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Any enquiries about or comments on this publication should be directed to:

Cardiovascular, Diabetes and Kidney unit

Australian Institute of Health and Welfare

GPO Box 570

Canberra ACT 2601

Phone: (02) 6244 1000

Email: diabetes@aihw.gov.au

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Contents

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Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
APEG	Australasian Paediatric Endocrine Group
ARIA	Accessibility/Remoteness Index of Australia
ASGC	Australian Standard Geographical Classification
ASR	age-standardised rate
CI	confidence interval
DoHA	Australian Government Department of Health and Ageing
ICD-10	International Statistical Classification of Diseases and Related Health Problems
IRSD	Index of Relative Socio-Economic Disadvantage
NDR	National Diabetes Register
NDSS	National Diabetes Services Scheme
SEIFA	Socio-Economic Indexes for Areas
SES	socioeconomic status
SMR	standardised mortality ratio

Symbols

. .	not applicable
no.	number

Statistical significance

In this report, use of the term 'significant' indicates statistical significance and is only used when the appropriate analyses have been performed to ensure that the statement is valid.

Summary

This report provides the latest information from Australia's National Diabetes Register (NDR). The register applies to Australians who began using insulin for diabetes since 1999.

The report covers trends between 2000 and 2007 in the incidence of Type 1 diabetes, insulin-treated Type 2 diabetes and gestational diabetes. It also provides information on deaths between 2000 and 2006 of those on the register.

Main findings

- The incidence of Type 1 and other insulin-treated diabetes in Australia is increasing.
- People with insulin-treated diabetes have significantly higher death rates than other Australians.

The evidence

Type 1 diabetes

- Australia is in the top 10 countries of those with the highest rates of Type 1 diabetes in children.
- The incidence of Type 1 diabetes in children has increased. The 990 new cases in 2007 among those aged 0–14 years represents a 30% increase compared with 2000.
- Between 2000 and 2007 there was a fall in the rate of new cases of Type 1 diabetes in people aged 40 years and over, but little change in incidence rates among people aged 15–39 years.

Insulin-treated Type 2 diabetes

- There was a 63% increase in new cases of insulin-treated Type 2 diabetes in Australia from 2000 to 2007 (21,400 in 2007).
- There were 900 new cases of insulin-treated Type 2 diabetes in people aged 15–24 years, and 4,800 new cases in those aged 25–34 years between 2000 and 2007. However, the majority (95%) of the new cases still occurred in people aged 35 years and over.

Gestational diabetes

- There was a 6-fold increase in the number of new cases of insulin-treated gestational diabetes among women aged 15–49 years in Australia between 2000 and 2007.

Deaths

- The death rate among people with insulin-treated diabetes was 3 times as high as the rest of the Australian population over 2000–2006.

1 Introduction

This report presents the latest results from Australia's National Diabetes Register (NDR).

Diabetes is one of the leading threats to the health of Australians—it is a large health, social and economic burden for individuals with the disease, their families and the community. It is associated with many complications, and has a major impact on quality of life and life expectancy.

The NDR was set up as an important part of Australia's monitoring system for diabetes. This monitoring is essential to improve Australia's capacity to plan preventive and treatment services, focus on priority population groups, track the impact of environmental change and of prevention and control strategies, and make decisions for cost-effective allocation of resources (AIHW: Dixon & Webbie 2006).

The NDR, which now has 9 years of data on more than 116,000 people, is an important resource for research. This report aims to provide important and relevant information on the incidence of insulin-treated diabetes for policy makers, researchers and health professionals to help in service planning and policy development. It provides general statistics, such as the demographic features of the NDR population, incidence estimates and trends, and the findings of mortality analyses. This information can be used to understand the changing patterns of insulin-treated diabetes, who the disease affects and where people with diabetes reside.

For a full list of NDR publications see <www.aihw.gov.au/diabetes/publications.cfm>.

1.1 Structure and content of this report

This report has 8 chapters. Following this introduction, Chapter 2 provides general information on diabetes. Chapter 3 focuses on children aged 0–14 years with Type 1 diabetes, and Chapter 4 covers people aged 15 years and over with Type 1 diabetes. Chapter 5 looks at people with other types of insulin-treated diabetes, and Chapter 6 examines the mortality of NDR registrants. Chapter 7 provides information for researchers, including those who may want to access the NDR data for diabetes research, and describes the demographic profile of the registrants on the NDR as at 31 December 2007. The Appendix, provides information for people wishing to register on the NDR, statistical notes relevant to the analyses done for this report, additional information about the data held on the NDR, and the Glossary defines some of the technical terms used in this report.

1.2 About the National Diabetes Register

The National Diabetes Register is a register of people living in Australia with insulin-treated diabetes. It holds information on people with all forms of insulin-treated diabetes, including Type 1, Type 2, gestational diabetes mellitus, and other types of diabetes (see Chapter 2). The NDR was established in 1999 and aims to record all new cases of people who use insulin to treat their diabetes, meaning it should cover all new cases of Type 1 diabetes because they all require insulin treatment. However, only a proportion of Type 2 and gestational diabetes cases require insulin treatment, so those that do not are excluded from the NDR. The

decision to establish a register based on insulin treatment rather than type of diabetes was made because a person's type of diabetes is not as easily defined as a person's insulin-using status (AIHW 2001). The NDR is currently used to monitor the incidence of new cases of insulin-treated diabetes; that is, the number of new cases since 1999. As the register gets older, it will also be used to monitor the prevalence of insulin-treated diabetes.

Good quality and timely data are essential for governments and researchers, for monitoring trends in the disease and its impact, and for understanding its epidemiology and improving its management. The NDR was established as a result of a recommendation of the National Diabetes Strategy and Implementation Plan (Colagiuri et al. 1998). It is managed by staff of the National Centre for Monitoring Diabetes at the Australian Institute of Health and Welfare (AIHW), and is largely funded by the Australian Government Department of Health and Ageing (DoHA).

Objectives

The main objectives of the NDR are to help in national diabetes monitoring and to facilitate research. The collection of information about new cases of insulin-treated diabetes helps the NDR:

- monitor and report on the incidence of insulin-treated diabetes
- provide a sampling frame for scientifically valid and ethically approved epidemiological and clinical studies of insulin-treated diabetes (see Chapter 7)
- provide information to health service providers and planners at Australian, state and local levels
- help monitor national diabetes indicators.

Eligibility criteria and data sources

People are eligible to be on the NDR only if they use insulin to treat their diabetes, and their insulin use started on or after 1 January 1999.

The NDR has two data sources:

- the National Diabetes Services Scheme database (NDSS)
- the Australasian Paediatric Endocrine Group's (APEG) state and territory databases, for those aged 0–14 years.

The NDSS is an Australian Government initiative, delivering diabetes-related products at subsidised prices, and providing information and support services to people with diabetes. Subsidised products include insulin syringes, insulin infusion pump consumables and diagnostic reagents (blood and urine testing strips). The scheme was established in 1987, and is administered by Diabetes Australia Ltd, which coordinates the supply of products in all states and territories.

APEG is the professional body in Australia that represents those involved in management and research of children with disorders of the endocrine system including diabetes. APEG's state-based databases collect diagnosis information on children and adolescents with all forms of insulin-treated diabetes.

In general, the information supplied by NDSS and APEG are similar. There are, however, some minor differences. For example, APEG supplies information on the child's carer or

guardian, while NDSS does not collect this information. Please see Table D.1 in the section on data held on the NDR in the Appendix for further detail on the data supplied by NDSS and APEG.

Change to consent process in 2003

When the NDR was established in 1999, the NDSS registration form was updated to include a section for registrants to consent to be included on the NDR. However, there were problems with this method because the form required the NDSS registrant's signature in two separate sections. On 21 July 2003, Diabetes Australia introduced a new NDSS registration form, which had been reviewed by the Office of the Federal Privacy Commissioner. This new NDSS registration form, which began to be used from August 2003, changed the NDSS consent arrangements by removing the NDR opt-in consent section and including specific information telling registrants how the information on the form would be used. So, from August 2003, all people registering for the NDSS on the new form who are eligible to be on the NDR are automatically included unless they specifically ask not to be. This means that once all old NDSS forms are out of circulation and the majority of all NDR-eligible NDSS registrants are registered on a new NDSS registration form, ascertainment for the NDR from the NDSS should approach 100%.

Implications of change to consent process

Improvement in NDSS ascertainment for the NDR means that the notification rate for new cases of insulin-treated diabetes from the NDSS increased from August 2003. It is therefore important to consider the impact of the improved NDSS ascertainment when interpreting trends over time in the incidence of insulin-treated diabetes based on data from the NDR. That is, it is necessary to distinguish the effect of the NDSS form change on any increase in incidence from the underlying trend (for more information see *National Diabetes Register: impact of changed consent arrangements on ascertainment from the National Diabetes Services Scheme* (AIHW 2006)). Therefore, when presenting incidence estimates for people aged 15 years and over with Type 1 diabetes (Chapter 4) and people with Type 2, gestational diabetes or other types of diabetes (Chapter 5), the results from the NDR were adjusted to account for missing cases using information from the de-identified NDSS data set (see the Data sources section of the Appendix for a description of the de-identified NDSS data set). Incidence estimates for those aged 0–14 years with Type 1 diabetes were not adjusted in this way, as the coverage rate across the two data sources for this age group is more than 97% (Table 3.1).

Box 1.1: Types of diabetes

Type 1 diabetes *mostly arises in children or young adults, though it can occur at any age. It is marked by severe insulin deficiency. People with Type 1 diabetes need insulin replacement for survival. Most cases are caused by an autoimmune condition that destroys the insulin-producing beta cells in the pancreas.*

Type 2 diabetes *is the most common form of diabetes, and occurs mostly in people aged 40 years and over (however, recent trends have indicated an increase in diagnosis in younger people). Many people with Type 2 diabetes produce insulin, but may not produce enough or cannot use it effectively. Some cases of Type 2 diabetes may be managed with changes to diet along with increased exercise and weight loss. Many require medications as well, usually oral glucose-lowering drugs, though non-insulin injectable medications are now also available. Many others require insulin in addition to the other treatments, particularly after longer duration of disease. Only insulin-treated cases of Type 2 diabetes are included on the NDR.*

Gestational diabetes mellitus *is a form of diabetes that develops during pregnancy in some women. It involves high blood glucose levels appearing for the first time during pregnancy among women who have not previously been diagnosed with other forms of diabetes. It is a transient form of diabetes and usually disappears after the baby is born; however, it can recur in later pregnancies. It is also a marker of increased risk of developing Type 2 diabetes later in life. Some cases of gestational diabetes may be managed with changes to diet and exercise alone, and some may require insulin treatment. Only insulin-treated cases of gestational diabetes are included on the NDR.*

Other types of diabetes *include certain conditions or syndromes, such as:*

- *genetic defects of beta-cell function (formerly referred to as maturity-onset diabetes of the young (MODY)*
- *genetic defects in insulin action*
- *other diseases of the pancreas (including cystic fibrosis and cancer of the pancreas)*
- *endocrine diseases (for example, acromegaly and Cushing's Syndrome)*
- *drug- or chemical-induced diabetes (for example, steroid-induced diabetes)*
- *infections (for example, congenital rubella)*
- *uncommon but specific forms of immune-mediated diabetes mellitus*
- *other genetic syndromes sometimes associated with diabetes (WHO 1999).*

These types of diabetes are relatively uncommon. Only those being treated with insulin for these types of diabetes are included on the NDR.

1.3 Derivation of diabetes type

There are several types of diabetes, with different causes and clinical histories, but the three main types are Type 1, Type 2 and gestational diabetes. These are explained briefly in Box 1.1 and in more detail in Chapter 2.

It is well known that reported diabetes type is not always reliable, particularly with people being reported to have Type 1 diabetes when they actually have Type 2 (described in more detail in Appendix B.3). Thus, to obtain a more accurate measure of type of diabetes, an algorithm (method of calculation) has been developed that assesses and classifies registrants with reported Type 1 diabetes, based on age at diagnosis and the period between diagnosis and first insulin use (for more information see Appendix B.3). A different algorithm is used to assess and reclassify women with gestational diabetes who are aged over 50 years at diagnosis.

Table 1.1 shows data on the NDR registrants diabetes type before (reported) and after (derived) the algorithm was applied. In all age groups, the number of registrants with Type 1 diabetes falls after the algorithm is applied. For example 42% of registrants in the age groups 45–54 years and 55–64 years who were reported to have Type 1 diabetes were reclassified into Type 2.

In total, the algorithm reclassified 4,137 people with reported Type 1 diabetes, and 44 women with gestational diabetes. There were 1,702 registrants who were unable to be reclassified using the algorithm, either because there was insufficient information or they were aged under 15 years and the time between diagnosis and first insulin use was more than 1 year.

Clearly, the algorithm helps to reduce the misrepresentation of the level of Type 1 diabetes and some cases of gestational diabetes on the NDR. For this reason, tables in this report involving type of diabetes are based on derived type of diabetes and not reported type of diabetes, unless otherwise stated. But even with the algorithm, there will still be some misclassification.

Table 1.1: Reported and derived diabetes type among NDR registrants, by age, 2000–2007

Age at diagnosis (years)	Reported diabetes type					Derived diabetes type					
	Type 1	Type 2	Gestational diabetes	Other	Total	Type 1	Type 2	Gestational diabetes	Other	Not derived	Total
0–4	1,569	31	. .	27	1,627	1,521	31	. .	27	48	1,627
5–9	2,612	40	. .	22	2,674	2,557	40	. .	22	55	2,674
10–14	3,276	137	1	68	3,482	3,206	137	1	68	70	3,482
15–24	3,114	1,072	1,268	118	5,572	2,906	1,280	1,268	118	. .	5,572
25–34	2,647	4,939	9,220	113	16,919	2,262	5,324	9,220	113	. .	16,919
35–44	1,888	10,143	5,097	132	17,260	1,442	10,589	5,097	132	. .	17,260
45–54	1,371	14,895	91	195	16,552	792	15,484	81	195	. .	16,552
55–64	1,098	13,586	10	191	14,885	632	14,062	. .	191	. .	14,885
65–74	622	8,319	6	112	9,059	366	8,581	. .	112	. .	9,059
75+	472	4,004	11	58	4,545	370	4,117	. .	58	. .	4,545
Not stated	1,522	16,463	7	95	18,087	0	16,463	. .	95	1,529	18,087
Total (number)	**20,191**	**73,629**	**15,711**	**1,131**	**110,662**	**16,054**	**76,108**	**15,667**	**1,131**	**1,702**	**110,662**
Total (per cent)	**18.2**	**66.5**	**14.2**	**1.0**	**100.0**	**14.5**	**68.8**	**14.2**	**1.0**	**1.5**	**100.0**

Source: National Diabetes Register (data extracted December 2008).

2 Diabetes

Diabetes is a serious illness requiring lifelong treatment and continuous monitoring by medical professionals. It is associated with many other illnesses, and if not properly managed can cause considerable morbidity, mortality and reduced quality of life.

Diabetes is one of the most prevalent chronic diseases in Australia and many other countries, sometimes described as an epidemic. It is estimated that if left unchecked, 1 in 14 adults, or 380 million people worldwide will have diabetes by 2025 (IDF 2006). Diabetes is associated with many complications, including coronary artery and peripheral vascular disease, stroke, diabetic neuropathy, amputations, renal failure and blindness. It can cause much disability, poor quality of life and premature death, especially if undiagnosed or poorly controlled (IDF 2006).

As a result of these complications, together with the need for constant and long-term treatment, diabetes imposes a large burden on the health system and on some communities; in 2003, diabetes accounted for more than 5% of the disease burden in Australia (Begg et al. 2007). The burden increases to 8.3% when the added risk of diabetes-related cardiovascular diseases is included, and the true burden would be even higher if other diabetes-related diseases were taken into account.

2.1 What is diabetes?

Diabetes mellitus is a disease in which the body is unable to regulate its blood glucose (sugar), the main source of energy for the body's cells. The pancreas makes the hormone insulin, which controls the amount of glucose in the blood and moves it from the blood into the cells where it is converted into energy or stored until needed. When glucose is absorbed into the bloodstream it stimulates the pancreas to produce insulin. Diabetes occurs when the pancreas is unable to make sufficient insulin, or when the body does not respond adequately to insulin.

These abnormalities lead to a rise in the glucose level in the blood. Symptoms such as thirst, frequent urination, tiredness and lack of energy, blurred vision, infections and weight loss may be the first signs of diabetes. In addition to these symptoms, diabetes causes many serious health complications, some of which occur within months of diagnosis while others may develop over a number of years.

Some of the short-term complications include diabetic ketoacidosis resulting from a severe lack of insulin, increased susceptibility to infections and reduced healing ability.

Longer-term complications include disease of the large blood vessels (macrovascular disease) such as coronary heart disease, stroke and peripheral vascular disease, as well as diseases of the small blood vessels (microvascular disease) such as retinopathy, kidney diseases and neuropathy (peripheral nerve disease).

2.2 What are the different types of diabetes?

There are three main types of diabetes, Type 1, Type 2 and gestational diabetes. In addition, a number of conditions or syndromes that cause diabetes have been put into a fourth category,

other types of diabetes (see Box 1.1). Each type of diabetes mellitus has different causes and requires different treatment. Below is a brief description of each type. For more descriptive data on the diabetes types of NDR registrants refer to Section 7.4.

Type 1 diabetes

Type 1 diabetes, also known as Insulin-Dependent Diabetes Mellitus (IDDM) or juvenile onset diabetes, accounts for about 13% of all diabetes in Australia, but more than 90% of diabetes in children aged 15 years and younger. It can occur at any age, though it usually arises in childhood or youth. Type 1 diabetes is characterised by progressive destruction of the insulin-producing cells in the pancreas. While the process may develop gradually over months or years, this type of diabetes is usually associated with a rapid onset of symptoms over a period of several weeks, when only small numbers of insulin-producing cells remain. People diagnosed with it require insulin replacement to survive (AIHW 2008b).

Type 1 diabetes is an autoimmune disease that develops when the body's immune system destroys the insulin-producing cells of the pancreas, a process which can take many years. When most of the insulin-producing cells have been destroyed, the glucose levels in the blood rise rapidly, causing increased frequency of urination as the kidneys rid the body of excess glucose. The body also begins to break down fat as an alternative source of energy, causing ketones to be produced in the blood, and resulting in rapid and unplanned weight loss. The excess of ketones makes the blood acidic (ketoacidosis), and without urgent medical intervention this can lead to coma and death.

Treatment is with insulin, given either by injection several times a day or continuously by an insulin pump, in conjunction with frequent monitoring of blood glucose level. This usually involves pricking a small needle into the tip of the finger and placing a drop of blood on a reagent strip, which provides a reading guiding the patient on the insulin dose the body needs. A well-balanced and healthy diet and ongoing monitoring of the diabetes by a medical professional is essential for continued health and minimising complications (NHMRC 2005).

Researchers believe that Type 1 diabetes is caused by a combination of environmental factors and a genetic predisposition. Some of the potential environmental risk factors being investigated include: viruses, dietary factors including early consumption of cow's milk, and low vitamin D exposure (Greer et al. 2007; Littorin et al. 2006; Vaarala 2005; Yoon et al. 1999).

Type 2 diabetes

This form of diabetes is the most common and accounts for more than 80% of all cases of diabetes. It occurs mostly in people aged 40 years and over; however the incidence is rising in children and younger adults.

Type 2 diabetes occurs when the body becomes resistant to the insulin being produced by the pancreas or the amount produced is inadequate to meet the body's needs. As mentioned above, this can be an inherited characteristic that is made worse by excess body fat being carried, particularly around the waist. In the early stages of Type 2 diabetes the pancreas continues to produce insulin, but in insufficient quantities to move the glucose from the bloodstream to the body's cells and organs to be used as energy. The result is higher than normal levels of glucose remaining in the blood stream over a longer period, with the potential to damage organs and blood vessels.

The symptoms of Type 2 diabetes may not appear unless the glucose levels are very high, which means that many people with the disease often remain undiagnosed for a long time. Symptoms are similar to those experienced by people with Type 1 diabetes, except that people with Type 2 diabetes do not usually experience rapid weight loss.

A number of lifestyle factors are implicated in the development of Type 2 diabetes, including obesity, physical inactivity and an unhealthy diet; family history, ethnic background and age are also risk factors. Each of these may individually be sufficient to cause Type 2 diabetes but they can, and often do, interact to increase risk.

When the disease is diagnosed, the blood glucose levels can often be controlled by lifestyle factors such as regular exercise and a healthy diet; however, tablets and insulin injections may eventually be required as the disease progresses. Pancreatic islet function decreases with age, especially if high levels of insulin are required to meet insulin resistance. This means that insulin is often required in patients with Type 2 diabetes as they age and with increasing duration of diabetes.

As at 30 June 2008, around one in every five people with Type 2 diabetes who were registered with the National Diabetes Services Scheme (NDSS) were using insulin to manage their diabetes. Data from the NDR and the NDSS indicate that, among Australians with Type 2 diabetes who began using insulin to manage their diabetes between 2000 and 2007, the estimated median time between diagnosis of Type 2 diabetes and first insulin use was 5.0 years. There was little difference in the median time to first insulin use by sex (males 5.2 years and females 4.9 years); however, it increased with age and was less than 1 year for people aged less than 25 years; 1.8 years for those aged 25–44 years; 5.2 years for those aged 45–64 years; and 6.7 years for people aged 65 years and over.

Gestational diabetes mellitus

This form of diabetes is temporary and only occurs during pregnancy when pregnancy hormones may prevent insulin from working properly, thus causing the blood glucose levels to rise. It is usually detected during routine screening tests at around 26–28 weeks into the pregnancy, though may appear at any time in pregnancy. Women who are at high risk for developing gestational diabetes should be tested earlier in pregnancy. Although gestational diabetes may disappear after pregnancy, it is an indication of a much greater risk of developing Type 2 diabetes later in life. An Australian study found that around 17% of women with gestational diabetes developed Type 2 diabetes within 10 years, and 26% within 15 years (Lee et al. 2007). Further, women with gestational diabetes were 9.6 times as likely to develop Type 2 diabetes at any time over the 15 year follow-up period as women with no history of gestational diabetes.

Women who are at greater risk of developing the disease include those:

- with a history of gestational diabetes in a previous pregnancy
- with a family history of diabetes
- aged over 30 years (risk increases with age)
- from certain ethnic groups, such as Aboriginal and Torres Strait Islander peoples, and people from the Indian subcontinent, Pacific Islands, Asia or the Middle East
- with a history of 'large for gestational age' babies
- who are overweight or obese before their pregnancy
- with polycystic ovarian syndrome (Lo et al. 2006).

Pregnant women who do not have any of these known risk factors are still at risk of developing gestational diabetes, so the Australasian Diabetes in Pregnancy Society and the Royal Australasian College of Obstetricians and Gynaecologists recommend screening for all women.

