in the liver. The body needs the hormone insulin to use glucose properly.

endocrine disorders: These are disorders of the endocrine system. The branch of medicine associated with endocrine disorders is known as endocrinology.

endocrinologist: A doctor who treats people who have problems with their endocrine glands. Diabetes is an endocrine disorder.

high blood pressure (hypertension): The definition of high blood pressure (also known as hypertension) can vary, but a well-accepted one is from the WHO: a systolic blood pressure of 140 mmHg or more or a diastolic blood pressure of 90 mmHg or more, or [the person is] receiving medication for high blood pressure.

impaired glucose tolerance: Slower metabolism of glucose due to insulin deficiency or resistance. Classified as fasting plasma glucose less than 7.0 mmol/L and 2-hour plasma glucose 7.8-11.0 mmol/L after oral glucose tolerance testing (OGTT).

implied diabetes status: A proxy diagnosis made on the basis of an individual accessing diabetes-specific services, medicines, pathology tests and doctors' services. Diabetes status can be implied from the MBS and PBS data.

incidence: The number of new cases (of an illness or event, and so on) occurring during a given period. Compare with *prevalence*.

insulin: A hormone that the pancreas produces to regulate the body's energy sources, most notably the sugar glucose.

insulin resistance: A condition in which insulin works inefficiently and the body compensates by producing an excess supply.

latent autoimmune diabetes (LADA): Is a concept introduced to describe slow-onset type 1 autoimmune diabetes in adults. Adults with LADA are often initially misdiagnosed as having type 2 diabetes based on their age.

monogenic: Monogenic diseases result from an alteration or a change in the structure of a single (mono) gene.

pre-diabetes: Is a condition in which blood glucose levels are higher than normal, although not high enough to be diabetes. Pre-diabetes has no signs or symptoms. People with pre-diabetes have a higher risk of developing type 2 diabetes and cardiovascular (heart and circulation) disease.

prevalence: The number or proportion (of cases, instances, and so on) present in a population at a given time. Compare with *incidence*.

risk factor: Any factor that represents a greater risk of a health disorder or other unwanted condition or event. Some risk factors are regarded as causes of disease, others are not necessarily so. Along with their opposites, protective factors, risk factors are known as determinants.

type 1 diabetes: A form of diabetes marked by a complete lack of insulin and needing insulin replacement for survival. This form of diabetes mostly arises in childhood or in young adults, but it can occur at any age.

type 2 diabetes: The most common form of diabetes, which is characterised by reduced insulin secretion or less effective insulin action. Management options may include lifestyle modification, such as changes in diet along with increased exercise and weight loss, and medications such as oral glucose-lowering drugs and insulin.

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Type 2 diabetes in Australia's children and young people identifies and describes national data sources to monitor incidence and prevalence of type 2 diabetes in children and young people and assesses their suitability for this task. This working paper also presents, for the first time, national incidence and prevalence estimates of type 2 diabetes in Australia's children and young people.