In 2005–06, around 5% of pregnant women aged 15–49 years developed gestational diabetes. A healthy, well-balanced diet may be sufficient in about a third of women to treat this type of diabetes without the need for insulin. National Diabetes Services Scheme data indicate that 30% of female registrants aged 15–49 years with gestational diabetes were treated with insulin in 2005–06 (AIHW: Templeton & Pieris-Caldwell 2008). Further, the proportion of female NDSS registrants with gestational diabetes who were treated with insulin increased with age from 17% among those aged 15–19 years, to 38% among the 45–49 year age group.

Other types of diabetes

There are a number of conditions or syndromes that come under this category, they include:

- genetic defects of beta-cell function (formerly referred to as maturity-onset diabetes of the young (MODY)
- genetic defects in insulin action
- other diseases of the pancreas (for example, cystic fibrosis and cancer of the pancreas)
- endocrine diseases (for example, acromegaly and Cushing's Syndrome)
- drug- or chemical-induced diabetes (for example, steroid-induced diabetes)
- infections (for example, congenital rubella)
- uncommon but specific forms of immune-mediated diabetes mellitus
- other genetic syndromes sometimes associated with diabetes (WHO 1999).

These types of diabetes are relatively uncommon. Only people being treated with insulin for these types of diabetes are included on the NDR.

2.3 Why is the National Diabetes Register important?

The National Diabetes Register is an important resource for researchers investigating the patterns of diabetes incidence and mortality in the population, and because it potentially contributes to a better understanding of the epidemiology and treatments of each of the three main types of diabetes. In addition, the NDR provides governments and the health sector with data that help them better allocate resources where the need is greatest; for example by supporting infrastructure, and providing equipment and medicines to people with diabetes.

There is likely to be strong growth in the burden of diabetes over the next 20 years, mostly as a direct result of increasing levels of obesity in the Australian population. The disability consequences of increasing obesity will be magnified as fatality rates for people with diabetes continue to decline. This increased survival will mean an increase in the risk of people developing disabling consequences of diabetes such as renal failure, vision loss, stroke and possible amputations. This expected increase in the number of Australians with diabetes, together with the associated ongoing expansion and improvement of the register, will make it an invaluable resource for informing policy and researchers alike.

3 Incidence of Type 1 diabetes in children aged 0–14 years

This chapter presents incidence estimates for the period from 2000 to 2007 for children with Type 1 diabetes aged 0–14 years at their first insulin use. It builds on data published recently that investigated trends in the incidence of Type 1 diabetes in children aged 0–14 years from 2000 to 2006 (Catanzariti et al. 2009). The information in this chapter extends to 2007, and presents information by age, sex, year of diagnosis, geographical location, socioeconomic status and Indigenous status. Additionally, results from Australia are compared to results from other countries.

3.1 Coverage using capture-recapture method

NDR data show that 7,278 people aged 0–14 years with Type 1 diabetes began using insulin between 2000 and 2007. Using the capture–recapture method (LaPorte et al. 1993) with the two independent data sources, the National Diabetes Services Scheme (NDSS) and the Australasian Paediatric Endocrine Group (APEG), coverage of those aged 0–14 years with Type 1 diabetes on the NDR over the 8-year period was estimated to be 97.4% (Table 3.1) (see Appendix B.8 for more information on this method). Based on this estimate it is expected that 193 cases were missed by both sources over the 8 years. The coverage rate has remained consistently high during the period 2000–2007, however coverage in 1999 was much lower and has therefore been excluded from the analyses presented in this report.

Table 3.1: Coverage of Type 1 diabetes on the NDR among children aged 0–14 years at their first insulin use, by year of first insulin use, 2000–2007

	Males			Females			Persons		
Year of first insulin use	NDR regis-trants	Missing cases[(a)]	Coverage rate[(b)] (per cent)	NDR regis-trants	Missing cases[(a)]	Coverage rate[(b)] (per cent)	NDR regis-trants	Missing cases[(a)]	Coverage rate[(b)] (per cent)
1999	363	35	91.1	353	29	92.5	716	64	91.8
2000	394	15	96.4	364	7	98.1	758	22	97.2
2001	451	15	96.8	397	13	96.9	848	28	96.8
2002	463	15	96.8	445	10	97.9	908	25	97.3
2003	498	12	97.6	478	12	97.5	976	25	97.5
2004	512	12	97.8	463	11	97.8	975	22	97.8
2005	472	12	97.6	433	22	95.3	905	33	96.5
2006	500	15	97.2	421	3	99.4	921	17	98.2
2007	523	14	97.4	464	7	98.5	987	22	97.9
Total 2000–2007	**3,813**	**109**	**97.2**	**3,465**	**84**	**97.6**	**7,278**	**193**	**97.4**

(a) Estimated number of missing cases using the capture–recapture method with the two independent data sources: NDSS and APEG.

(b) Coverage rate = (NDR registrants/[NDR registrants + Estimated missing cases]) x100.

Note: Columns and rows may not add to totals due to rounding.

Source: National Diabetes Register (data extracted December 2008).

3.2 Incidence

This section uses NDR data only; that is, the numbers are not adjusted for missing cases. This is because the coverage of Type 1 diabetes among those aged 0–14 years on the NDR from 2000 to 2007 is considered high. The NDR alone can therefore be used to produce reliable estimates of Type 1 diabetes incidence in children.

Between 2000 and 2007, there were 7,278 new cases of Type 1 diabetes among children aged 0–14 years registered on the NDR—3,813 boys and 3,465 girls (Table C3.1). The total number of new cases equates to more than 2 new cases per day over the 8-year period.

The average age-standardised rate of new cases (per 100,000 population) per year was 23.1 for males and 22.1 for females (Table 3.2; Figure 3.1). Between 2000 and 2007, the age-standardised incidence rate for Type 1 diabetes among children aged 0–14 years increased significantly from 19.1 to 24.2 (per 100,000). Based on Poisson regression modelling which accounts for both the fluctuation across time and the variability at each time point, the estimated average increase was 2.2% per year (see Appendix B.6 for more information). No significant differences in incidence were found between boys and girls (Figure 3.2), which is consistent with the findings of a Western Australian study by Haynes et al. (2004) and a Victorian study by Chong et al. (2007); but in contrast to a New South Wales study by Taplin et al. (2005).

Among those aged 5–9 years, the annual age-standardised rate increased significantly by 2.2% per year between 2000 and 2007 from 20.5 to 25.8 (Table 3.2; Figure 3.3). In the 10–14 year age group, the incidence rate per 100,000 also increased significantly from 24.3 in 2000 to 31.3 in 2007, an average annual increase of 2.7%. In the 0–4 year age group the incidence rate increased from 12.2 per 100,000 in 2000 to 15.1 in 2007, equal to an average annual increase of 1.3%; however, this did not reach statistical significance.

In every year, the Type 1 diabetes incidence rate increased significantly with increasing age for both sexes (Table 3.2; Figure 3.3). Between 2000 and 2007, the average annual rate was lowest in the 0–4 year age group (14.7 per 100,000) and highest in the 10–14 year age group (29.0 per 100,000), with the 5–9 year age group sitting in between at 23.8 per 100,000.

When comparing boys and girls in different age groups over the 8-year period, the incidence rate was significantly higher among boys aged 0–4 years (15.8 per 100,000) than girls of the same age (13.5) (Table 3.2; Figure 3.1). However, there was no evidence of differences in incidence rates between boys and girls aged 5–9 years or 10–14 years.

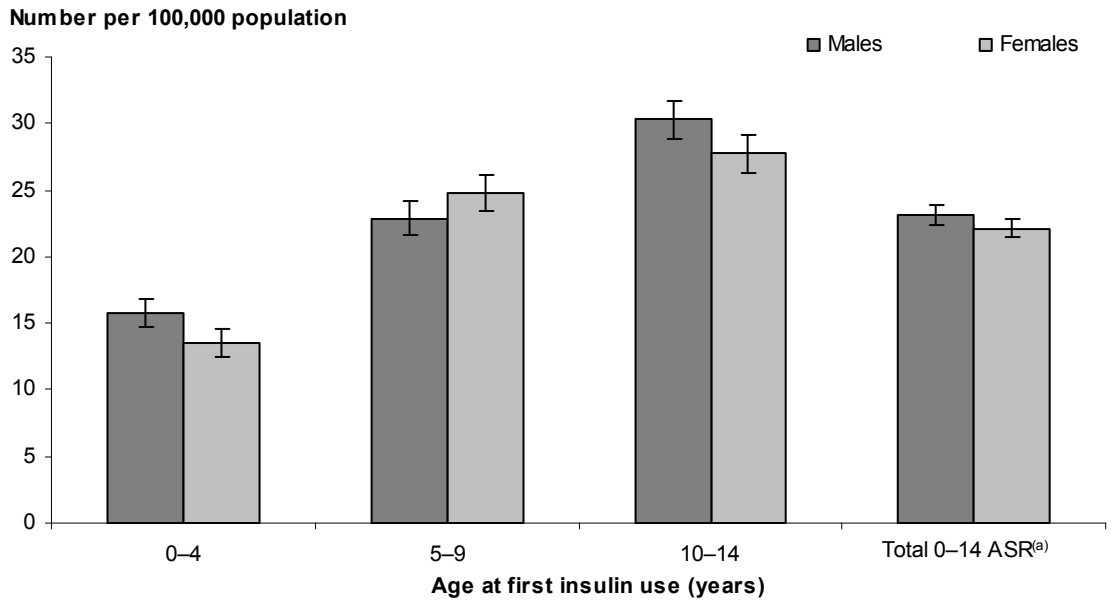
Table 3.2: Incidence (rate) of Type 1 diabetes among children aged 0–14 years: sex and age, by year of first insulin use, 2000–2007

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000 –2007[a]
	Age-specific rate (number per 100,000 population)								
Males									
0–4	13.0	16.1	16.2	19.3	16.2	16.2	14.4	15.0	15.8
5–9	19.9	20.6	22.2	22.8	25.5	22.8	23.3	25.9	22.9
10–14	25.0	29.1	28.9	30.3	32.3	29.1	33.8	33.6	30.3
Males 0–14 ASR[b]	*19.4*	*22.1*	*22.6*	*24.2*	*24.8*	*22.8*	*24.0*	*25.0*	*23.1*
(95% CI)	*(17.5–21.4)*	*(20.1–24.2)*	*(20.6–24.7)*	*(22.1–26.4)*	*(22.7–27.0)*	*(20.8–24.9)*	*(21.9–26.2)*	*(22.9–27.2)*	*(22.4–23.9)*
Females									
0–4	11.4	12.2	14.0	14.6	13.7	14.6	12.5	15.2	13.5
5–9	21.1	23.7	24.7	28.3	27.0	24.0	23.3	25.6	24.7
10–14	23.6	25.0	29.3	30.0	29.8	27.3	27.7	28.9	27.7
Females 0–14 ASR[b]	*18.8*	*20.4*	*22.8*	*24.5*	*23.7*	*22.1*	*21.3*	*23.4*	*22.1*
(95% CI)	*(17.0–20.9)*	*(18.5–22.5)*	*(20.8–25.1)*	*(22.3–26.8)*	*(21.6–25.9)*	*(20.0–24.2)*	*(19.3–23.5)*	*(21.3–25.6)*	*(21.4–22.9)*
Persons									
0–4	12.2	14.2	15.1	17.0	15.0	15.4	13.5	15.1	14.7
5–9	20.5	22.1	23.4	25.5	26.2	23.4	23.3	25.8	23.8
10–14	24.3	27.1	29.1	30.1	31.0	28.2	30.9	31.3	29.0
Total persons									
0–14 ASR[b]	**19.1**	**21.3**	**22.7**	**24.3**	**24.2**	**22.4**	**22.7**	**24.2**	**22.6**
(95% CI)	**(17.8–20.5)**	**(19.9–22.7)**	**(21.2–24.2)**	**(22.8–25.9)**	**(22.7–25.8)**	**(21.0–24.0)**	**(21.3–24.2)**	**(22.7–25.8)**	**(22.1–23.2)**

(a) The rate is the average annual rate for the 8 years.

(b) Age-standardised to the 2001 Australian population—see Appendix B.4.

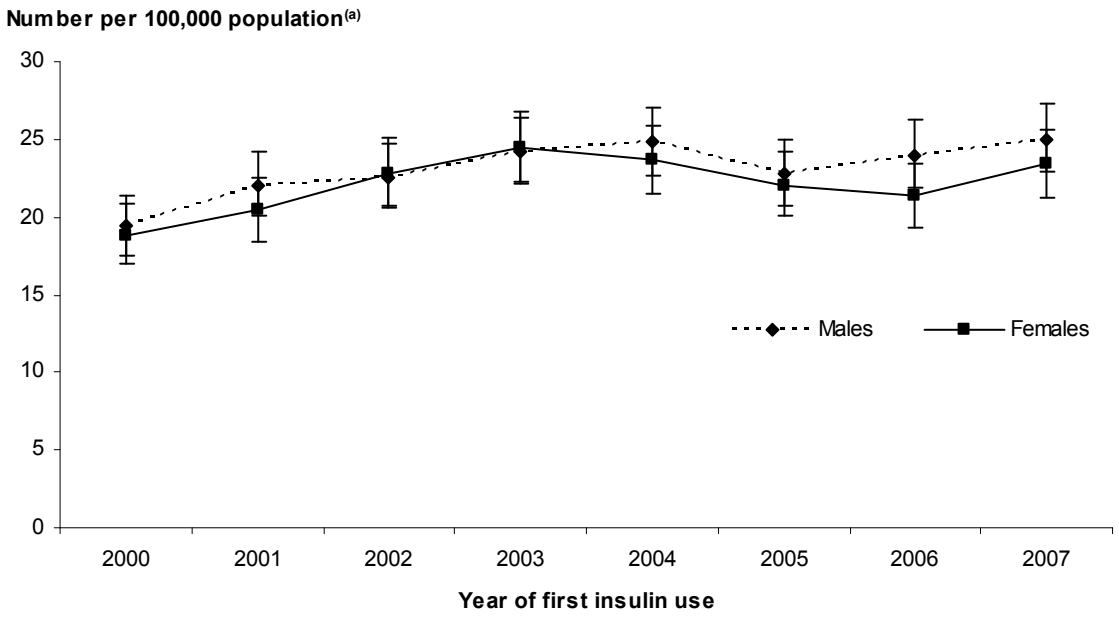
Source: National Diabetes Register (data extracted December 2008).



(a) The total rate for those aged 0–14 years is age-standardised to the 2001 Australian population—see Appendix B.4.

Source: National Diabetes Register (data extracted December 2008).

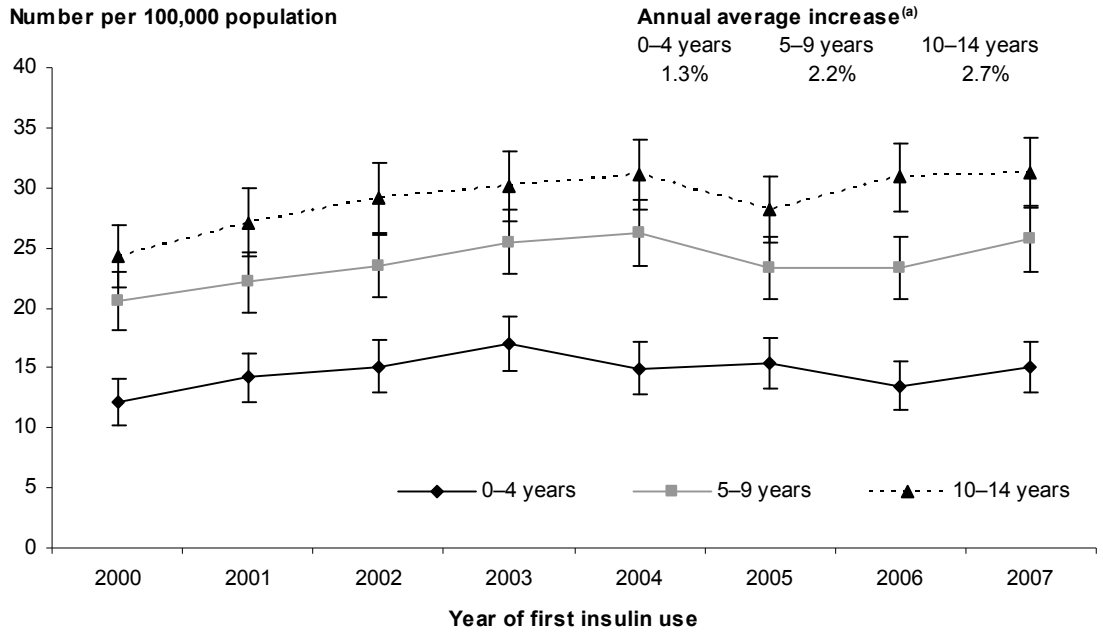
Figure 3.1: Incidence of Type 1 diabetes in children aged 0–14 years, by age and sex, 2000–2007



(a) Age-standardised to the 2001 Australian population—see Appendix B.4.

Source: National Diabetes Register (data extracted December 2008).

Figure 3.2: Incidence of Type 1 diabetes in children aged 0–14 years, by sex



(a) Estimate based on Poisson regression modelling—See Appendix B.6 for more information.

Source: National Diabetes Register (data extracted December 2008).

Figure 3.3: Incidence of Type 1 diabetes in children aged 0–14 years, by year of first insulin use

3.3 Geographical location

A major area of research interest in diabetes is whether geographic location influences incidence patterns of diabetes. The rapid increase in the incidence of Type 1 diabetes observed in Australia and around the world suggests that environmental factors rather than genetic factors are involved. A number of hypotheses have been proposed, including differences in environmental temperature, infections and stress (Dahlquist 1998).

Looking at the incidence of Type 1 diabetes by geographical location is useful because Australia is a large country, covering almost 7.7 million square kilometres (ABS 2008). Australia also has distinctive geography with a wide range of climatic zones. Statistically significant differences in the incidence between geographical locations could indicate possible environmental drivers in the cause of this disease. This information can also be used to better understand where people who have Type 1 diabetes currently live, and can therefore assist in future service planning.

A registrant's geographical location (state/territory, remoteness category, statistical division) is derived from postcode data (see Appendix B.9 for more information). This can be done using postcode of current usual residence or postcode at diagnosis. Analyses by current residence may be more useful for resource planning, whereas those done by residence at diagnosis may be of particular interest for research into patterns of occurrence. The NDR data for current residence are more complete than for residence at diagnosis, so only tables based on current residence have been presented here.

States and territories

Over the period 2000–2007, the rate of new cases of Type 1 diabetes among those aged 0–14 years differed between the states and territories (Table 3.3). On average, Tasmania had the highest incidence rate of Type 1 diabetes among those aged 0–14 years, at 27.6 per 100,000 population. The rate of new cases in Tasmania was significantly higher than the rate of new cases in New South Wales (20.6), the Northern Territory (9.8) and the Australian average (22.6). The Northern Territory had the lowest rate, at 9.8 per 100,000 population, which was significantly lower than that in any other jurisdiction. However, care should be taken when interpreting rates for the smaller states and territories because of the small numbers involved.

There was a consistent trend of increasing incidence of Type 1 diabetes among those aged 0–14 years with increasing age in all states and territories (Table 3.4). Overall, there were no significant differences in incidence rates between males and females, and this was true in each state and territory.

Remoteness

The geographic distribution of NDR registrants aged 0–14 years with Type 1 diabetes from 2005 to 2007 inclusive is shown in Table 3.5. *Major city* areas had the highest age-standardised rate of new cases per year at 25.1 per 100,000, closely followed by *Inner regional* areas at 22.5 per 100,000 population. Both *Major city* and *Inner regional* areas had significantly higher age-standardised rates than *Outer regional and Remote/Very remote* areas. For each age group, rates of new cases of Type 1 diabetes in children decreased with increasing remoteness.

Table 3.3: Incidence (rate) of Type 1 diabetes among children aged 0–14 years: year of first insulin use, by state/territory of current residence, 2000–2007

Year of first insulin use	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
	Age-standardised rate (number per 100,000 population)[(a)]								
2000	18.7	19.2	19.9	17.9	24.4	14.9	16.8	5.9	19.1
2001	20.1	22.1	22.7	21.1	21.1	25.1	22.9	10.3	21.3
2002	21.3	23.9	21.3	25.3	26.4	25.5	24.4	6.0	22.7
2003	20.5	26.5	25.9	25.9	29.9	30.7	18.3	10.3	24.3
2004	23.3	23.4	25.2	23.0	28.4	30.6	31.4	16.2	24.2
2005	20.0	24.6	23.5	20.4	21.4	41.0	28.9	5.8	22.4
2006	20.0	24.9	23.2	21.9	27.1	32.8	19.2	11.9	22.7
2007	21.2	27.0	26.0	26.1	19.3	20.7	44.4	11.8	24.2
Average 2000–2007 (95% CI)	**20.6 (19.8–21.5)**	**24.0 (22.9–25.1)**	**23.5 (22.3–24.7)**	**22.7 (21.1–24.4)**	**24.8 (22.8–26.9)**	**27.6 (24.1–31.5)**	**25.7 (21.5–30.5)**	**9.8 (7.0–13.4)**	**22.6 (22.1–23.2)**

(a) Age-standardised to the 2001 Australian population—see Appendix B.4.

Note: Columns may not add to the Australian total, as 1 record has an unknown state of current residence.

Source: National Diabetes Register (data extracted December 2008).

Table 3.4: Incidence (rate) of Type 1 diabetes among children aged 0–14 year: sex and age, by states and territories of current residence, 2000–2007

Sex and age at first insulin use (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
	Average annual age-specific rate (number per 100,000 population)								
Males									
0–4	13.3	16.2	17.8	16.5	19.4	23.1	16.6	4.1	15.8
5–9	20.5	23.2	24.5	25.1	25.1	26.0	30.1	8.4	22.9
10–14	28.8	32.3	29.5	27.9	34.1	43.2	31.0	16.2	30.3
Total males 0–14 ASR[(a)] (95% CI)	*21.0 (19.8–22.2)*	*24.0 (22.5–25.6)*	*24.0 (22.4–25.8)*	*23.3 (21.1–25.8)*	*26.3 (23.5–29.4)*	*30.9 (25.7–36.8)*	*26.1 (20.2–33.0)*	*9.7 (5.9–14.9)*	*23.1 (22.4–23.9)*
Females									
0–4	13.7	14.2	13.7	12.2	14.1	14.3	12.3	2.9	13.5
5–9	21.1	27.0	24.8	27.5	29.4	31.3	31.0	7.6	24.7
10–14	25.8	30.2	29.9	26.0	25.4	26.2	32.2	18.9	27.7
Total females 0–14 ASR[(a)] (95% CI)	*20.3 (19.1–21.5)*	*24.0 (22.4–25.6)*	*23.0 (21.3–24.7)*	*22.1 (19.8–24.5)*	*23.1 (20.4–26.1)*	*24.1 (19.4–29.6)*	*25.4 (19.6–32.4)*	*9.9 (6.0–15.5)*	*22.1 (21.4–22.9)*
Persons									
0–4	13.5	15.2	15.8	14.4	16.8	18.8	14.5	3.5	14.7
5–9	20.8	25.0	24.6	26.3	27.2	28.6	30.6	8.0	23.8
10–14	27.3	31.3	29.7	27.0	29.9	34.9	31.6	17.5	29.0
Total persons 0–14 ASR[(a)] (95% CI)	**20.6 (19.8–21.5)**	**24.0 (22.9–25.1)**	**23.5 (22.3–24.7)**	**22.7 (21.1–24.4)**	**24.8 (22.8–26.9)**	**27.6 (24.1–31.5)**	**25.7 (21.5–30.5)**	**9.8 (7.0–13.4)**	**22.6 (22.1–23.2)**

(a) Age-standardised to the 2001 Australian population—see Appendix B.4.

Source: National Diabetes Register (data extracted December 2008).

Table 3.5: Incidence (rate) of Type 1 diabetes among children aged 0–14 years at their first insulin use: geographical locations based on postcode of current residence[a], 2005–2007

Age at first insulin use (years)	Major cities	Inner regional	Outer regional	Remote/ Very remote	Australia
	Average annual age-specific rate (number per 100,000 population)				
0–4	15.6	14.6	12.2	9.1	14.7
5–9	26.3	23.7	19.4	10.3	24.1
10–14	33.0	28.8	25.8	8.3	30.1
Total persons 0–14 ASR[b] (95% CI)	**25.1 (24.0–26.3)**	**22.5 (20.8–24.3)**	**19.2 (17.0–21.7)**	**9.2 (6.7–12.2)**	**23.1 (22.3–24.0)**

(a) Registrants are classified according to the Australian Standard Geographical Classification (ASGC) Remoteness Areas based on postcode of current residence (AIHW population database)—see Appendix B.9.

(b) Age-standardised to the 2001 Australian population—see Appendix B.4.

Source: National Diabetes Register (data extracted December 2008).

3.4 Socioeconomic status

Socioeconomic status is a complex concept, and it is well established that it has a strong influence on health (AIHW 2008a). It is often conceptualised around three main features: education, employment and income.

In this report, socioeconomic status has been measured using the Index of Relative Socio-Economic Disadvantage (IRSD). The IRSD is one of the four Socio-Economic Indexes for Areas (SEIFAs) compiled by the Australian Bureau of Statistics (see Appendix B.10 for more information).

For the analysis presented here, an area group comprising the fifth of the population with the greatest overall level of disadvantage is described as the 'lowest SES group'. The group at the other end of the scale—the top fifth—is described as the 'highest SES group'. It is important to note that the IRSD reflects the overall or average level of disadvantage of the population of an area; it does not show how individuals living in the same area differ from each other in their SES (Krieger et al. 1997). However, it has been demonstrated that people of similar socioeconomic groups tend to live near each other, making this area-based measure a good indication of socioeconomic position. Being an average, the score is also likely to reduce the apparent differences between area groups, so area-based indexes like SEIFA provide a broad guide to individuals' relative socioeconomic status (Glover et al. 2004).

The incidence of Type 1 diabetes in children by socioeconomic status is shown in Table 3.6. The rate of new cases remained fairly stable across the different socioeconomic groups; however, for all age groups, the highest incidence occurred in the lowest socioeconomic group (Group 1). These results are in contrast to a study done in Western Australia where it was found that a higher incidence of Type 1 diabetes in children was associated with a higher socioeconomic status (Haynes et al. 2006).

Table 3.6: Incidence (rate) of Type 1 diabetes among children aged 0–14 years: socioeconomic status (SES) based on postcode of current residence[a], 2005–2007

Age at first insulin use (years)	Group 1 (lowest SES)	Group 2	Group 3	Group 4	Group 5 (highest SES)	Australia
			Age-specific rate (number per 100,000 population)			
0–4	16.3	15.0	14.8	13.3	14.6	14.8
5–9	26.2	24.8	25.0	23.0	22.5	24.2
10–14	37.7	26.1	33.3	26.2	28.2	30.2
Total persons 0–14 ASR[b] (95% CI)	**26.9 (24.9–29.2)**	**22.1 (20.3–24.0)**	**24.5 (22.6–26.6)**	**21.0 (19.2–22.9)**	**21.9 (20.1–23.8)**	**23.2 (22.4–24.1)**

(a) Registrants are classified according to the Index of Relative Socio-Economic Disadvantage (IRSD) based on postcode of current residence (AIHW population database)—see Appendix B.10.

(b) Age-standardised to the 2001 Australian population—see Appendix B.4.

Source: National Diabetes Register (data extracted December 2008).

3.5 Indigenous Australians

Over the period 2005–2007, 2.8% of the new cases of Type 1 diabetes in those aged 0–14 years occurred in people who were recorded as being of Aboriginal and/or Torres Strait Islander origin (Table 3.7). Indigenous status was not stated for one in every five new cases (20%), and this should be taken into account when interpreting these results.

For all groups in this table—'Indigenous', 'non-Indigenous' and 'not stated'—the number of cases increased with age.

Data on the Indigenous status of NDR registrants are presented only for 2005–2007 because of the way these data were captured in the NDSS database before 2005 (see Appendix B.11 for more information).

Table 3.7: New cases of insulin-treated Type 1 diabetes in children aged 0–14 years: Indigenous status, 2005–2007

Age at first insulin use (years)	Indigenous	non-Indigenous	Not stated	Total persons
		Number		
0–4	15	438	124	577
5–9	23	749	198	970
10–14	40	968	258	1,266
Total persons 0–14	**78**	**2,155**	**580**	**2,813**
		Per cent		
0–4	2.6	75.9	21.5	100.0
5–9	2.4	77.2	20.4	100.0
10–14	3.2	76.5	20.4	100.0
Total persons 0–14	**2.8**	**76.6**	**20.6**	**100.0**

Source: National Diabetes Register (data extracted December 2008).

3.6 Seasonal variation

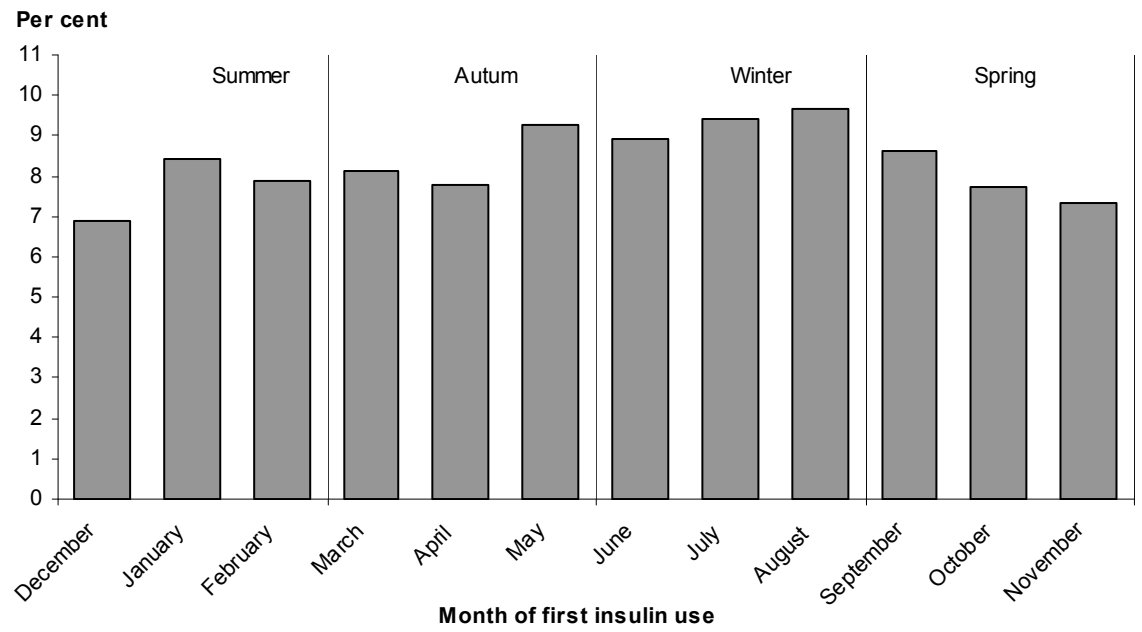
This report shows that the incidence of Type 1 diabetes in children has increased between 2000 and 2007 (Table 3.2; Figure 3.2). This pattern of increase has also been observed in other countries around the world (DIAMOND Project Group 2006).

While the exact causes of Type 1 diabetes are still unknown, researchers believe that Type 1 diabetes is caused by a combination of environmental factors and a genetic predisposition. Seasonal variation in the time of diagnosis may suggest that environmental factors, such as infections, may trigger Type 1 diabetes.

Earlier studies investigating pooled data from many different countries have shown significant seasonality in the date of diagnosis of Type 1 diabetes. These studies showed that the rate of new cases reached a maximum in the winter period and a minimum in the summer period (Levy-Marchal et al. 1995; Green & Patterson 2001). Other studies using data from individual countries have shown significant seasonal variation in the date of diagnosis (Green et al. 1992; Samuelsson et al. 2006; Svensson et al. 2008) for all but one study in Japan where no seasonal variation was found (Kida et al. 2000).

Figure 3.4 displays information from Australia's NDR on the percentage of children who began to use insulin for the first time for Type 1 diabetes in each calendar month. This brief snapshot shows that the highest proportion of children were diagnosed in the cooler months (June, July, August), at 28% of all new cases, and the lowest proportion occurred in the warmer months (November, December, January), at 23%.

Further investigation into the seasonal variation of the diagnosis of Type 1 diabetes in Australia, and higher level statistical analyses are needed to investigate whether any statistical significance in the variation between seasons is evident.



Source: National Diabetes Register (data extracted December 2008).

Figure 3.4: Month of first insulin use of children aged 0–14 years with Type 1 diabetes, 2000–2007

3.7 Country of origin

The NDR receives information on the country of birth of registrants supplied by both the APEG and the NDSS databases. Data supplied by the NDSS also contain some information on their language spoken at home. Information on both country of birth and language spoken at home is often not well reported, with 14.5% of children aged 0–14 years with Type 1 diabetes on the NDR having inadequately described information for their country of birth, and 86% for their language spoken at home.

Of children aged 0–14 years with Type 1 diabetes on the NDR with a country of birth recorded, 93% were born in Australia. The next highest region was North-West Europe, with 2% of children reporting a country of birth in that region. The proportion on the NDR who were born overseas is consistent with the 5% of children aged 0–14 years in the general Australian population who were born overseas as at 30 June 2005 (ABS 2006c).

It is important to note that country of birth does not necessarily represent country or ethnic origin, as many people today are born in Australia but have other ethnic origins. Therefore, with improved data quality for country of birth combined with language spoken at home, the NDR could be used to more accurately assess whether there are any associations between the incidence of Type 1 diabetes in children and country of origin.

3.8 International comparisons

The number of children developing Type 1 diabetes in Australia is high when compared with available data from other countries. It is important to note that international data on diabetes are not always available for comparable time periods. A study that looked at the worldwide incidence of Type 1 diabetes over the period 1990–1999 found variation from 0.1 cases per 100,000 per year in China and Venezuela to 40.9 cases per 100,000 per year in Finland (DIAMOND Project Group 2006). This variability may partly be due to the different distributions of risk genes and different environmental exposures. However, it may also be due to a lack of available data from particular countries especially those with very low gross domestic product and the largest child populations such as Africa and South East Asia (IDF 2006 and DIAMOND Project Group 2006).

Table 3.8 presents data from the *Diabetes atlas* (IDF 2006) together with the Australian rate from the NDR. The data periods for the countries shown range over the years from 1990 to 2003. This worldwide research done by the International Diabetes Federation found Australia to be one of the top 10 countries in incidence rates for Type 1 diabetes in children (IDF 2006). The top 10 countries in descending order were Finland, Sweden, Norway, United Kingdom, Canada, Australia, Denmark, Germany, New Zealand and Puerto Rico. Again, it is important to note that the data were compiled from multiple studies about childhood-onset diabetes, and so should be interpreted cautiously and considered as general indicators only (IDF 2006).

Table 3.8: Incidence of Type 1 diabetes in children aged 0–14 years: Australia compared with selected countries, various years

Region[(a)] and country	Period	New cases per 100,000 population per year	Population 0–14 years ('000s)
Australia[(b)]	**2000–2003**	**21.9**	**3,987**
New Zealand	1999–2000	18.0	850
Europe			
Uzbekistan (lowest)	2000	1.2	8,642
United Kingdom	1999–2003	22.5	10,491
Finland (highest)	1990–1999	41.4	887
North America			
Mexico (lowest)	1990–1993	1.5	32,621
United States of America	1990–1999	16.1	62,136
Canada (highest)	1990–1999	21.7	5,557
Eastern Mediterranean and Middle East			
Pakistan (lowest)	1990–1999	0.5	61,196
Kuwait (highest)	1992–1999	22.3	685
South and Central America			
Venezuela (lowest)	1992	0.1	8,413
Puerto Rico (highest)	1990–1999	16.8	865
South-East Asia			
Mauritius (lowest)	1990–1994	1.4	302
India (highest)	1991	4.2	354,299
Other Western Pacific[(c)]			
Papua New Guinea (lowest)	1996–2000	0.1	2,395
Singapore (highest)	1992–1994	2.5	799

(a) Regions reflect those used by the International Diabetes Foundation (IDF 2006).

(b) Incidence rate for Australia is the average annual age-standardised rate for 2000–2003.

(c) Excluding Australia and New Zealand.

Notes

1. Countries in this table displayed as having the lowest or highest rate in a region may have had rates equal to other countries in the region. Countries were included where the rates were from data specific to that country and excluded where the rates were extrapolated from data in a different country.
2. The African region was excluded because rates were available only for one country/territory and the data were notably older than the other countries shown.

Sources: IDF 2006; National Diabetes Register for Australia.

4 Incidence of Type 1 diabetes in people aged 15 years and over

4.1 Coverage

The coverage rate for people aged 15 years and over with Type 1 diabetes on the NDR (the proportion of NDSS registrants consenting to be on the NDR) has steadily increased from 49.0% in 1999 to 96.4% in 2007 (Table 4.1). The recent increases are largely due to the change to the NDSS registration form in 2003 as described in the Introduction. As the use of the new form continues to increase, the consent rate should approach 100%. More detail about the change to the registration form and the impact on the NDR's ascertainment from the NDSS can be found in *National Diabetes Register: impact of changed consent arrangements on ascertainment from the National Diabetes Services Scheme* (AIHW 2006).

The coverage rates presented here show the rate of consent of NDSS registrants to join the NDR, and do not show how well the NDSS covers new cases of Type 1 diabetes in people aged 15 years and over in Australia. A second source of information on people aged 15 years and over with diabetes is required to do this.

The NDSS database is a good source of information on people with diabetes; however, the increasing prevalence of Type 2 diabetes means that with increasing age there is less certainty around a diagnosis of Type 1 diabetes. In adults, Type 1 diabetes sometimes occurs in a slowly progressive condition known as latent autoimmune diabetes in adults (LADA). At presentation, LADA appears to be similar to Type 2 diabetes, and can be treated with lifestyle changes or tablets, but in fact it is a slowly progressive form of autoimmune or Type 1 diabetes that ultimately requires insulin injections. Therefore, the quality of the type of diabetes variable for people aged 15 years and over may be slightly less reliable and should be used with some caution.

Table 4.1: Coverage of Type 1 diabetes on the NDR among people aged 15 years and over at their first insulin use, by year of first insulin use, 1999–2007

	Males			Females			Persons		
Year of first insulin use	NDR registrants	Missing cases[(a)]	Coverage rate[(b)] (per cent)	NDR registrants	Missing cases[(a)]	Coverage rate[(b)] (per cent)	NDR registrants	Missing cases[(a)]	Coverage rate[(b)] (per cent)
1999	718	650	52.5	505	622	44.8	1,223	1,272	49.0
2000	733	196	78.9	440	152	74.3	1,173	348	77.1
2001	717	200	78.2	473	138	77.4	1,190	338	77.9
2002	594	153	79.5	325	103	75.9	919	256	78.2
2003	646	147	81.5	364	94	79.5	1,010	241	80.7
2004	683	55	92.5	381	24	94.1	1,064	79	93.1
2005	628	49	92.8	376	28	93.1	1,004	77	92.9
2006	708	28	96.2	388	27	93.5	1,096	55	95.2
2007	860	35	96.1	460	14	97.0	1,320	49	96.4
Total 2000–2007	**5,569**	**863**	**86.6**	**3,207**	**580**	**84.7**	**8,776**	**1,443**	**85.9**

(a) Missing cases refers to NDR-eligible NDSS registrants who are not on the NDR.

(b) Coverage rate = (NDR registrants/[NDR registrants + Estimated missing cases]) x100.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

4.2 Incidence

This section presents incidence estimates for people aged 15 years and over with Type 1 diabetes. The tables in this section are produced using results from the NDR that have been adjusted to account for missing cases using information from the de-identified NDSS data set. Adjusting the NDR results in this way ensures that more accurate incidence estimates are presented. For further details about these data sets please see the Data Sources section in the Appendix.

Type 1 diabetes not only develops in childhood but can arise at any age. However, the disease develops at a lower rate throughout adulthood compared to during childhood (AIHW 2008b; Bruno et al. 2005; Daneman 2006; Lammi et al. 2007; Molbak et al. 1994).

Data from the NDR indicate that, between 2000 and 2007, an estimated 10,219 new cases of Type 1 diabetes in people aged 15 years and over occurred in Australia (Table C4.1). This is equal to an average of 1,277 new cases per year or 3–4 new cases per day.

The rate of new cases of Type 1 diabetes among people aged 15 years and over decreased significantly with age until around 45 years of age where it plateaued (Figure 4.1). The highest rate occurred in people aged 15–19 years at diagnosis, at 16.8 new cases per 100,000 each year, and fell to 4.8 new cases for people aged over 40 years (Table C4.2). The rate for people aged 15–24 years was notably lower (14.9 per 100,000) than the rate for children aged 0–14 years (22.6) (tables 3.2 and C4.2), and, although the data are not fully comparable, it appears that the peak incidence rate of Type 1 diabetes occurs before the age of 15 years.

Over the period 2000–2007, males aged 15 years and over had a higher incidence of Type 1 diabetes than females of the same age (Figure 4.1). Males accounted for 63% of new

cases while females accounted for 37% (Table C4.1). Among those aged 15–24 years, the average age-adjusted incidence rate for males (17.6 per 100,000) was 1.5 times as high as that for females (11.9) (Table 4.2). The male rate was 1.4 times as high as the female rate among those aged 15–19 years (19.3 compared with 14.1 per 100,000), and 1.6 times as high among 20–24 year olds (15.8 compared with 9.7 per 100,000) (Table C4.2). The rate among males aged 25–39 years was twice as high as the female rate (13.5 compared with 6.7 per 100,000), and the male rate for those aged 40 years and over was 1.7 times as high as the female rate of the same age (6.1 compared with 3.6 per 100,000). This male excess in the older age group is consistent with the findings of various other studies (including Gale & Gillespie 2001; Kyvik et al. 2004; Weets et al. 2002).

Between 2000 and 2007, the age-standardised incidence of Type 1 diabetes among people aged 15–24 years and 25–39 years remained fairly stable (Figure 4.2). However, there was a significant decrease in incidence rates among people aged 40 years and over, with the rate decreasing from 7.6 to 4.6 per 100,000. The majority of this decrease occurred between 2001 and 2002, with the rate remaining stable thereafter. A similar pattern was observed for both males and females (Table 4.2).

The results presented in this report show that, from 2000 to 2007, the incidence of Type 1 diabetes increased significantly among those aged 0–14 years, remained stable for those aged 15–24 and 25–39 years, and decreased significantly among people aged 40 years and over. This is consistent with studies that show that the incidence of Type 1 diabetes is increasing among children but not among young adults (IDF 2006), and may indicate a shift to a younger age at onset.

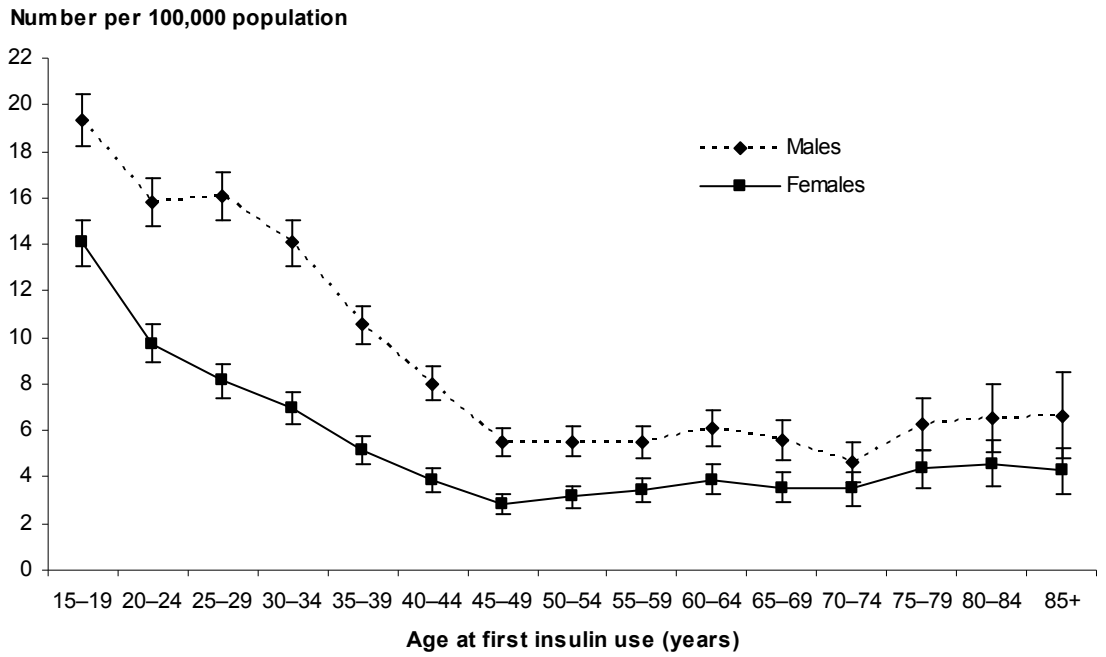
Table 4.2: Incidence (rate) of Type 1 diabetes among people aged 15 years and over: sex and age, by year of first insulin use, 2000–2007

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000–2007[a]
	Age-standardised rate (number per 100,000 population)[b]								
Males									
15–24 ASR (95% CI)	16.4 (14.3–18.8)	18.0 (15.8–20.4)	17.2 (15.1–19.5)	18.4 (16.2–20.7)	17.6 (15.5–19.9)	17.8 (15.7–20.1)	17.0 (14.9–19.2)	18.5 (16.4–20.8)	17.6 (16.8–18.4)
25–39 ASR (95% CI)	15.2 (13.6–16.9)	14.7 (13.1–16.4)	11.8 (10.4–13.4)	13.9 (12.4–15.6)	13.5 (12.0–15.1)	11.7 (10.3–13.2)	11.8 (10.4–13.4)	15.4 (13.8–17.1)	13.5 (13.0–14.1)
40+ ASR (95% CI)	9.7 (8.7–10.7)	8.9 (8.0–9.8)	6.1 (5.4–6.9)	5.6 (4.9–6.3)	4.5 (3.9–5.2)	3.7 (3.2–4.3)	5.0 (4.4–5.7)	5.8 (5.2–6.6)	6.1 (5.8–6.3)
15+ ASR (95% CI)	*12.4 (11.6–13.2)*	*12.1 (11.3–12.9)*	*9.6 (9.0–10.4)*	*10.1 (9.4–10.9)*	*9.3 (8.7–10.0)*	*8.4 (7.8–9.0)*	*9.0 (8.4–9.7)*	*10.7 (10.0–11.5)*	*10.2 (9.9–10.4)*
Females									
15–24 ASR (95% CI)	13.0 (11.1–15.1)	13.2 (11.3–15.3)	11.8 (10.0–13.8)	13.0 (11.1–15.0)	10.6 (8.9–12.5)	12.0 (10.3–14.0)	10.7 (9.1–12.6)	11.5 (9.8–13.4)	11.9 (11.3–12.6)
25–39 ASR (95% CI)	8.5 (7.3–9.8)	7.6 (6.5–8.8)	5.5 (4.6–6.6)	7.1 (6.0–8.3)	6.6 (5.6–7.8)	5.5 (4.6–6.6)	6.6 (5.6–7.8)	6.3 (5.3–7.5)	6.7 (6.3–7.1)
40+ ASR (95% CI)	5.6 (4.9–6.3)	6.2 (5.5–7.0)	3.3 (2.8–3.9)	2.8 (2.4–3.3)	2.5 (2.1–3.0)	2.5 (2.1–3.0)	2.5 (2.1–3.0)	3.5 (3.0–4.1)	3.6 (3.4–3.8)
15+ ASR (95% CI)	*7.7 (7.1–8.3)*	*7.8 (7.2–8.4)*	*5.4 (4.9–5.9)*	*5.8 (5.2–6.3)*	*5.1 (4.6–5.6)*	*5.0 (4.5–5.5)*	*5.1 (4.6–5.6)*	*5.7 (5.2–6.2)*	*5.9 (5.7–6.1)*
Persons									
15–24 ASR (95% CI)	14.8 (13.3–16.3)	15.6 (14.2–17.2)	14.5 (13.1–16.1)	15.7 (14.3–17.3)	14.2 (12.8–15.6)	15.0 (13.6–16.5)	13.9 (12.6–15.4)	15.1 (13.7–16.6)	14.8 (14.3–15.3)
25–39 ASR (95% CI)	11.8 (10.8–12.9)	11.1 (10.1–12.1)	8.7 (7.8–9.6)	10.5 (9.5–11.5)	10.1 (9.1–11.0)	8.6 (7.8–9.5)	9.2 (8.3–10.2)	10.9 (9.9–11.9)	10.1 (9.8–10.4)
40+ ASR (95% CI)	7.6 (7.0–8.2)	7.5 (6.9–8.1)	4.7 (4.3–5.2)	4.1 (3.7–4.6)	3.5 (3.1–3.9)	3.1 (2.8–3.5)	3.7 (3.3–4.2)	4.6 (4.2–5.1)	4.8 (4.6–4.9)
15+ ASR (95% CI)	**10.0 (9.5–10.5)**	**9.9 (9.4–10.4)**	**7.5 (7.1–8.0)**	**7.9 (7.5–8.4)**	**7.2 (6.8–7.6)**	**6.7 (6.3–7.1)**	**7.0 (6.6–7.5)**	**8.2 (7.8–8.6)**	**8.0 (7.9–8.2)**

(a) Average annual rate for 2000–2007.

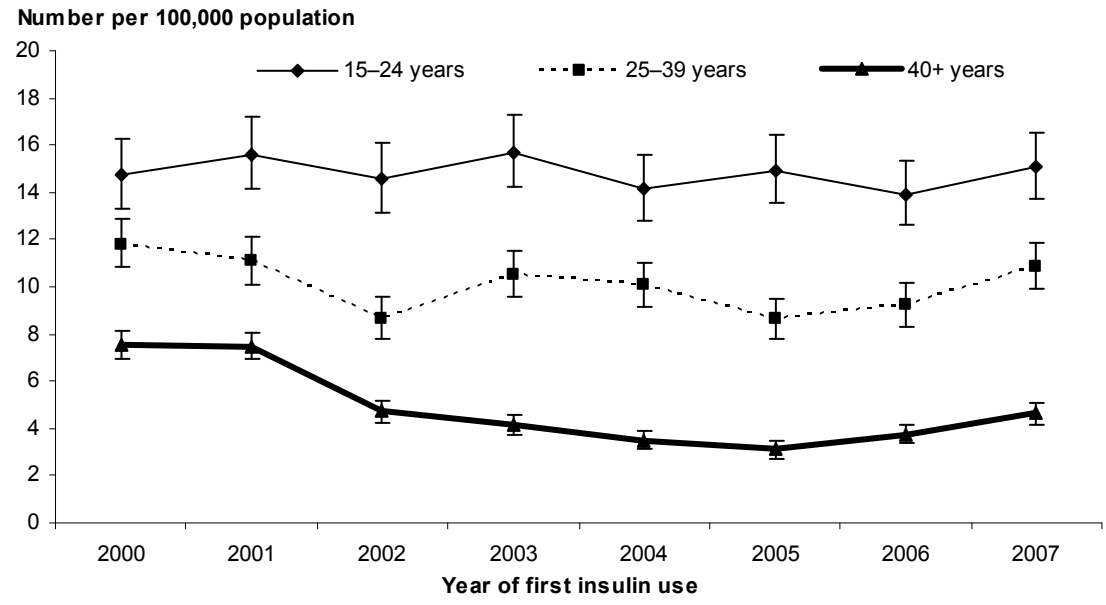
(b) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).



Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Figure 4.1: Incidence rate of Type 1 diabetes among people aged 15 years and over, by age and sex, 2000–2007



(a) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Figure 4.2: Incidence rate of Type 1 diabetes among people aged 15 years and over, by year and age, 2000–2007

4.3 Geographical location

As mentioned in Chapter 3, a major area of research interest in diabetes is whether geographic location influences incidence patterns of diabetes. The geographical location data in this report have been derived from each registrant's postcode of current usual residence.

States and territories

The incidence rates of Type 1 diabetes in people aged 15 years and over varied between the states and territories and year of first insulin use (Table 4.3). Tasmania had the highest incidence rate of Type 1 diabetes in people aged 15 years and over, with an average of 9.7 new cases per 100,000 population per year. This rate was significantly greater than the rate for all other states except Western Australia and South Australia. The Australian Capital Territory and the Northern Territory had the lowest rates, with an average of 6.5 new cases per 100,000.

For all states and territories, rates were highest in the younger age groups (15–24 years), and rates were higher for males than females (Table 4.4). Care should be taken, however, when interpreting these rates for the smaller states and territories because of the small numbers involved.

Remoteness

The incidence rate of Type 1 diabetes in people aged 15 years and over varies across the different geographical location groups (Table 4.5). For all age groups, the highest average annual rate occurred in people living in *Major cities* and the lowest average annual rate occurred in people living in *Remote/Very remote* areas. The average annual rate generally decreased with increasing age in all areas, in line with the national pattern.

Table 4.3: Incidence (rate) of Type 1 diabetes among people aged 15 years and over: year of first insulin use, by state/territory of current residence, 2000–2007

Year of first insulin use	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
	Age-standardised rate (number per 100,000 population)[(a)]								
2000	10.6	7.8	9.8	11.0	11.3	17.1	9.3	7.5	10.0
2001	9.7	10.1	8.2	12.2	9.9	10.1	10.2	7.2	9.9
2002	7.3	7.4	6.8	9.4	8.3	9.9	4.9	1.7	7.5
2003	7.0	7.9	8.6	9.1	8.3	8.3	6.5	8.3	7.9
2004	6.0	7.9	7.5	8.8	7.5	8.2	3.4	8.4	7.2
2005	5.7	6.8	7.5	7.6	6.8	6.8	7.7	7.5	6.7
2006	6.1	7.1	6.8	10.0	7.6	7.7	6.3	7.1	7.0
2007	9.2	7.5	8.4	7.4	7.4	9.7	4.7	5.0	8.2
Average 2000–2007 (95% CI)	**7.7 (7.4–7.9)**	**7.8 (7.5–8.1)**	**7.9 (7.6–8.3)**	**9.4 (8.9–9.9)**	**8.3 (7.8–8.9)**	**9.7 (8.6–10.9)**	**6.5 (5.5–7.7)**	**6.5 (5.2–8.1)**	**8.0 (7.9–8.2)**

(a) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Table 4.4: Incidence (rate) of Type 1 diabetes among people aged 15 years and over: sex and age, by states and territories of current residence, 2000–2007

Sex and age at first insulin use (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
	Average annual rate (number per 100,000 population)[(a)]								
Males									
15–24 ASR (95% CI)	16.6 (15.3–18.0)	17.4 (15.9–19.0)	18.6 (16.9–20.5)	20.1 (17.6–22.8)	16.5 (13.9–19.5)	17.3 (12.6–23.2)	20.1 (14.5–27.1)	12.8 (7.4–20.5)	17.6 (16.8–18.4)
25–39 ASR (95% CI)	12.0 (11.1–12.9)	12.8 (11.8–13.9)	16.0 (14.6–17.4)	16.2 (14.3–18.2)	12.9 (11.0–15.1)	16.9 (12.9–21.8)	8.4 (5.5–12.3)	12.1 (8.0–17.7)	13.5 (13.0–14.1)
40+ ASR (95% CI)	6.3 (5.9–6.8)	6.0 (5.5–6.5)	4.4 (3.9–4.9)	7.7 (6.8–8.7)	7.0 (6.0–8.0)	7.3 (5.6–9.4)	3.0 (1.7–4.9)	4.8 (2.7–7.8)	6.1 (5.8–6.3)
15+ ASR (95% CI)	*9.7 (9.3–10.2)*	*9.9 (9.4–10.4)*	*10.1 (9.5–10.7)*	*12.2 (11.4–13.1)*	*10.3 (9.4–11.3)*	*11.8 (10.0–13.7)*	*7.5 (5.9–9.2)*	*8.3 (6.3–10.7)*	*10.2 (9.9–10.4)*
Females									
15–24 ASR (95% CI)	10.9 (9.8–12.0)	10.9 (9.7–12.2)	14.3 (12.7–15.9)	12.7 (10.6–15.0)	11.8 (9.6–14.5)	15.0 (10.6–20.6)	14.4 (9.7–20.6)	7.4 (3.4–14.0)	11.9 (11.3–12.6)
25–39 ASR (95% CI)	6.1 (5.5–6.8)	6.5 (5.7–7.3)	7.1 (6.3–8.1)	7.6 (6.4–9.0)	7.8 (6.4–9.6)	7.9 (5.3–11.3)	7.3 (4.6–10.9)	5.6 (2.9–9.8)	6.7 (6.3–7.1)
40+ ASR (95% CI)	3.8 (3.4–4.1)	3.8 (3.4–4.2)	2.3 (2.0–2.7)	4.0 (3.3–4.7)	3.9 (3.3–4.7)	5.0 (3.7–6.7)	1.8 (0.9–3.4)	3.4 (1.1–7.4)	3.6 (3.4–3.8)
15+ ASR[)] (95% CI)	*5.6 (5.3–6.0)*	*5.8 (5.4–6.1)*	*5.7 (5.3–6.2)*	*6.5 (5.9–7.2)*	*6.4 (5.7–7.2)*	*7.6 (6.2–9.1)*	*5.5 (4.3–7.1)*	*4.7 (2.9–7.0)*	*5.9 (5.7–6.1)*
Persons									
15–24 ASR (95% CI)	13.8 (13.0–14.7)	14.2 (13.2–15.3)	16.5 (15.3–17.7)	16.5 (14.9–18.2)	14.2 (12.5–16.2)	16.2 (12.9–20.0)	17.3 (13.6–21.8)	10.2 (6.6–14.9)	14.8 (14.3–15.3)
25–39 ASR (95% CI)	9.0 (8.5–9.6)	9.6 (9.0–10.3)	11.5 (10.7–12.4)	11.9 (10.8–13.1)	10.4 (9.2–11.8)	12.4 (12.9–20.0)	7.8 (5.8–10.4)	8.9 (6.4–12.2)	10.1 (9.8–10.4)
40+ ASR (95% CI)	5.0 (4.7–5.3)	4.8 (4.5–5.2)	3.3 (3.0–3.6)	5.8 (5.2–6.4)	5.4 (4.8–6.0)	6.2 (5.1–7.5)	2.4 (1.6–3.6)	4.1 (2.5–6.4)	4.8 (4.6–4.9)
15+ ASR (95% CI)	**7.7 (7.4–7.9)**	**7.8 (7.5–8.1)**	**7.9 (7.6–8.3)**	**9.4 (8.8–9.9)**	**8.3 (7.8–8.9)**	**9.7 (8.6–10.9)**	**6.5 (5.5–7.7)**	**6.5 (5.2–8.1)**	**8.0 (7.9–8.2)**

(a) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Table 4.5: Incidence (rate) of Type 1 diabetes among people aged 15 years and over at their first insulin use: geographical locations based on postcode of current residence[a], 2005–2007

Age at first insulin use (years)	Major cities	Inner regional	Outer regional	Remote/ Very remote	Australia
			Average annual rate (number per 100,000 population)[b]		
15–24 ASR	15.7	13.1	13.1	11.0	14.7
(95% CI)	(14.7–16.8)	(11.7–14.9)	(10.7–15.8)	(7.4–15.7)	(13.8–15.4)
25–39 ASR	10.2	8.0	10.0	5.9	9.6
(95% CI)	(9.6–10.9)	(6.9–9.1)	(8.1–11.7)	(3.8–8.5)	(9.1–10.1)
40+ ASR	4.2	3.3	3.3	2.6	3.8
(95% CI)	(3.9–4.5)	(2.8–3.7)	(2.7–4.0)	(1.6–3.9)	(3.6–4.0)
15+ ASR	**7.9**	**6.3**	**6.9**	**5.0**	**7.3**
(95% CI)	**(7.6–8.2)**	**(5.8–6.8)**	**(6.2–7.7)**	**(3.9–6.2)**	**(7.1–7.6)**

(a) Registrants are classified according to the Australian Standard Geographical Classification (ASGC) Remoteness Areas based on postcode of current residence (AIHW population database)—see Appendix B.9.

(b) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

4.4 Socioeconomic status

Socioeconomic status is a complex concept, and it is well established that it has a strong influence on health (AIHW 2008a). It is often conceptualised around three main features: education, employment and income. The Index of Relative Socioeconomic Disadvantage (IRSD) has been used to derive socioeconomic status in this report. This method has been described in more detail in Chapter 3 and Appendix B.10.

Table 4.6 shows the incidence of Type 1 diabetes in people aged 15 years and over by socioeconomic group over the period 2005–2007. For all age groups, the incidence rate of Type 1 diabetes remained fairly stable across the different socioeconomic groups, with no significant differences found. These results suggest that the incidence of Type 1 diabetes in people aged 15 years and over in Australia is not influenced by socioeconomic status.

Table 4.6: Incidence (rate) of Type 1 diabetes among people aged 15 years and over at their first insulin use: socioeconomic status (SES) based on postcode of current residence[a], 2005–2007

Age at first insulin use (years)	Group 1 (lowest SES)	Group 2	Group 3	Group 4	Group 5 (highest SES)	Australia
			Average annual rate (number per 100,000 population)[b]			
15–24 ASR	15.5	15.3	15.7	13.5	13.7	14.8
(95% CI)	(13.7–17.4)	(13.6–17.3)	(13.9–17.7)	(11.8–15.4)	(11.9–15.6)	(14.0–15.6)
25–39 ASR	10.5	8.4	10.0	9.1	10.1	9.6
(95% CI)	(9.2–11.7)	(7.4–9.5)	(8.8–11.2)	(8.0–10.4)	(8.9–11.5)	(9.1–10.2)
40+ ASR	3.5	3.4	4.1	3.5	4.5	3.8
(95% CI)	(3.0–4.0)	(2.9–3.9)	(3.6–4.7)	(3.1–4.1)	(4.0–5.1)	(3.6–4.0)
15+ ASR	**7.5**	**6.9**	**7.8**	**6.8**	**7.7**	**7.3**
(95% CI)	**(7.0–8.1)**	**(6.4–7.4)**	**(7.2–8.3)**	**(6.3–7.4)**	**(7.1–8.3)**	**(7.1–7.6)**

(a) Registrants are classified according to the Index of Relative Socio-Economic Disadvantage (IRSD) based on postcode of current residence (AIHW population database)—see Appendix B.10.

(b) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

4.5 Indigenous Australians

Over the period 2005–2007, 1.9% of the new cases of Type 1 diabetes in people aged 15 years and over occurred in Aboriginal and/or Torres Strait Islander peoples (Table 4.7). Reporting against the Indigenous status variable was higher in this age group than it was for children aged 0–14 years. However, Indigenous status was still not stated for 11% of new cases, and this should be taken into account when interpreting the results.

Data on the Indigenous status of NDR registrants are presented only for 2005–2007 because of the way these data were captured in the NDSS database before 2005. See Appendix B.11 for more information.

Table 4.7: New cases of insulin-treated Type 1 diabetes in people aged 15 years and over: Indigenous status, 2005–2007

Age at first insulin use (years)	Indigenous	Non-Indigenous	Not stated	Total persons
		Number		
15–24	28	1,086	150	1,264
25–39	23	1,135	114	1,272
40+	16	915	134	1,065
Total persons 15+	**67**	**3,136**	**398**	**3,601**
		Per cent		
15–24	2.2	85.9	11.9	100.0
25–39	1.8	89.2	9.0	100.0
40+	1.5	85.9	12.6	100.0
Total persons 15+	**1.9**	**87.1**	**11.1**	**100.0**

Source: National Diabetes Register (data extracted December 2008).

4.6 Country of origin

The NDR receives information on country of birth and language spoken at home for registrants aged 15 years and over, supplied by the NDSS databases. Information on both country of birth and language spoken at home is often not well reported, with 34% of people aged 15 years and over with Type 1 diabetes on the NDR having inadequately described information for their country of birth, and 88% for their language spoken at home.

Of people aged 15 years and over with Type 1 diabetes on the NDR with a country of birth recorded, 68% were born in Australia. The next highest region was North-West Europe with 11% reporting a country of birth in that region, followed by Southern and Eastern Europe with 6%. The proportion on the NDR who were born overseas is similar to the proportion of people born overseas in the general Australian population, with about 28% of people aged 15 years and over born overseas as at 30 June 2005 (ABS 2006c).

It is important to note that country of birth does not necessarily represent country or ethnic origin, as many people today are born in Australia but have other ethnic origins. Therefore, with improved data quality for country of birth combined with language spoken at home, the NDR could be used to more accurately assess whether there are any associations between the incidence of Type 1 diabetes and country of origin.

5 Other forms of insulin-treated diabetes

This chapter describes the characteristics of people who have types of insulin-treated diabetes other than Type 1. These include people with insulin-treated Type 2 diabetes, gestational diabetes mellitus, and other types such as diabetes caused by cystic fibrosis and by genetic defects of beta-cell function ('MODY') (see Glossary for more information). The estimates presented in this chapter were derived using results from the NDR that have been adjusted to account for missing cases using information from the de-identified NDSS data set. Adjusting the NDR results in this way ensures that more accurate incidence estimates are presented. Detailed information on the coverage rate (the proportion of NDSS registrants consenting to be on the NDR) for these groups can be found in the tables following and in *National Diabetes Register: impact of changed consent arrangements on ascertainment from the National Diabetes Services Scheme* (AIHW 2006). The following tables present data only on new cases of insulin-treated Type 2, gestational diabetes and other types of diabetes, and do not include data for the many cases of these conditions where insulin is not used.

5.1 Insulin-treated Type 2 diabetes

Coverage

The coverage rate of new cases of insulin-treated Type 2 diabetes on the NDR improved from 44% in 2000 to 72% in 2006, but then fell slightly in 2007 to 70% (Table 5.1).

Table 5.1: NDR coverage rates for NDR-eligible NDSS registrants with insulin-treated ype 2 diabetes, 2000–2007

	Males			Females			Persons		
Year of first insulin use	NDR regis-trants	Missing cases	Coverage rate[(a)] (per cent)	NDR regis-trants	Missing cases	Coverage rate[(a)] (per cent)	NDR regis-trants	Missing cases	Coverage rate[(a)] (per cent)
2000	3,065	3,918	43.9	2,708	3,453	44.0	5,773	7,371	43.9
2001	3,281	3,752	46.7	2,927	3,326	46.8	6,208	7,078	46.7
2002	3,744	3,812	49.6	3,140	3,240	49.2	6,884	7,052	49.4
2003	4,473	4,008	52.7	3,890	3,337	53.8	8,363	7,345	53.2
2004	5,845	3,978	59.5	4,709	3,184	59.7	10,554	7,162	59.6
2005	6,298	2,834	69.0	5,135	2,368	68.4	11,433	5,202	68.7
2006	6,529	2,661	71.0	5,466	1,989	73.3	11,995	4,650	72.1
2007	8,335	3,653	69.5	6,563	2,822	69.9	14,898	6,475	69.7
Total 2000–2007	**41,570**	**28,616**	**59.2**	**34,538**	**23,719**	**59.3**	**76,108**	**52,335**	**59.3**

(a) Coverage rate = (Number on NDR/[Number on NDR + Number not on NDR]) x100.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).

Profile of registrants

Age and sex

The age and sex distribution of the total number of new cases of insulin-treated Type 2 diabetes between 2000 and 2007 is shown in Table 5.2 (see Table C5.1 for more detail by individual year of first insulin use).

- Over the 8-year period from 2000 to 2007, it is estimated that there were nearly 130,000 new cases of insulin-treated Type 2 diabetes. The largest increase over this period occurred between 2006 and 2007, when the number of new cases of insulin-treated Type 2 diabetes rose by 28% from 16,645 to 21,373 (Table C5.1). This increase could be due to an actual increase in the underlying incidence of insulin-treated Type 2 diabetes, or to an increase in the number of people with insulin-treated Type 2 diabetes registering with the NDSS, or a combination of both.
- Most (87%) of the new cases of insulin-treated Type 2 diabetes occurred in people aged 45 years and over at their first insulin use, with the highest number occurring in the 55–64 year age group (34,035).
- Among those aged less than 45 years, 57% of new cases occurred in females. In contrast, among people aged 45 years and over, most (56%) new cases occurred in males.
- There were 156 reported cases of insulin-treated Type 2 diabetes in 0–14 year olds and 896 cases among 15–24 year olds between 2000 and 2007. Recent evidence indicates that people are developing Type 2 diabetes at younger ages (Berry et al. 2006; Rosenbloom et al. 2008; Craig et al. 2007). Due to data quality issues, particularly the possibility of misclassification of diabetes type, these statistics for children with insulin-treated Type 2 diabetes may be overestimated.

Table 5.2: New cases of insulin-treated Type 2 diabetes: sex and age, by year of first insulin use 2000–2007

Age at first insulin use (years)	Males		Females		Persons	
	Number	Per cent	Number	Per cent	Number	Per cent
0–14[(a)]	69	0.1	87	0.1	156	0.1
15–24	311	0.4	585	1.0	896	0.7
25–34	1,540	2.2	3,301	5.7	4,841	3.8
35–44	5,172	7.4	5,371	9.2	10,543	8.2
45–54	13,044	18.6	9,703	16.7	22,747	17.7
55–64	20,291	28.9	13,744	23.6	34,035	26.5
65–74	17,925	25.5	13,509	23.2	31,434	24.5
75–84	10,162	14.5	9,489	16.3	19,651	15.3
85+	1,672	2.4	2,468	4.2	4,140	3.2
Total	**70,186**	**100.0**	**58,257**	**100.0**	**128,443**	**100.0**

(a) It is possible that some of these cases have been misclassified as Type 2 when they are in fact Type 1 or other (for example, secondary) types of diabetes.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).

Geographical location

For the 3-year period from 2005 to 2007, of the new cases of insulin-treated Type 2 diabetes, 65% lived in *Major cities*, 22% in *Inner regional* areas, 11% in *Outer regional* areas, and 3% in *Remote/Very remote* areas (Table 5.3).

Table 5.3: Number of new cases of insulin-treated Type 2 diabetes: age at first insulin use, by geographic location[(a)] based on postcode of current residence, 2005–2007

Age (years)	Major cities	Inner regional	Outer regional	Remote/Very remote	Australia[(b)]
0–14[(c)]	48	8	3	8	68
15–24	236	89	54	34	413
25–34	1,332	349	173	108	1,968
35–44	2,870	856	490	190	4,408
45–54	5,929	1,952	1,108	380	9,372
55–64	9,303	3,276	1,656	389	14,639
65–74	8,288	2,959	1,477	232	12,976
75–84	5,934	1,931	756	111	8,753
85+	1,396	467	165	18	2,056
Total	**35,335**	**11,888**	**5,883**	**1,469**	**54,653**
Per cent	**64.7**	**21.8**	**10.8**	**2.7**	**100.0**

(a) Registrants are classified to geographic locations according to the Australian Standard Geographic Classification (ASGC) Remoteness Areas Classification 2006 based on postcode of current residence—see Appendix B.9.

(b) Includes 78 people for whom geographic location could not be derived, so sub-components do not add to total.

(c) It is possible that some of these cases have been misclassified as Type 2 when they are in fact Type 1 or other (for example, secondary) types of diabetes.

Note: Columns and rows may not add to totals due to rounding.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).

Indigenous Australians

Over the period from 2005 to 2007, 2.6% of the new cases of insulin-treated Type 2 diabetes occurred in people who were reported as being of Aboriginal and/or Torres Strait Islander origin (Table 5.4). The proportion of new cases occurring in Indigenous Australians varied by state and territory, with the highest proportion in the Northern Territory (35%) followed by Queensland and Western Australia (both 6%).

Overall, Indigenous status was not known for one in every 20 new cases (5%) but this also varied considerably by state and territory from 2% in the Northern Territory to 13% in Tasmania.

It should be noted that the number of new cases does not reflect the much higher prevalence of Type 2 diabetes in Indigenous Australians compared with other Australians (AHMAC 2008). For more information on possible reasons why the NDR may underestimate the number of Aboriginal and Torres Strait Islander registrants see Appendix B.11.

Table 5.4: New cases of insulin-treated Type 2 diabetes: Indigenous status, by state and territory of current residence, 2005–2007

Indigenous status	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia[(a)]
					Number				
Indigenous	297	36	619	223	71	16	6	129	1,397
Non-Indigenous	19,755	11,157	9,586	3,443	4,420	1,243	550	233	50,452
Not stated	603	1,413	271	160	134	182	30	7	2,804
Total persons	**20,655**	**12,606**	**10,476**	**3,826**	**4,625**	**1,441**	**586**	**369**	**54,653**
					Per cent				
Indigenous	1.4	0.3	5.9	5.8	1.5	1.1	1.0	35.0	2.6
Non-Indigenous	95.6	88.5	91.5	90.0	95.6	86.3	93.9	63.1	92.3
Not stated	2.9	11.2	2.6	4.2	2.9	12.6	5.1	1.9	5.1
Total persons	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Includes 69 people for whom state of current residence was not reported, so sub-components do not add to total.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).

Incidence

Over the 8-year period from 2000 to 2007, the average annual age-adjusted rate of new cases of insulin-treated Type 2 diabetes was 78.2 per 100,000 population (Table 5.5). Males had a significantly higher average rate (89.0 per 100,000) than females (68.4), although there was marked variation with age.

Between 2000 and 2004, the age-standardised rate of new cases of insulin-treated Type 2 diabetes increased from 69.3 to 85.4 per 100,000, then fell to 76.9 in 2006 before rising again to 96.2 in 2007 (Table 5.5). These patterns are influenced by: trends in the underlying incidence of Type 2 diabetes; the likelihood of insulin use for treating people with Type 2 diabetes; and the likelihood of people registering with the NDSS. There was no difference in the trend by sex; however, the age-standardised rate was significantly higher in males than females in each year (Figure 5.1).

Table 5.5: New cases of insulin-treated Type 2 diabetes: sex and age, by year of first insulin use, 2000–2007

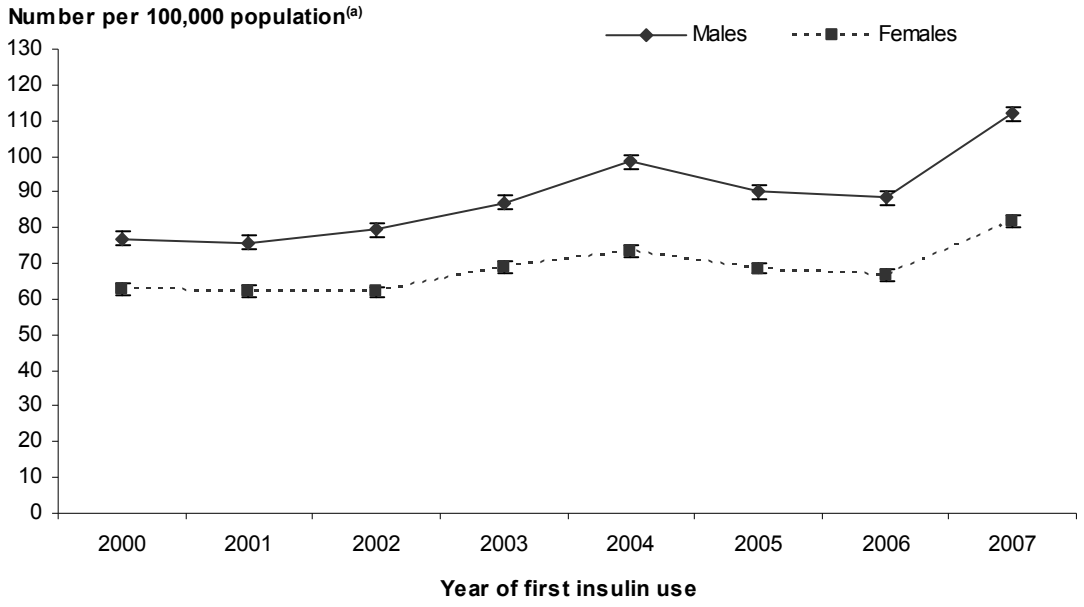
Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000 –2007[a]
					Number per 100 100,000 population				
Males									
0–14[b]	0.3	0.6	0.2	0.3	0.6	0.6	0.3	0.4	0.4
15–24	2.5	2.0	2.0	2.4	2.3	3.2	4.5	3.0	2.7
25–34	10.8	11.1	11.7	12.7	14.7	14.2	15.1	16.5	13.4
35–44	35.6	39.2	39.2	41.7	46.9	43.3	44.1	55.3	43.2
45–54	108.4	102.4	108.6	120.2	129.2	118.6	114.2	149.7	119.3
55–64	216.8	209.7	225.6	232.9	276.3	239.1	236.0	310.8	245.5
65–74	303.5	282.4	299.9	342.6	384.0	335.2	327.4	412.9	337.2
75–84	260.8	280.4	272.4	318.2	351.4	350.7	334.7	424.9	327.6
85+	158.7	185.5	203.9	192.2	241.6	249.3	268.3	276.7	226.6
Males ASR[c]	*77.0*	*75.8*	*79.3*	*87.1*	*98.5*	*89.9*	*88.4*	*111.9*	*89.0*
(95% CI)	*(75.2–78.8)*	*(74.1–77.6)*	*(77.5–81.1)*	*(85.2–89.0)*	*(96.6–100.5)*	*(88.1–91.8)*	*(86.5–90.2)*	*(109.9–113.9)*	*(88.4–89.7)*
Females									
0–14[b]	0.3	0.3	0.5	0.6	0.7	0.5	0.8	0.9	0.6
15–24	5.8	4.8	4.2	4.2	5.9	6.3	6.2	5.6	5.4
25–34	27.7	27.2	26.0	27.2	30.2	29.1	32.1	28.6	28.5
35–44	38.7	40.3	38.7	44.7	46.1	48.0	44.3	53.1	44.3
45–54	80.3	80.3	83.2	89.1	94.9	85.9	83.7	104.0	87.9
55–64	164.9	158.0	158.4	168.4	187.5	157.7	151.2	197.1	168.4
65–74	225.9	229.7	214.3	245.7	245.9	239.4	230.3	288.9	240.5
75–84	185.5	185.1	201.5	234.3	256.3	236.3	228.9	296.0	229.2
85+	119.3	115.6	125.7	140.8	158.9	173.4	182.3	202.5	154.8
Females ASR[c]	*62.6*	*62.2*	*62.0*	*68.7*	*73.5*	*68.5*	*66.6*	*81.7*	*68.4*
(95% CI)	*(61.0–64.2)*	*(60.6–63.7)*	*(60.4–63.5)*	*(67.1–70.3)*	*(71.9–75.1)*	*(67.0–70.1)*	*(65.1–68.2)*	*(80.0–83.4)*	*(67.9–69.0)*
Persons									
0–14[b]	0.3	0.5	0.4	0.5	0.6	0.5	0.5	0.6	0.5
15–24	4.1	3.4	3.1	3.3	4.1	4.7	5.3	4.2	4.0
25–34	19.3	19.2	18.9	20.0	22.4	21.7	23.6	22.5	20.9
35–44	37.2	39.8	38.9	43.2	46.5	45.6	44.2	54.2	43.8
45–54	94.4	91.3	95.8	104.6	111.9	102.1	98.8	126.6	103.5
55–64	191.2	184.2	192.3	200.9	232.2	198.6	193.6	253.9	207.2
65–74	263.3	255.2	255.8	292.8	313.1	286.1	277.7	349.6	287.5
75–84	216.7	225.0	231.4	270.1	297.2	285.9	275.2	352.8	271.4
85+	131.4	137.2	150.0	156.8	184.9	197.6	210.2	227.0	177.5
Persons ASR[c] (95% CI)	**69.3 (68.2–70.5)**	**68.4 (67.3–69.6)**	**70.1 (69.0–71.3)**	**77.4 (76.2–78.7)**	**85.4 (84.1–86.6)**	**78.6 (77.4–79.8)**	**76.9 (75.7–78.1)**	**96.2 (94.9–97.5)**	**78.2 (77.7–78.6)**

(a) The rate for 2000–2007 is the average annual rate for the 8 years.

(b) It is possible that some of these cases of reported Type 2 diabetes among children aged 0–14 years have been misclassified as Type 2 when they are in fact Type 1 or other (for example, secondary) types of diabetes.

(c) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).



(a) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Figure 5.1: Rate of new cases of insulin-treated Type 2 diabetes, by sex, 2000–2007

5.2 Insulin-treated gestational diabetes mellitus

Coverage

The coverage rate of new cases of insulin-treated gestational diabetes on the NDR among women aged 15–49 years has improved markedly since 2000, from 67% to 95% in 2007 (Table 5.6).

Table 5.6: NDR coverage rates for NDR-eligible NDSS registrants with insulin-treated gestational diabetes mellitus: women aged 15–49 years, 2000–2007

Year of first insulin use	NDR registrants	Missing cases	Coverage rate[(a)] (per cent)
2000	563	281	66.7
2001	695	390	64.1
2002	1,027	384	72.8
2003	900	340	72.6
2004	1,617	245	86.8
2005	2,659	238	91.8
2006	3,426	148	95.9
2007	4,775	234	95.3
Total 2000–2007	**15,662**	**2,260**	**87.4**

(a) Coverage rate = (Number on NDR/[Number on NDR + Number not on NDR]) x100.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).

Profile of registrants aged 15–49 years

Age

The total number of new cases of insulin-treated gestational diabetes among women aged 15–49 years between 2000 and 2007 is shown in Table 5.7 (see Table C5.2 for more detail by individual year of first insulin use).

- There were nearly 18,000 new cases of insulin-treated gestational diabetes between 2000 and 2007. The largest increase in the number of new cases over this period occurred between 2006 and 2007, when the number of new cases of insulin-treated gestational diabetes increased by 40% from 3,574 to 5,009 (Table C5.2). This increase could be due to: an actual increase in the underlying incidence of gestational diabetes; an increase in the use of insulin among women with gestational diabetes; an increase in the number of women with insulin-treated gestational diabetes registering with the NDSS; an increase in the rate of screening for gestational diabetes; or a combination of all.
- As gestational diabetes occurs during pregnancy, 85% of females with insulin-treated gestational diabetes were between the ages of 25 and 39 years at their first use of insulin (15,219 new cases).

Table 5.7: New cases of insulin-treated gestational diabetes mellitus among women aged 15–49 years, 2000–2007

Age at first insulin use (years)	Number	Per cent
15–19	132	0.7
20–24	1,080	6.0
25–29	3,763	21.0
30–34	6,432	35.9
35–39	5,024	28.0
40–44	1,382	7.7
45–49	109	0.6
Total	**17,922**	**100.0**

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).

Geographical location

Among the new cases of insulin-treated gestational diabetes between 2005 and 2007, 82% lived in *Major cities*, 12.5% in *Inner regional* areas, 4% in *Outer regional* areas, and 1% in *Remote/Very remote* areas (Table 5.8).

Table 5.8: Number of new cases of insulin-treated gestational diabetes mellitus among women aged 15–49 years: age at first insulin use, by geographic location[(a)] based on postcode of current residence, 2005–2007

Age at first insulin use (years)	Major cities	Inner regional	Outer regional	Remote/ Very remote	Australia[(b)]
15–19	47	22	5	5	79
20–29	2,384	411	157	32	2,988
30–39	6,193	888	298	57	7,436
40–49	824	115	30	8	977
Total	**9,447**	**1,435**	**490**	**102**	**11,480**
Per cent	**82.3**	**12.5**	**4.3**	**0.9**	**100.0**

(a) Registrants are classified to geographic locations according to the Australian Standard Geographic Classification (ASGC) Remoteness Areas Classification 2006 based on postcode of current residence—see Appendix B.9.

(b) Includes 5 women for whom geographic location could not be derived, so sub-components do not add to total.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).

Indigenous Australians

Over the period from 2005 to 2007, 2% of the new cases of insulin-treated gestational diabetes among women aged 15–49 years occurred in women who were reported as being of Aboriginal and/or Torres Strait Islander origin (Table 5.9).

Indigenous status was not known for one in every 10 new cases. Further, there was considerable variation by state and territory in the proportion of new cases where Indigenous status was not known (from 4% in Queensland to 43% in Tasmania). The proportion of registrants with 'not-stated' Indigenous status in most jurisdictions makes detailed comparisons problematic.

Table 5.9: New cases of insulin-treated gestational diabetes mellitus among women aged 15–49 years: Indigenous status, by state and territory of current residence, 2005–2007

Indigenous status	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia[(a)]
					Number				
Indigenous	78	10	101	22	13	3	2	23	252
Non-Indigenous	4,332	2,784	1,814	265	589	97	164	34	10,084
Not stated	260	587	71	52	58	75	38	3	1,144
Total persons	**4,670**	**3,381**	**1,986**	**339**	**660**	**175**	**204**	**60**	**11,480**
					Per cent				
Indigenous	1.7	0.3	5.1	6.5	2.0	1.7	1.0	38.3	2.2
Non-Indigenous	92.8	82.3	91.3	78.2	89.2	55.4	80.4	56.7	87.8
Not stated	5.6	17.4	3.6	15.3	8.8	42.9	18.6	5.0	10.0
Total persons	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Includes 5 women for whom state of current residence was not reported, so sub-components do not add to total.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).

Incidence

Over the 8-year period from 2000 to 2007, the average annual age-adjusted rate of new cases of insulin-treated gestational diabetes among women aged 15–49 years was 44.8 per 100,000 population. The age-standardised rate increased significantly between 2000 and 2007, from 17.1 to 98.0 per 100,000, a 6-fold increase, equating to an average annual increase of 28% per year (Figure 5.2; Table 5.10).

The NDR is not the only data source to show an increase in the incidence of gestational diabetes in recent years. Templeton & Pieris-Caldwell (2008) reported a 20% increase in the incidence rate of hospital confinements for women of child-bearing age with gestational diabetes between 2000–01 and 2005–06.

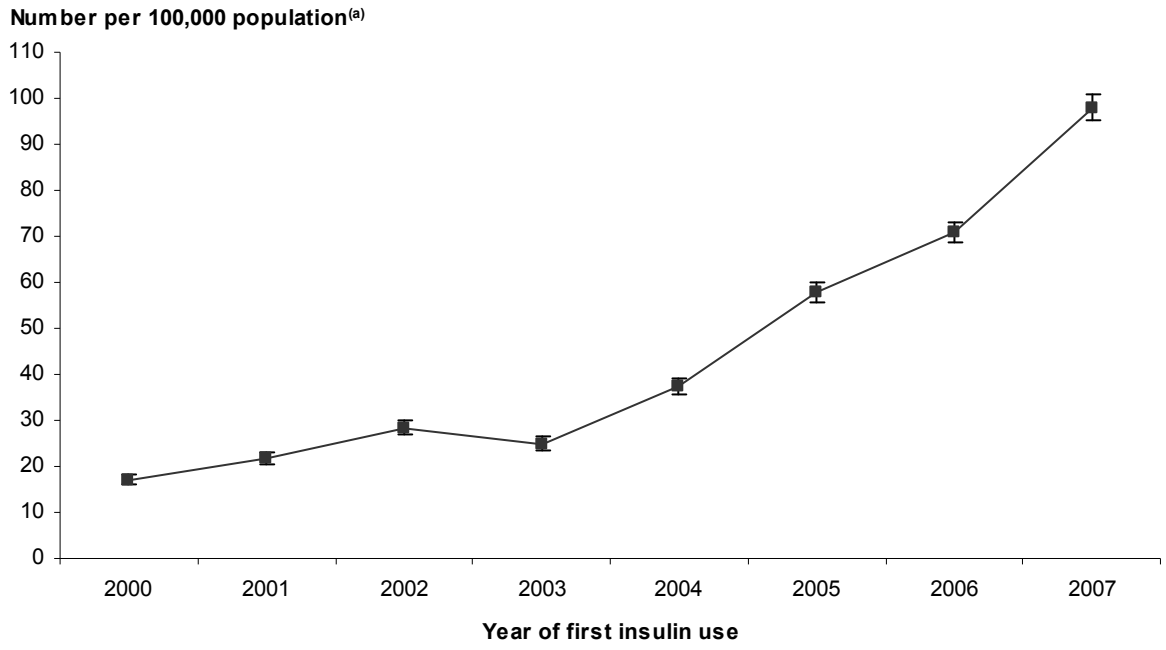
Table 5.10: Number of new cases of insulin-treated gestational diabetes mellitus among women aged 15–49 years: age, by year of first insulin use, 2000–2007

Age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000 –2007[(a)]
					Number per 100,000 population				
15–19	1.2	1.7	1.6	1.8	1.6	3.1	4.4	4.0	2.4
20–24	8.8	10.4	13.0	11.3	16.3	24.5	28.1	41.8	19.8
25–29	27.8	40.5	49.1	38.7	54.7	84.0	103.4	140.4	67.5
30–34	44.8	52.7	67.7	54.6	91.4	137.3	172.0	236.6	107.2
35–39	25.8	34.8	46.8	49.4	68.6	114.9	133.5	185.9	83.4
40–44	7.8	8.9	13.7	13.2	19.4	26.5	37.8	52.7	22.7
45–49	0.6	0.6	1.7	0.6	1.4	2.7	2.4	4.8	1.9
Total 15–49 ASR[(b)] (95% CI)	**17.1 (16.0–18.3)**	**21.9 (20.6–23.2)**	**28.4 (26.9–29.9)**	**24.9 (23.5–26.3)**	**37.3 (35.6–39.0)**	**57.8 (55.7–60.0)**	**70.9 (68.6–73.2)**	**98.0 (95.3–100.8)**	**44.8 (44.1–45.5)**

(a) The rate for 2000–2007 is the average annual rate for the 8 years.

(b) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).



(a) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Figure 5.2: Rate of new cases of insulin-treated gestational diabetes mellitus among women aged 15–49 years, 2000–2007

5.3 Other types of insulin-treated diabetes

Coverage

The coverage rate of new cases of other types of insulin-treated on the NDR improved from 71% in 2000 to 96% in 2006, but then fell to 89% in 2007 (Table 5.11).

Table 5.11: NDR coverage rates for NDR-eligible NDSS registrants with insulin-treated other diabetes, 2000–2007

	Males			Females			Persons		
Year of first insulin use	Number on NDR	Number not on NDR	Coverage rate[(a)] (per cent)	Number on NDR	Number not on NDR	Coverage rate[(a)] (per cent)	Number on NDR	Number not on NDR	Coverage rate[(a)] (per cent)
2000	52	25	67.5	49	17	74.2	101	42	70.6
2001	86	34	71.7	69	16	81.2	155	50	75.6
2002	66	23	74.2	47	18	72.3	113	41	73.4
2003	59	19	75.6	40	19	67.8	99	38	72.3
2004	68	13	84.0	54	14	79.4	122	27	81.9
2005	82	11	88.2	64	13	83.1	146	24	85.9
2006	111	4	96.5	89	4	95.7	200	8	96.2
2007	116	12	90.6	79	12	86.8	195	24	89.0
Total 2000–2007	**640**	**141**	**81.9**	**491**	**113**	**81.3**	**1,131**	**254**	**81.7**

(a) Coverage rate = (Number on NDR/[Number on NDR + Number not on NDR]) x100.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).

Profile of registrants

Over the 8-year period from 2000 to 2007, there were nearly 1,400 new cases of other types of insulin-treated diabetes in Australia (Table 5.12). The relatively small number of other types of insulin-treated diabetes makes it difficult to look at the incidence of new cases by time, age and sex. However, around 20% of the new cases of other types of insulin-treated diabetes occurred in people aged less than 25 years; 41% in people aged 25–54 years; 32% in people aged 55–74 years; and 8% in people aged 75 years and over. There were proportionately more new cases of other types of insulin-treated diabetes in males (56.4%) than females. It is possible that type of diabetes was not known at the time of diagnosis or was misclassified as 'other' for some of these cases, particularly among children.

The average annual age-adjusted rate of new cases of other types of insulin-treated diabetes over 2000–2007 was 0.9 per 100,000 population (Table C5.3). Males had a significantly higher average rate (1.0 per 100,000) than females (0.7).

Between 2000 and 2007, the age-standardised rate of new cases of other types of insulin-treated diabetes increased slightly from 0.8 to 1.0 per 100,000 population but this increase was not statistically significant (Table C5.4).

Table 5.12: New cases of insulin-treated other diabetes: sex and age, by year of first insulin use 2000–2007

Age at first insulin use (years)	Males		Females		Persons	
	Number	Per cent	Number	Per cent	Number	Per cent
0–14[(a)]	58	7.4	77	12.7	135	9.7
15–24	65	8.3	72	11.9	137	9.9
25–34	78	10.0	78	12.9	156	11.3
35–44	92	11.8	68	11.3	160	11.6
45–54	162	20.7	88	14.6	250	18.1
55–64	162	20.7	92	15.2	254	18.3
65–74	103	13.2	80	13.2	183	13.2
75–84	54	6.9	33	5.5	87	6.3
85+	7	0.9	16	2.6	23	1.7
Total	**781**	**100.0**	**604**	**100.0**	**1,385**	**100.0**

(a) It is possible that some of these cases of reported other diabetes among children aged 0–14 years have been misclassified as other when they are in fact Type 1 diabetes.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS (data extracted December 2008).

6 Mortality

At the time of publishing this report, cause of death data for 2007 were not available, so this chapter only looks at deaths occurring between 2000 and 2006 in NDR registrants who began using insulin over this period.

6.1 Number of deaths

All NDR records for people who began using insulin between 2000 and 2006 were matched against the AIHW National Death Index. Of the 88,085 NDR registrants who began using insulin during the period, 8,953 (10%) were identified as having died (Table 6.1).

Almost 95% of deaths occurred in registrants aged 50 years and over, suggesting that the majority of deaths were for people with insulin-treated Type 2 diabetes. There were 12 deaths in registrants aged 0–14 years and 162 deaths in registrants aged 15–39 years, 0.1% and 1.8% of all registrant deaths, respectively. Sixty per cent of deaths occurred in males.

When interpreting the mortality statistics in this chapter it is important to note that in the early years of the NDR, the overall proportion of NDSS registrants consenting to be on the NDR was low (see AIHW 2006 for more details), so the number of deaths in people with insulin-treated diabetes is likely to be higher than shown here.

Table 6.1: NDR registrants[(a)]: deaths, 2000–2006

Age at death (years)	Males		Females		Persons	
	Number	Per cent	Number	Per cent	Number	Per cent
0–14	7	0.1	5	0.1	12	0.1
15–19	7	0.1	12	0.3	19	0.2
20–24	15	0.3	10	0.3	25	0.3
25–29	10	0.2	10	0.3	20	0.2
30–34	26	0.5	9	0.2	35	0.4
35–39	38	0.7	25	0.7	63	0.7
40–44	58	1.1	47	1.3	105	1.2
45–49	140	2.6	83	2.3	223	2.5
50–54	260	4.9	142	3.9	402	4.5
55–59	434	8.2	195	5.4	629	7.0
60–64	555	10.4	284	7.8	839	9.4
65–69	672	12.6	369	10.2	1,041	11.6
70–74	843	15.8	461	12.7	1,304	14.6
75–79	920	17.3	628	17.3	1,548	17.3
80+	1,335	25.1	1,353	37.2	2,688	30.0
Total	**5,320**	**100.0**	**3,633**	**100.0**	**8,953**	**100.0**

(a) Year of first insulin use 2000–2006.

Source: National Diabetes Register (data extracted December 2008).

6.2 Cause of death

Death certificate data provide an underlying cause of death and up to 20 associated causes for each death. The underlying cause is the primary disease or injury causing the death, and associated causes are all other conditions, diseases or injuries that are considered to have contributed to the death. Causes of death are classified according to the International Statistical Classification of Diseases and Related Health Problems ICD–10 (WHO 1992).

Diabetes, which is a specific disease group that forms part of the broad level group of all endocrine, nutritional and metabolic diseases, was the underlying cause of death (that is, the primary cause) recorded on the death certificate for 13.6% of deaths in NDR registrants between 2000 and 2006. Deceased female registrants were more likely than their male counterparts to have diabetes recorded as the underlying cause of death (15% compared with 12%) (Table 6.2).

Other features of the underlying cause of death data for NDR registrants (people with insulin-treated diabetes only who began using insulin between 2000 and 2006) who died in 2000–2006 were as follows (Table 6.2):

- At the broad group level, neoplasms—including cancers and benign tumours—were the most common underlying cause of death, accounting for just over a third of all deaths in NDR registrants (36%). They accounted for a higher proportion of male deaths (39%) than female deaths (32%). This was followed by diseases of the circulatory system, which accounted for 29% of all deaths in NDR registrants.
- At the specific group level, ischaemic heart disease (also known as coronary heart disease) was the most commonly recorded cause of death, accounting for 18% of all deaths. This was followed by cancer of the pancreas, causing 7.5% of all deaths. Note that diabetes commonly occurs in people with cancer of the pancreas.
- A higher proportion of males died from cancer of the bronchus and lung (6.5%) than females (3%).
- A slightly higher proportion of females died from diseases of the circulatory system (30%) than males (27.5%).

Comparisons between mortality rates for the NDR population compared with those for the whole Australian population were made using standardised mortality ratios (SMRs), which use indirect standardisation to account for any differences in the age structure between the two populations (see Appendix B.5 for more information). An SMR of 1.0 means that there is no difference in the death rate between NDR registrants and the Australian population.

NDR registrants who died between 2000 and 2006 died at a significantly higher rate than expected based on the death rates of the Australian population over the same period. For deaths from all causes, there were 3 times as many deaths as expected among both males and females on the NDR (Table 6.2). Not surprisingly, deaths from diabetes occurred at a rate that was more than 14 times as high as the rate in the general population. Deaths from cancer of the pancreas was 14 times as high, though it is likely that a fair proportion of these diabetes cases are secondary to the pancreatic cancer. Ischaemic heart disease is a major complication of diabetes, reflected in the SMR of 3 in this population group.

Note that it is not possible to directly compare the SMR for males with those for females because different standard populations have been used (see Appendix B.5 for information about the method used to calculate the SMRs).

Table 6.2: NDR registrants[(a)]: underlying causes of death and standardised mortality ratios (SMRs)[(b)], 2000–2006

Underlying cause of death	Males			Females			Persons		
	No.	Per cent	SMR[(b)] (95% CI)	No.	Per cent	SMR[(b)] (95% CI)	No.	Per cent	SMR[(b)] (95% CI)
All endocrine, nutritional and metabolic diseases	701	13.2	10.23 (9.49–11.02)	596	16.4	12.14 (11.19–13.16)	1,297	14.5	11.03 (10.44–11.65)
Diabetes mellitus	660	12.4	12.83 (11.87–13.85)	556	15.3	16.07 (14.76–17.47)	1,216	13.6	14.13 (13.35–14.95)
Neoplasms	2,067	38.8	3.31 (3.17–3.46)	1,176	32.4	3.42 (3.23–3.62)	3,243	36.2	3.35 (3.24–3.47)
Cancer of the pancreas	383	7.2	13.52 (12.20–14.95)	284	7.8	13.71 (12.17–15.40)	667	7.5	13.60 (12.59–14.68)
Cancer of the bronchus and lung	347	6.5	2.50 (2.25–2.78)	112	3.1	2.05 (1.69–2.47)	459	5.1	2.38 (2.16–2.60)
Diseases of the circulatory system	1,462	27.5	2.35 (2.23–2.48)	1,102	30.3	2.33 (2.19–2.47)	2,564	28.6	2.34 (2.25–2.44)
Ischaemic heart disease	966	18.2	2.71 (2.54–2.88)	630	17.3	2.87 (2.65–3.11)	1,596	17.8	2.77 (2.64–2.91)
Cerebrovascular diseases	217	4.1	1.65 (1.44–1.89)	223	6.1	1.64 (1.44–1.88)	440	4.9	1.65 (1.50–1.81)
Diseases of the respiratory system	344	6.5	2.06 (1.85–2.29)	238	6.5	2.26 (1.98–2.57)	582	6.5	2.14 (1.97–2.32)
All other diseases	746	14.0	2.34 (2.18–2.52)	521	14.3	2.02 (1.85–2.20)	1,267	14.2	2.20 (2.08–2.32)
All causes	**5,320**	**100.0**	**2.96 (2.88–3.04)**	**3,633**	**100.0**	**2.96 (2.86–3.05)**	**8,953**	**100.0**	**2.96 (2.90–3.02)**

(a) Year of first insulin use 2000–2006.

(b) Standardised mortality ratio (SMR) comparing the observed number of deaths among NDR registrants with the number expected based on death rates in the Australian population—see Appendix B.5.

Source: National Diabetes Register (data extracted December 2008).

6.3 Diabetes on the death certificate

Diabetes has been shown to be under-reported on death certificates (Whittall et al. 1990). Further, when it is recorded on the death certificate, diabetes is often not recorded as the underlying cause of death. This is due to a variety of issues including: diabetes often causes death indirectly because it is a strong risk factor for common causes of death such as heart and other circulatory diseases (AIHW: Dixon & Webbie 2005); many people have other chronic diseases in addition to diabetes, so selecting a single underlying cause of death for these people may be difficult (AIHW: Mathur et al. 2000; AIHW 2008a).

Just under half (48.8%) of the deceased NDR registrants—people known to have diabetes—who died between 2000 and 2006 had diabetes listed on their death certificate (Table 6.3). This is slightly lower than the proportion reported for the period 1999–2005 (49.7%) (AIHW: Catanzarti et al. 2007). A higher proportion of females than males had diabetes listed on their death certificate, 50% compared with 48%. It is not expected that 100% of these death certificates would mention diabetes because for some, causes of death diabetes would make

no contribution. However, less than half seems low, particularly as the broad group 'diseases of the circulatory system'—a group with a strong link to diabetes—also had low rates of diabetes on death certificates. This makes it difficult to assess the full contribution of diabetes to death rates based solely on the death certificate data.

At the broad group level, diabetes was listed on the death certificate in: 97% of deaths with an underlying cause of 'all endocrine, nutritional and metabolic diseases'; 54% of deaths with an underlying cause of 'diseases of the circulatory system'; 47% of deaths with an underlying cause of 'diseases of the respiratory system'; 30% of deaths with an underlying cause of 'neoplasms', which includes malignant (cancers) and benign tumours.

Table 6.3: NDR registrants[(a)]: underlying causes of death[(b)] and proportion with diabetes listed on the death certificate, 2000–2006

	Males			Females			Persons		
Underlying cause of death	**No.**	**Per cent**	**Percentage with diabetes on death certificate**	**No.**	**Per cent**	**Percentage with diabetes on death certificate**	**No.**	**Per cent**	**Percentage with diabetes on death certificate**
All endocrine, nutritional and metabolic diseases	689	13.2	97.7	585	16.4	96.2	1,274	14.5	97.0
Diabetes mellitus	649	12.4	100.0	545	15.3	100.0	1,194	13.6	100.0
Neoplasms	2,031	38.8	30.0	1,153	32.4	29.2	3,184	36.2	29.7
Cancer of the pancreas	376	7.2	28.7	279	7.8	25.1	655	7.5	27.2
Cancer of the bronchus and lung	341	6.5	28.2	110	3.1	30.0	451	5.1	28.6
Diseases of the circulatory system	1,437	27.5	54.6	1,081	30.3	53.5	2,518	28.6	54.1
Ischaemic heart disease	949	18.2	57.6	618	17.3	55.0	1,567	17.8	56.6
Cerebrovascular diseases	213	4.1	51.6	219	6.1	52.1	432	4.9	51.9
Diseases of the respiratory system	338	6.5	45.6	233	6.5	49.8	571	6.5	47.3
All other diseases[(b)]	733	14.0	37.8	511	14.3	38.4	1,244	14.2	38.0
All causes[(b)]	**5,228**	**100.0**	**47.8**	**3,563**	**100.0**	**50.2**	**8,791**	**100.0**	**48.8**

(a) Year of first insulin use 2000–2006.

(b) Results refer only to those registrants for whom an underlying cause of death was available.

Source: National Diabetes Register (data extracted December 2008).

7 Supplementary information for researchers

This chapter provides a general description of the characteristics of the NDR population, a snapshot as at December 2007. Summary data are presented for registrants' age, sex, geographical location, socioeconomic status, diabetes type, deaths, Indigenous status, and country of birth to inform researchers of the type of information held on the register and its potential to help them in future research.

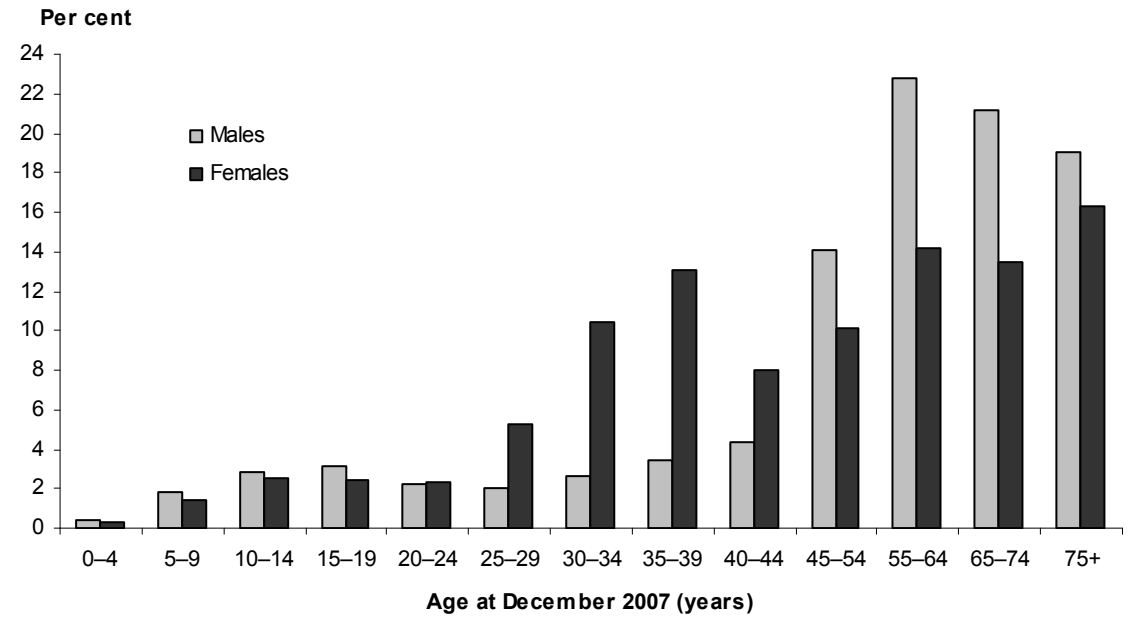
See section 7.8 for information on accessing the NDR for research purposes.

7.1 Current age and sex

The age distribution of people on the NDR shows the number of registrants increases with age, particularly after 45 years, where 65% of registrants reside (Figure 7.1; Table C7.1). In contrast, only 10% of registrants are aged less than 25 years.

Among registrants of all ages, there is a slightly higher proportion of females than males on the register, at 53% and 47% respectively; however, these proportions vary throughout the age groups. Males and females are evenly represented throughout childhood. From early adulthood up until the age of 44 years the proportion of females is much higher than males, mainly because of the effect of gestational diabetes mellitus in these age groups. Males make up a greater proportion of registrants in all age groups from 45 years of age until 75 years and over when the difference diminishes.

While the higher proportion of women with diabetes aged 20–44 years can be largely attributed to gestational diabetes, the differences between males and females are not so easily explained for those registrants aged over 45 years. However, Type 2 diabetes is more common in people aged over 45 years, and its main risk factors, overweight and obesity, affect more males than females (ABS 2006a), which may account for some of this disparity. The difference in the proportion of males to females disappears after age 75, possibly because there are more females in these older age groups owing to their longer life expectancy.



Source: National Diabetes Register (data extracted December 2008).

Figure 7.1: NDR registrants with first insulin use in 2000-2007: distribution, by current age and sex

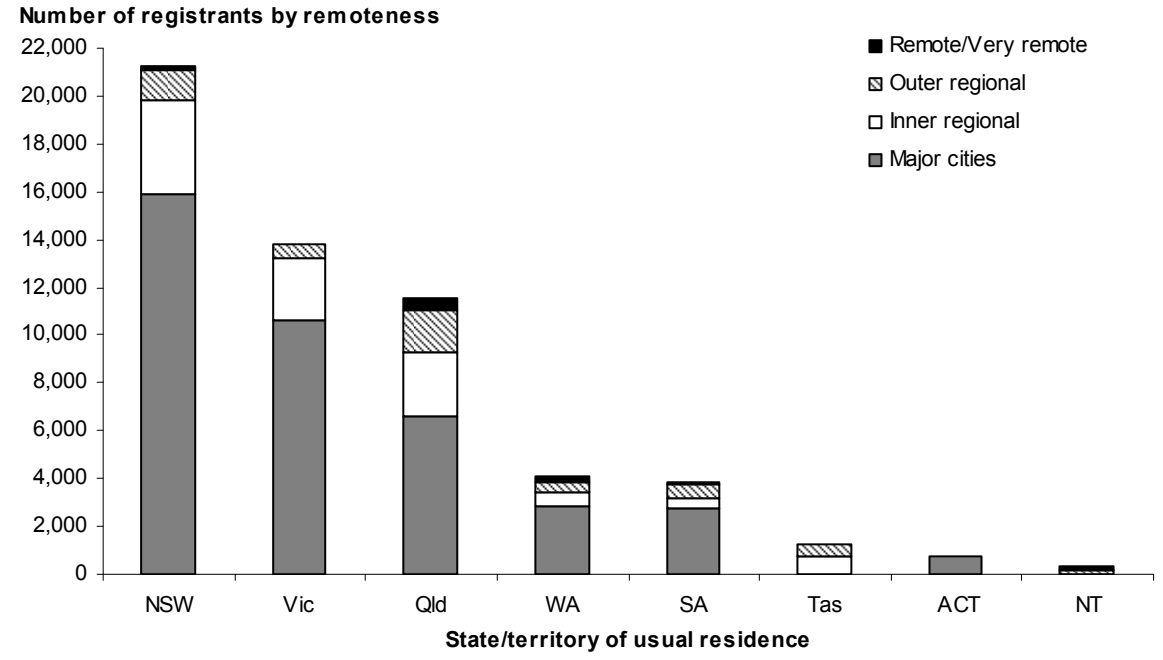
7.2 Geographical location

The distribution of registrants according to their remoteness classification varies in each jurisdiction. Results are shown in Figure 7.2 and Table C7.2, based on the ABS Australian Standard Geographic Classification (see Appendix B.9 for more information).

Nationally, two-thirds of registrants live in *Major cities* (69%), followed by *Inner regional* areas (20%), *Outer regional* (9%) and only 2% in *Remote/Very remote* areas. This general pattern is similar to the geographic distribution of the Australian population in 2005–2007, when there were 66% living in *Major cities*, 21% *Inner regional*, 10% *Outer regional*, and only 3% living in *Remote/Very remote* areas. This pattern was also the case for New South Wales, Victoria, Queensland and Western Australia. South Australia differed from these states only in that it had a slightly higher proportion of registrants in outer rather than inner regional areas (Figure 7.2; Table C7.2).

Tasmania and the Northern Territory are more difficult to compare with other jurisdictions because they do not have a *Major cities* classification and the Northern Territory has only *Outer regional* and *Remote/Very remote* classifications. However, more than half (61%) of Tasmania's registrants live in *Inner regional*, followed by *Outer regional* and *Remote/Very remote* areas. More than half of the registrants in the Northern Territory live in *Remote/Very remote* areas with the remaining in *Outer regional* regions.

The ACT has only two classifications, *Major city* and *Inner regional*, with almost all of its registrants residing in the *Major city*.



Source: National Diabetes Register (data extracted December 2008).

Figure 7.2: Number of NDR registrants: states and territories, by remoteness, 2005–2007

7.3 Socioeconomic status

In this report, socioeconomic status has been measured using the Index of Relative Socio-Economic Disadvantage (IRSD). The IRSD is one of the four Socio-Economic Indexes for Areas (SEIFAs) compiled by the Australian Bureau of Statistics (see Appendix B.10 for more information). In the data presented below, an area group comprising the fifth of the population with the greatest overall level of disadvantage is described as the 'lowest SES group' (Group 1). The group at the other end of the scale—the top fifth—is described as the 'highest SES group' (Group 5).

Overall, NDR registrants are more likely to be from lower socioeconomic groups.

During 2005–2007, the largest proportion of registrants was in Group 1, the lowest socioeconomic group, followed by registrants in Group 3 (Table 7.1).

However, there was some variation according to age. In the youngest age groups there was a fairly even spread of registrants across each socioeconomic group. Yet in the older age groups, there were more registrants from the lower socioeconomic groups.

Table 7.1: NDR registrants: age at December 2007, by socioeconomic status (SES) based on postcode of current residence[(a)], 2005–2007

Age at December 2007 (years)	Group 1 (lowest SES)	Group 2	Group 3	Group 4	Group 5 (highest SES)	Unknown	Australia
0–4	79	65	71	72	76	0	363
5–9	187	191	186	194	186	1	945
10–14	270	229	310	237	294	1	1,341
15–19	230	186	201	231	237	0	1,085
20–24	337	293	265	191	185	4	1,275
25–29	795	558	581	497	380	3	2,814
30–34	1,302	888	1,051	842	886	6	4,975
35–39	1,396	988	1,175	1,015	1,120	4	5,698
40–44	1,003	656	711	584	635	4	3,593
45–54	2,131	1,443	1,449	1,064	1,046	8	7,141
55–64	3,103	2,130	2,074	1,562	1,534	21	10,424
65–74	2,761	1,808	1,851	1,335	1,316	12	9,083
75+	2,339	1,563	1,633	1,274	1,364	8	8,181
Total	**15,933**	**10,998**	**11,558**	**9,098**	**9,259**	**72**	**56,918**

(a) Registrants are classified according to the Index of Relative Socio-Economic Disadvantage (IRSD) based on postcode of current residence (AIHW population database)—see Appendix B.10.

Source: National Diabetes Register (data extracted December 2008).

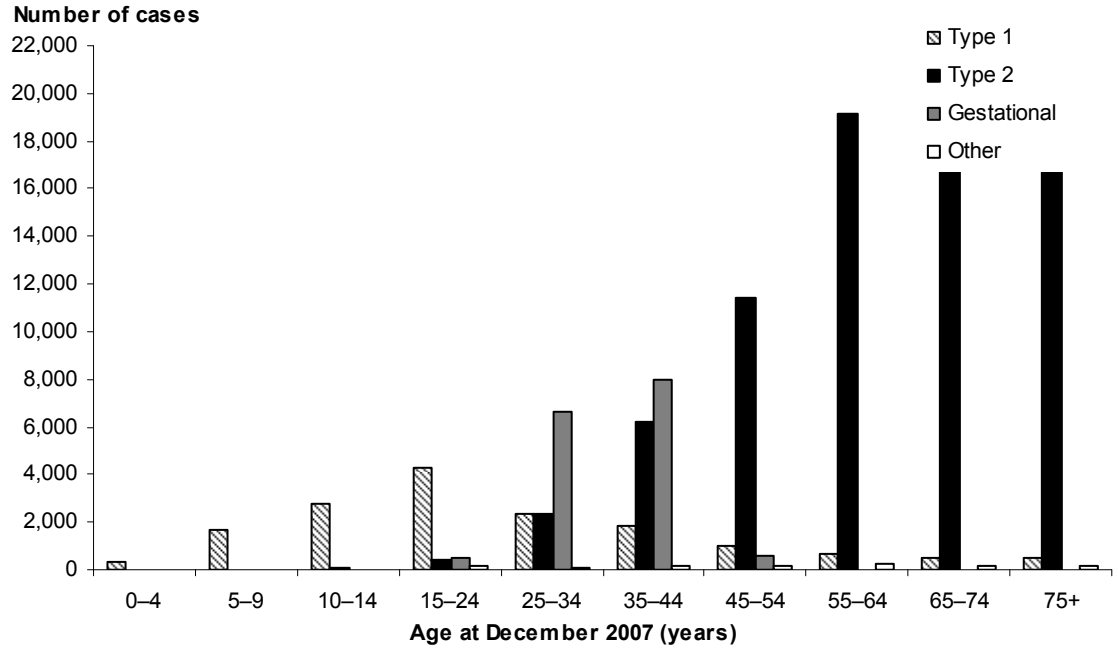
7.4 Types of diabetes

The NDR contains 110,662 records for people who began using insulin since 2000. Almost 70% of these registrants have Type 2 diabetes, 15% Type 1, 14% gestational diabetes and 1% other types of diabetes.

- For registrants with Type 1 diabetes, at 30 December 2007, 30% were aged 0–14 years, 27% were aged 15–24 years, 26% were aged 25–44 years and 17% were aged 45 years and over (Figure 7.3).
- For registrants with Type 2 diabetes, less than 1% were aged 0–14 and 15–24 years, 11% were aged 25–44, and 88% were aged 45 years and over.
- For registrants with gestational diabetes, 3% were aged 15–24 years, 93% were aged 25–44 years, and 4% were aged 45 years and over.
- Of the 1,131 registrants with other types of diabetes, 6% were aged 0–14 years, 11% were aged 15–24 years, 21% were aged 25–44 years, and 61% were aged 45 years and over.

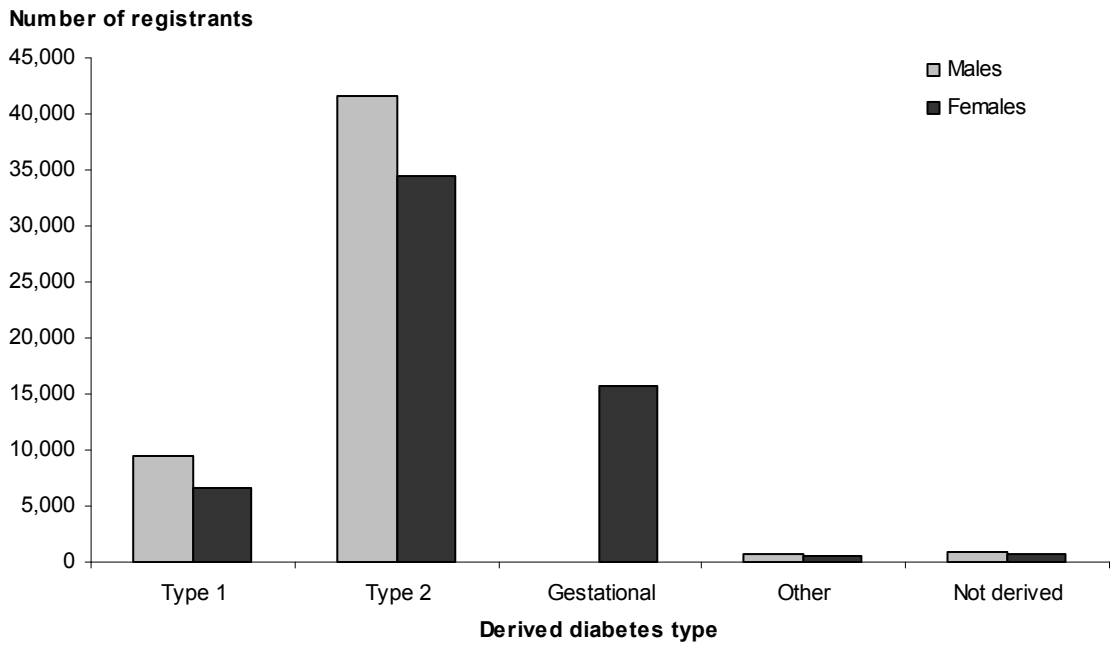
There was considerable variation in the distribution of the types of diabetes between males and females (Figure 7.4). While overall there were more females (58,163) than males (52,499) on the NDR (Table 7.2), if gestational diabetes (15,667) were excluded, males would have outnumbered females for each of the different types of diabetes.

During 2000–2007, almost 80% of male registrants had Type 2 diabetes compared with almost 60% of females (Table 7.2). Furthermore, of the 16,054 registrants with Type 1 diabetes, 58% were males.



Source: National Diabetes Register (data extracted December 2008).

Figure 7.3: NDR registrants with first insulin use in 2000–2007: derived diabetes type, by age at December 2007



Source: National Diabetes Register (data extracted December 2008).

Figure 7.4: NDR registrants: number of cases of derived diabetes type, by sex, 2000–2007

Table 7.2: NDR registrants: derived diabetes type, by sex, 2000–2007

	Males		Females		Persons	
Type of diabetes	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Type 1	9,382	17.9	6,672	11.5	16,054	14.5
Type 2	41,570	79.2	34,538	59.4	76,108	68.8
Gestational	. .	. .	15,667	26.9	15,667	14.2
Other	640	1.2	491	0.8	1,131	1.0
Not derived	907	1.7	795	1.4	1,702	1.5
Total	**52,499**	**100.0**	**58,163**	**100.0**	**110,662**	**100.0**

Source: National Diabetes Register (data extracted December 2008).

7.5 Vital status

NDR records were matched with the National Death Index to determine which registrants had died by the end of 2007 (see Appendix for details). Around 11,200 registrants, or 10%, who started using insulin between 2000 and 2007 were identified as having died as at 31 December 2007 (Table 7.3).

Proportions of deceased registrants varied among states and territories, ranging from 8% in the Australian Capital Territory to 12% in Tasmania. More detailed analyses on deaths are presented in Chapter 6.

Table 7.3: NDR registrants: vital status, by states and territories[a], 2000-2007

Vital status	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia[b]
					Number				
Alive	36,081	24,215	20,061	8,644	6,294	2,262	1,276	604	99,454
Deceased	3,813	2,976	2,179	1,048	711	302	116	59	11,208
Total	**39,894**	**27,191**	**22,240**	**9,692**	**7,005**	**2,564**	**1,392**	**663**	**110,662**
					Per cent				
Alive	90.4	89.1	90.2	89.2	89.9	88.2	91.7	91.1	89.9
Deceased	9.6	10.9	9.8	10.8	10.1	11.8	8.3	8.9	10.1
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) State/territory of current residence.

(b) Total includes records where state or territory of current residence was unknown.

Source: National Diabetes Register (data extracted December 2008).

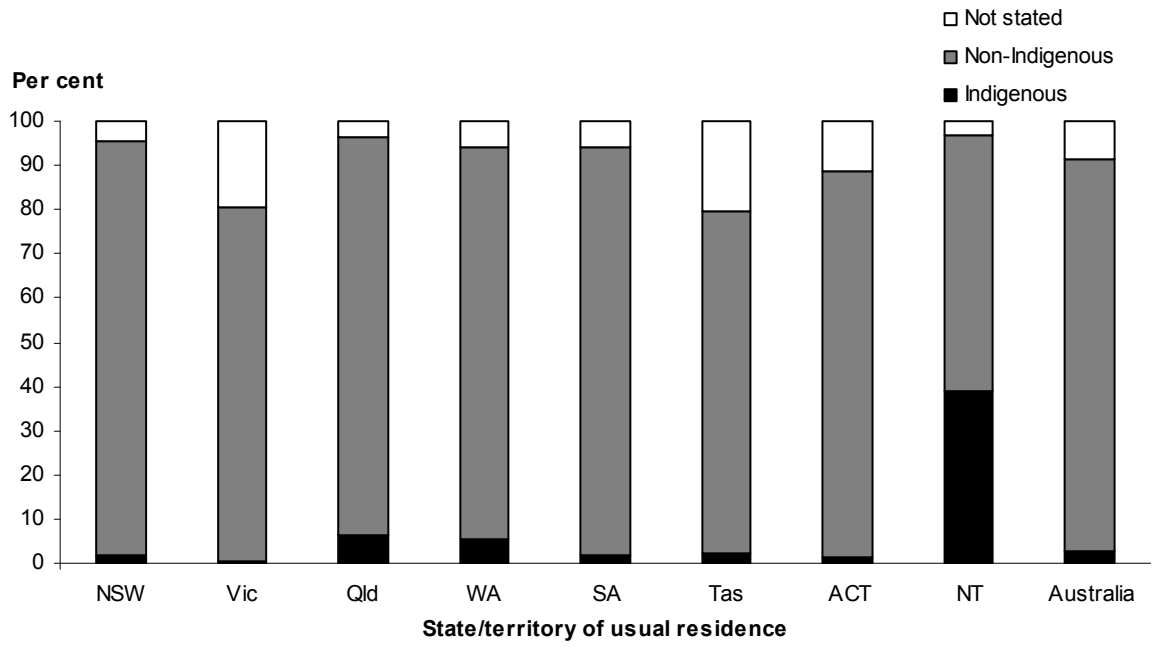
7.6 Indigenous Australians

For the period 2005–2007, 2.9% of people on the NDR were recorded as being of Aboriginal and/or Torres Strait Islander origin (Table 7.4). This percentage is slightly higher than the percentage of Aboriginal and Torres Strait Islander peoples in the Australian population, which is estimated as 2.5% in 2006 (ABS 2008).

The proportion of registrants on the NDR who recorded being Aboriginal and/or Torres Strait Islander varied between the states and territories (Figure 7.5). The Northern Territory had by far the highest proportion of registrants recorded as Indigenous (38.9%) followed by Queensland (6.3%), while Victoria had the lowest (0.4%). This largely reflects the relative proportion of the Indigenous population in those states and territories.

There was also considerable variation among states and territories in the proportion of registrants with their Indigenous status not recorded. In Tasmania and Victoria one-fifth of registrants did not have their Indigenous status recorded; in contrast, in the Northern Territory and Queensland, all but 3.1% and 3.7%, respectively, of registrants had their Indigenous status recorded. The proportion of 'not stated' from the remaining states and territories ranged between 4.7% and 11.2%.

Data on the Indigenous status of NDR registrants are presented only for 2005–2007 because of how these data were captured in the NDSS database before 2005. Also, the NDR does not reflect the much higher prevalence of diabetes (particularly Type 2) in Indigenous Australians. More information on these data issues can be found in Appendix B.11.



Source: National Diabetes Register (data extracted December 2008).

Figure 7.5: NDR registrants: Indigenous status, by states and territories, 2005–2007

Table 7.4: NDR registrants: Indigenous status, by states and territories[(a)], 2005–2007

Indigenous status	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia[(b)]
					Number				
Indigenous	401	51	727	229	79	26	11	124	1,648
Non-Indigenous	19,828	11,056	10,431	3,600	3,573	988	648	185	50,316
Not stated	1,000	2,708	423	235	228	262	83	10	4,954
Total persons	**21,229**	**13,815**	**11,581**	**4,064**	**3,880**	**1,276**	**742**	**319**	**56,918**
					Per cent				
Indigenous	1.9	0.4	6.3	5.6	2.0	2.0	1.5	38.9	2.9
Non-Indigenous	93.4	80.0	90.1	88.6	92.1	77.4	87.3	58.0	88.4
Not stated	4.7	19.6	3.7	5.8	5.9	20.5	11.2	3.1	8.7
Total persons	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) State/territory of current residence.

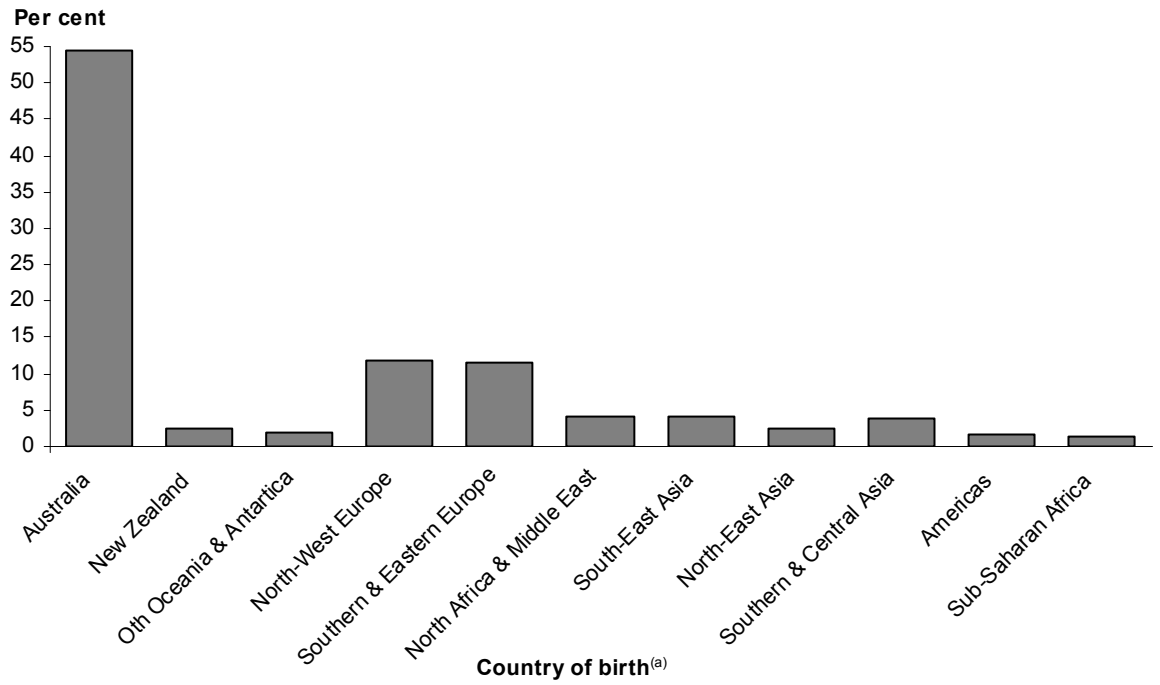
(b) Totals include records where state or territory of current residence was unknown.

Source: National Diabetes Register (data extracted December 2008).

7.7 Country of birth

Almost one-third of the 110,662 NDR registrants did not have their country of birth reported (28%; 31,356); however, of those who did 55% (79,306) were born in Australia, and 45% were born overseas (36,036) (Figure 7.6). The proportion of registrants born overseas was much higher than the proportion of the general Australian population who were born overseas, which was 25% in 2007 (ABS 2006c). Even if all the registrants in the 'not stated' category were Australian born, the proportion of overseas-born registrants on the NDR (33%) would still be greater than in the overall population.

The over-representation of overseas-born registrants on the NDR is consistent with previous findings showing higher rates of diabetes in this group than in the Australian-born population (ABS 2006b; AIHW: Holdenson et al. 2003).



Source: National Diabetes Register (data extracted December 2008).

(a) Does not include records where country of birth was unknown.

Figure 7.6: NDR registrants: country of birth, 2000–2007

7.8 Accessing the NDR for research

One of the major aims of the NDR is to provide a resource for research on diabetes. Researchers are now able to use the NDR as an important source of information for clinical and population studies of the causes, complications and patterns of diabetes.

Information on how to access the NDR for research is available on the AIHW website at <www.aihw.gov.au> or by contacting:

The Project Officer, National Diabetes Register
Cardiovascular, Diabetes and Kidney Unit
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Phone: (02) 6244 1000

Applications to access the NDR for research will be considered only if the applicant provides assurance of scientific quality, evidenced either by the project having been funded through a competitive peer-reviewed grant process or by review by independent peers acceptable to the Institute.

Before a project can proceed, approval must be obtained from the investigator's host Ethics Committee and the AIHW Ethics Committee.

Appendix

Appendix A: NDR registration

You are eligible to join the National Diabetes Register (NDR) if you started to use insulin to manage your diabetes on or after 1 January 1999. We welcome enquiries if you would like to learn more about the NDR, or if you would like to register on the NDR.

There are three ways to join the National Diabetes Register:

- Register with the National Diabetes Services Scheme, administered by Diabetes Australia Ltd. The scheme is an Australian Government initiative that provides blood and urine testing strips, insulin pump consumables, and syringes and needles for special injection systems at subsidised prices to people who register for its benefits.
- If you are under the age of 15 years, you can be registered with the Australasian Paediatric Endocrine Group, and give agreement on their registration form to share your information with the National Diabetes Register.
- Contact the National Diabetes Register staff by email at diabetes@aihw.gov.au or write to:

  The Project Officer, National Diabetes Register
  National Centre for Monitoring Diabetes
  Australian Institute of Health and Welfare
  GPO Box 570
  Canberra ACT 2601

Please note that there is no obligation to participate in research projects, and NDR registrants can withdraw from any research project or from the NDR at any time, by giving written notice.

Appendix B: Statistical notes and methods

B.1 Calculation of age at diagnosis

The method used to derive age at diagnosis depends on whether the data are sourced from NDSS only, APEG only, or both.

NDSS only records

Age at diagnosis = NDSS date of diagnosis – date of birth
If diagnosis date is missing and diabetes type is gestational diabetes, then registration date is used as a substitute for diagnosis date but only if the resulting age at diagnosis is greater than or equal to 18 years.

APEG only, or both NDSS and APEG records*

Age at diagnosis = APEG date of first injection – date of birth, or else

Age at diagnosis = APEG registration date – date of birth, or else

Age at diagnosis = NDSS date of diagnosis – date of birth, or else

Age at diagnosis = NDSS date of first injection – date of birth

Note that diagnosis date is not available for most APEG records, so first injection date is used as a substitute. Among international studies of Type 1 diabetes incidence, the date of first injection is the accepted definition for date of diagnosis (LaPorte et al. 1985).

B.2 Calculation of year of first insulin use

The method used to derive the year of first insulin use depends on whether the data are sourced from NDSS only, APEG only, or both.

APEG only

Year of first insulin use = APEG year of first injection date, or

Year of first insulin use = APEG year of registration date

Both NDSS and APEG

Year of first insulin use = APEG year of first injection date, or

Year of first insulin use = NDSS year of first injection date, or

Year of first insulin use = NDSS year of first syringe purchase date, or

Year of first insulin use = APEG year of registration date

NDSS only

Year of first insulin use = NDSS year of injection date, or

Year of first insulin use = NDSS year of first syringe purchase date

B.3 Derivation of diabetes type

Diabetes is a complex and chronic disease. The term 'diabetes' is used to describe a group of different disorders with common elements, including high blood glucose (sugar) levels and glucose intolerance. This is due to insulin deficiency, impaired effectiveness of insulin action, or both (IDF 2006). Diabetes is classified into four types:

- Type 1 diabetes
- Type 2 diabetes
- gestational diabetes mellitus
- other specific types.

All these types of diabetes may be treated with insulin; once diagnosed, Type 1 diabetes is always treated with insulin (although individuals may have a brief and temporary remission phase after diagnosis during which insulin is not needed).

Over the years, the classifications and terminology used for the different types of diabetes have changed as understanding of the disease has grown. For example, it is now known that a large proportion of people with Type 1 diabetes are diagnosed in their adult years (37% of people with Type 1 on the NDR were aged 25 or older at diagnosis; see Table 1.1), that many people diagnosed with Type 2 diabetes actually have Type 1 diabetes (but a slow onset form known as latent autoimmune diabetes in adults (LADA), and that Type 2 diabetes is appearing in younger ages than previously seen (McMahon et al. 2004; Pinhas-Hamiel & Zeitler 2005; Craig et al. 2007). Terms such as juvenile-onset diabetes, insulin-dependent diabetes (IDDM) and non-insulin-dependent diabetes (NIDDM) are no longer favoured (Gale 2001; Daneman 2006). This has contributed to some confusion in the community 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.

The most important misconception for the NDR 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 they use insulin, when, in fact, they have another form of insulin-treated diabetes. A small survey done with registrants' certifying doctors in 2000 confirmed this misclassification (AIHW 2001). In 44% of replies, the doctor indicated that the reported Type 1 diabetes should have been Type 2.

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, and the 1999–00 Australian Diabetes, Obesity and Lifestyle Study) have used algorithms to classify people with diabetes to Type 1 or Type 2, creating a derived diabetes type. For example, in the 1995 National Health Survey, almost half of those who reported having Type 1 diabetes were later reclassified as having Type 2 diabetes on the basis of other information they reported that did not reconcile with a diagnosis of Type 1 diabetes.

In light of this, the then NDR Management Committee recommended the use of an algorithm to derive diabetes type (for NDSS-only records) to more accurately describe the distribution of registrants' diabetes type—this has been in place since before the first statistical profile report on the NDR. Because of the correlation between type of diabetes and age of diagnosis, the algorithm was originally based on age at diagnosis and the period between diagnosis and the start of insulin treatment. It was originally aimed at registrants believed to be incorrectly reported as Type 1 rather than Type 2.

The algorithm has been updated several times over the years, in consultation and with, agreement from, the National Diabetes Data Working Group, and the current algorithm is shown in Box B.1. The algorithm was revised in March 2007 to reduce the time between diagnosis and insulin use to 1 year (previously 2 years), and to reduce the age for which the algorithm is applied to those aged over 15 years at diagnosis (previously 35 and 40 years). The change was required because of the increasing incidence of Type 2 diabetes in adolescents and young adults, and changing management guidelines, which recommend considering insulin as an early treatment option for people with Type 2 diabetes (Nathan et al. 2006). Note that with or without the algorithm, there will always be some level of misclassification. The algorithm cannot reclassify all records that have been misreported.

Records of registrants reporting Type 2 diabetes or other types of diabetes are excluded from this derivation, so the reclassification does not include cases of Type 1 diabetes that have been misclassified as Type 2 and that, in fact, have a slow onset form of Type 1 diabetes known as latent autoimmune diabetes in adults (LADA) (Turner et al. 1997).

Data collection issues

NDSS

The NDSS form did not have an option for insulin-treated Type 2 diabetes until 2002.

Type of diabetes is reported on the NDSS registration form by either a medical practitioner or an accredited diabetes educator.

APEG

In the APEG collection, diabetes type is nearly always certified by a medical specialist, and in most paediatric centres nationwide tests are done to determine whether diabetes-associated autoantibodies are present, which serves to confirm the diagnosis of Type 1 diabetes. When a difference in diabetes type is found on NDR records sourced from both NDSS and APEG, the APEG-reported type is used.

Box B.1 NDR 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 2 or other, then the derived diabetes type equals the reported diabetes type*
- *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 gestational diabetes:*
  - *if the age at diagnosis is less than 50 years, then the derived diabetes type equals the reported diabetes type, that is, gestational diabetes*
  - *if the age at diagnosis is greater than or equal to 50 years, then the derived diabetes type equals Type 2*
  - *if the age at diagnosis is missing, then the derived diabetes type is unable to be derived.*

B.4 Age-standardised rates

Age-standardisation is a technique used to eliminate the effect of differences in population age structures when comparing rates for different periods, and/or different geographic areas and/or different population groups. Definitions are included in the *National health data dictionary* (HDSC 2006).

There are two methods of age-standardisation, direct and indirect. The direct method was used for the incidence rates reported in chapters 3, 4 and 5, and the indirect method was used as the basis for calculating the standardised mortality ratios in Chapter 6.

Direct age-standardisation

To control for any effects of varying age structures of population, direct age-standardisation is used to calculate rates. The 2001 Australian population was used as the standard population in calculating age-standardised rates, using the following formula (HDSC 2006):

$$SR = \frac{\sum (r_i p_i)}{\sum p_i}$$

where SR = the age-standardised rate for the population being studied, r_i = the age-group specific rate for age group i in the population being studied, and p_i = the population of age group i in the Australian standard population (persons) as at 30 June 2001.

Indirect age-standardisation

The indirect method is recommended for use when calculating rates for small populations where fluctuations in age-specific rates can affect the reliability of rates calculated using the direct method (HDSC 2006). The formula is as follows:

$$SR = \frac{c}{\sum (r_i p_i)} \times r$$

where SR = the age-standardised rate for the population being studied, c = the actual number of cases in the population being studied, r_i = the age-group specific rate for age group i in the population being studied, p_i = the population for age group i for the population being studied, and r = crude rate in the standard population.

B.5 Standardised mortality ratios

Comparisons between mortality rates for the NDR population and those for the whole Australian population were made using standardised mortality ratios (SMRs), which use indirect standardisation to account for any differences in the age structure between the two populations.

The SMRs were calculated using the following steps for each cause of death group:

1. The 'observed' number (that is, the actual number) of deaths for the NDR population was calculated for males and females.
2. There were 162 deaths (92 in males and 70 in females) for which the cause of death was unknown. These deaths were 'allocated' to a cause of death, based on the distribution of the known causes of death among NDR registrants for males and females separately, and added to the actual number (from Step 1) to calculate the total 'observed' number of deaths for each cause.
3. The number of people on the NDR at risk of dying as at June of each year (2000 to 2006) was estimated for each sex and 5-year age group.
4. The death rates for the comparison group, which is the whole Australian population, were calculated for each sex, year and 5-year age group.
5. The 'expected' number of deaths in the NDR population were calculated for each year, sex and 5-year age group by applying the sex- and age-specific rates for the comparison group (from Step 4) to the NDR population at risk (from Step 2).
6. The total number of expected deaths was calculated by summing the expected number of deaths (from Step 5) across all age, sex and year groups.
7. The SMR was then calculated as the total observed deaths divided by the total expected deaths (from Step 6). An SMR of 1.0 means that there is no difference in the death rate between NDR registrants and the Australian population.
8. The confidence interval was calculated using the method outlined in Appendix B.7.

B.6 Estimated average annual rate of change

Poisson regression was used to estimate the average annual rate of change in incidence rates over time. The Poisson model used was:

$$\log_e(E_t) = \log_e(N_t) + \beta_0 + \beta_1 t$$

where

t is the period; that is, 2000 to 2007

E_t is the number of new cases in year t

N_t is the mid-year population in year t

β_0 and β_1 are estimated in the model

β_1 represents the estimated annual rate of increase or decrease

Thus, the average annual percentage change can then be calculated as:

$$\text{Average annual percentage change} = \left(e^{\beta_1} - 1\right) \times 100$$

In previous reports of the NDR, the geometric formula was used to estimate the average annual rate of change in the age-standardised incidence rate of Type 1 diabetes among children aged 0–14 years (AIHW 2008c). However, the geometric formula only takes into account the first and last time points in the time series under investigation, whereas the Poisson regression model uses all the time points in the time series, so accounts for both the fluctuation across time and the variability at each time point. Further, use of Poisson regression also allows for calculation of a confidence interval for the annual average rate of change.

B.7 Confidence intervals

The 95% confidence intervals in this report indicate the variation that might be expected in incidence numbers purely by chance. The confidence intervals for the age-standardised incidence rates were calculated assuming a Poisson distribution of cases and using a method developed by Dobson et al. (1991). This method calculates approximate confidence intervals for a weighted sum of Poisson parameters. The confidence intervals are used to provide an approximate indication of the differences between rates. Where the confidence intervals of two direct age-standardised rates do not overlap, this indicates that the corresponding rates can be considered statistically significantly different from each other. As with all statistical comparisons, care should be exercised in interpreting the results of the comparison. If two rates are statistically significantly different from each other, this means that the difference is unlikely to have arisen by chance. Judgment should, however, be exercised in deciding whether the difference is of any practical significance.

The confidence intervals for the standardised mortality ratios (SMR) were estimated using the square root transform method (Breslow & Day 1987). The 95% confidence interval around an SMR gives an indication of the precision of that estimate. A 95% confidence interval that does not include the value 1.0 indicates that the calculated SMR is significantly different from 1.0 and therefore unlikely to be due to chance. In other words, there may be a real difference between NDR registrants and the Australian population.

B.8 Assessing coverage of the NDR using the capture-recapture method

The capture-recapture method as described by LaPorte et al. (1993) can be applied to the calculation of incidence rates of insulin-treated diabetes when multiple sources are being used to identify new cases. In capture-recapture, the cases provided by both sources (that is, the duplicates) provide important information about the degree to which cases may have been missed. The duplicates represent 'recaptured' people who have diabetes, and the degree of under-count can be estimated. The formula used to calculate ascertainment is below (see LaPorte et al. 1993 for more information).

$$N = \frac{(M+1)(n+1)}{m+1} - 1$$

where

N = estimate of Number

M = number in first sample (those marked)

n = number in second sample

m = number of 'marked' items in second sample

B.9 Remoteness areas

Since the early 1990s three geographical classifications have been developed and used to report on remoteness. They are: Rural, Remote and Metropolitan Areas (RRMA);

Accessibility/Remoteness Index of Australia (ARIA) based on ARIA index values; and Australian Standard Geographical Classification (ASGC) Remoteness Areas (based on ARIA+ index values—an enhanced version of the ARIA index values).

A detailed review of these three classifications is presented in *Rural, regional and remote health: a guide to remoteness classifications* (AIHW 2004). The ASGC Remoteness Areas was used to report on remoteness in this publication. The ASGC is an ABS classification which provides a hierarchy of geographic area codes used to classify a wide range of social and economic data (ABS 2001). In this report, tables presenting information by remoteness areas contain data for 2005–2007 only. This is because the concordance of postcode of current residence to remoteness areas are based on the classification as at the 2006 Census of Population and Housing, and the concordance becomes less accurate for years further away from the census year.

ASGC Remoteness Areas categorises areas as *Major cities*, *Inner regional*, *Outer regional*, *Remote* and *Very remote*. For this report, *Remote* and *Very remote* areas were combined.

Postcodes are classified into these four regions based on their score on the ARIA (DoHA 2001). This index is based on how distant a place is by road from urban centres of different sizes, providing a relative indication of how difficult it might be for residents to access certain services such as health care and education.

B.10 Socioeconomic status

The measure of socioeconomic disadvantage—the ABS Socioeconomic Index of Areas (SEIFA)—used in this section is a measure constructed at the level of geographic area of residence. The Index of Relative Socio-Economic Disadvantage (IRSD) is one of four SEIFAs compiled by the ABS after each Census of Population and Housing. The SEIFAs aim at representing the socioeconomic status of Australian communities and identifying areas of advantage and disadvantage. The IRSD scores each area by summarising attributes of the population, such as low educational attainment, high unemployment, and jobs in relatively unskilled occupations.

B.11 Indigenous data limitations

On the NDSS form before 2005, if the response to the Indigenous status question was not completed on the registration form, the person was recorded as non-Indigenous. This may have overestimated the number of non-Indigenous registrants and underestimated the number of Aboriginal and Torres Strait Islander registrants. In early 2005, the NDSS database was amended to add an extra value to the Indigenous status variable —Inadequate/Not stated— and this was made the default, in accordance with the *National health data dictionary* (HDSC 2006). As such, data for Indigenous status in this report are presented from 2005–2007 only.

It should also be noted that the NDR may underestimate the number of Indigenous registrants with insulin-treated diabetes. This may be the result of factors including low registration rates for the NDSS and subsequently the NDR among Aboriginal and Torres Strait Islander peoples, or possible under-reporting of Indigenous status. For example, Indigenous communities in remote areas may use services and products provided by Aboriginal Health Services and Aboriginal Community Councils, rather than the NDSS. The provisions of section 100 of the *National Health Act 1953*, might also result in an

under-coverage of Aboriginal and Torres Strait Islander peoples on the NDSS. Under the provisions of section 100, Indigenous Australians living in remote areas who are clients of approved remote area Aboriginal Health Services are able to access Pharmaceutical Benefits Scheme medicines free of charge without a prescription from the Aboriginal Health Services at the time of medical consultation. As supplies for diabetes are available for free through the PBS under section 100, it is likely that most Aboriginal and Torres Strait Islander peoples in remote areas will use these arrangements rather than the NDSS, which requires a co-payment. In addition, NDSS sub-agents are not always available in remote areas. Therefore, as the NDR uses the NDSS to ascertain eligible registrants, the number of Indigenous Australians with insulin-treated diabetes will be under-counted.

Appendix C: Additional tables

Chapter 3 appendix tables

Table C3.1: Incidence (number) of Type 1 diabetes among children aged 0–14 years: sex and age, by year of first insulin use, 2000–2007

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000 –2007
Males									
0–4	85	106	106	126	106	107	97	103	836
5–9	138	143	154	157	175	156	160	178	1,261
10–14	171	202	203	215	231	209	243	242	1,716
Total males 0–14	*394*	*451*	*463*	*498*	*512*	*472*	*500*	*523*	*3,813*
Females									
0–4	71	76	87	91	85	91	80	99	680
5–9	139	156	162	185	176	156	152	168	1,294
10–14	154	165	196	202	202	186	189	197	1,491
Total females 0–14	*364*	*397*	*445*	*478*	*463*	*433*	*421*	*464*	*3,465*
Persons									
0–4	156	182	193	217	191	198	177	202	1,516
5–9	277	299	316	342	351	312	312	346	2,555
10–14	325	367	399	417	433	395	432	439	3,207
Total persons 0–14	**758**	**848**	**908**	**976**	**975**	**905**	**921**	**987**	**7,278**

Source: National Diabetes Register (data extracted December 2008).

Table C3.2: Incidence (number) of Type 1 diabetes among children aged 0–14 years: year of first insulin use, by state/territory of current residence, 2000–2007

Year of first insulin use	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
2000	249	184	152	72	72	15	11	3	758
2001	269	212	175	85	62	25	15	5	848
2002	286	231	167	102	77	25	16	3	908
2003	274	257	207	104	87	30	12	5	976
2004	311	227	204	93	82	30	20	8	975
2005	266	239	194	83	62	40	18	3	905
2006	266	243	194	90	78	32	12	6	921
2007	282	265	221	109	56	20	28	6	987
2000–2007	**2,203**	**1,858**	**1,514**	**738**	**576**	**217**	**132**	**39**	**7,278**

Note: Columns may not add to the Australian total, as 1 record has an unknown state of current residence.

Source: National Diabetes Register (data extracted December 2008).

Table C3.3: Incidence (number) of Type 1 diabetes among children aged 0–14 years: sex and age, by states and territories of current residence, 2000–2007

Sex and age at first insulin use (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
Males									
0–4	236	207	188	87	72	29	14	3	836
5–9	375	308	271	140	100	35	26	6	1,261
10–14	537	439	335	163	142	61	28	11	1,716
Total males 0–14	*1,148*	*954*	*794*	*390*	*314*	*125*	*68*	*20*	*3,813*
Females									
0–4	231	172	137	61	50	17	10	2	680
5–9	367	340	260	144	112	40	26	5	1,294
10–14	457	392	323	143	100	35	28	12	1,491
Total females 0–14	*1,055*	*904*	*720*	*348*	*262*	*92*	*64*	*19*	*3,465*
Persons									
0–4	467	379	325	148	122	46	24	5	1,516
5–9	742	648	531	284	212	75	52	11	2,555
10–14	994	831	658	306	242	96	56	23	3,207
Total persons 0–14	**2,203**	**1,858**	**1,514**	**738**	**576**	**217**	**132**	**39**	**7,278**

Note: Columns may not add to the Australian total, as 1 record has an unknown state of current residence.

Source: National Diabetes Register (data extracted December 2008).

Table C3.4: Incidence (number) of Type 1 diabetes among children aged 0–14 years at their first insulin use: geographical locations based on postcode of current residence[(a)], 2005–2007

Age at first insulin use (years)	Major cities	Inner regional	Outer regional	Remote/ Very remote	Australia
0–4	376	135	52	15	577
5–9	624	239	90	17	970
10–14	810	314	128	13	1,266
Total 0–14 ASR[(b)]	**1,810**	**688**	**270**	**45**	**2,813**

(a) Registrants are classified according to the Australian Standard Geographical Classification (ASGC) Remoteness Areas based on postcode of current residence (AIHW population database)—see Appendix B.9.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Table C3.5: Incidence (number) of Type 1 diabetes among children aged 0–14 years: socioeconomic status (SES) based on postcode of current residence[(a)], 2005–2007

Age at first insulin use (years)	Group 1 (lowest SES)	Group 4	Group 3	Group 2	Group 5 (highest SES)	Australia
0–4	120	119	116	102	120	577
5–9	194	199	200	186	191	970
10–14	296	218	278	225	249	1,266
Total persons 0–14	**610**	**536**	**594**	**513**	**560**	**2,813**

(a) Registrants are classified according to the Index of Relative Socio-Economic Disadvantage (IRSD) based on postcode of current residence (AIHW population database)—see Appendix B.10.

Source: National Diabetes Register (data extracted December 2008).

Chapter 4 appendix tables

Table C4.1: Incidence (number) of Type 1 diabetes among people aged 15 years and over: sex and age, by year of first insulin use, 2000–2007

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000–2007
Males									
15–19	119	124	132	142	140	145	145	148	1,095
20–24	100	119	104	114	109	111	104	132	893
15–24	*219*	*243*	*236*	*256*	*249*	*256*	*249*	*280*	*1,988*
25–29	119	117	96	129	107	98	93	142	901
30–34	117	110	104	90	95	102	106	108	832
35–39	94	91	57	82	90	55	62	97	628
25–39	*330*	*318*	*257*	*301*	*292*	*255*	*261*	*347*	*2,361*
40–49	134	95	104	95	90	80	93	101	792
50–59	94	81	57	69	52	41	71	83	548
60–69	75	92	45	32	30	29	37	43	383
70–79	52	63	33	21	14	9	21	21	234
80+	25	25	15	19	11	7	4	20	126
40+	*380*	*356*	*254*	*236*	*197*	*166*	*226*	*268*	*2,083*
Total males 15+ (number)	*929*	*917*	*747*	*793*	*738*	*677*	*736*	*895*	*6,432*
Total males 15+ (per cent)	*61.1*	*60.0*	*63.6*	*63.4*	*64.6*	*62.6*	*63.9*	*65.4*	*62.9*
Females									
15–19	100	105	87	98	82	95	90	104	761
20–24	67	67	69	76	62	71	60	59	531
15–24	*167*	*172*	*156*	*174*	*144*	*166*	*150*	*163*	*1,292*
25–29	76	64	51	55	47	48	51	61	453
30–34	69	56	43	55	62	43	46	44	418
35–39	42	46	27	44	36	30	49	37	311
25–39	*187*	*166*	*121*	*154*	*145*	*121*	*146*	*142*	*1,182*
40–49	59	60	45	34	41	51	46	64	400
50–59	48	59	34	35	35	26	32	54	323
60–69	65	53	20	24	19	19	19	27	246
70–79	37	64	26	18	12	12	11	15	195
80+	29	37	26	19	9	9	11	9	149
40+	*238*	*273*	*151*	*130*	*116*	*117*	*119*	*169*	*1,313*
Total females 15+ (number)	*592*	*611*	*428*	*458*	*405*	*404*	*415*	*474*	*3,787*
Total females 15+ (per cent)	*38.9*	*40.0*	*36.4*	*36.6*	*35.4*	*37.4*	*36.1*	*34.6*	*37.1*

(continued)

Table C4.1 (continued): Incidence (number) of Type 1 diabetes among people aged 15 years and over: sex and age, by year of first insulin use, 2000–2007

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000–2007
Persons									
15–19	219	229	219	240	222	240	235	252	1,856
20–24	167	186	173	190	171	182	164	191	1,424
15–24	*386*	*415*	*392*	*430*	*393*	*422*	*399*	*443*	*3,280*
25–29	195	181	147	184	154	146	144	203	1,354
30–34	186	166	147	145	157	145	152	152	1,250
35–39	136	137	84	126	126	85	111	134	939
25–39	*517*	*484*	*378*	*455*	*437*	*376*	*407*	*489*	*3,543*
40–49	193	155	149	129	131	131	139	165	1,192
50–59	142	140	91	104	87	67	103	137	871
60–69	140	145	65	56	49	48	56	70	629
70–79	89	127	59	39	26	21	32	36	429
80+	54	62	41	38	20	16	15	29	275
40+	*618*	*629*	*405*	*366*	*313*	*283*	*345*	*437*	*3,396*
Total persons 15+ (number)	**1,521**	**1,528**	**1,175**	**1,251**	**1,143**	**1,081**	**1,151**	**1,369**	**10,219**

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Table C4.2: Incidence (rate) of Type 1 diabetes among people aged 15 years and over: sex and age, by year of first insulin use, 2000–2007

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000–2007[a]
					Number per 100,000 population				
Males									
15–19	17.6	18.0	18.9	20.2	19.8	20.2	20.0	19.9	19.3
20–24	15.3	18.0	15.4	16.4	15.3	15.2	13.9	17.1	15.8
15–24 ASR[b]	*16.4*	*18.0*	*17.2*	*18.4*	*17.6*	*17.8*	*17.0*	*18.5*	*17.6*
(95% CI)	*(14.3–18.8)*	*(15.8–20.4)*	*(15.1–19.5)*	*(16.2–20.8)*	*(15.5–19.9)*	*(15.7–20.1)*	*(14.9–19.2)*	*(16.4–20.8)*	*(16.9–18.4)*
25–29	16.5	16.7	13.9	18.9	15.7	14.2	13.1	19.3	16.1
30–34	16.5	15.1	14.0	11.9	12.6	13.6	14.3	14.7	14.1
35–39	12.6	12.3	7.8	11.3	12.4	7.5	8.2	12.4	10.6
25–39 ASR[b]	*15.2*	*14.7*	*11.8*	*13.9*	*13.5*	*11.7*	*11.8*	*15.4*	*13.5*
(95% CI)	*(13.6–16.9)*	*(13.1–16.4)*	*(10.4–13.4)*	*(12.4–15.6)*	*(12.0–15.1)*	*(10.3–13.2)*	*(10.4–13.3)*	*(13.8–17.1)*	*(12.9–14.0)*
40–49	9.7	6.7	7.2	6.5	6.1	5.4	6.2	6.7	6.8
50–59	8.4	7.0	4.8	5.6	4.1	3.2	5.4	6.3	5.5
60–69	10.2	12.3	5.8	4.0	3.7	3.4	4.2	4.6	5.9
70–79	10.0	11.9	6.1	3.9	2.6	1.6	3.8	3.7	5.4
80+	12.7	11.9	6.8	8.2	4.5	2.7	1.5	7.0	6.6
40+ ASR[b]	*9.7*	*8.9*	*6.1*	*5.6*	*4.5*	*3.7*	*5.0*	*5.8*	*6.1*
(95% CI)	*(8.7–10.7)*	*(8.0–9.8)*	*(5.4–6.9)*	*(4.9–6.3)*	*(3.9–5.2)*	*(3.2–4.3)*	*(4.4–5.7)*	*(5.2–6.6)*	*(5.8–6.3)*
15+ ASR[b]	*12.4*	*12.1*	*9.6*	*10.1*	*9.3*	*8.4*	*9.0*	*10.7*	*10.2*
(95% CI)	*(11.6–13.2)*	*(11.3–12.9)*	*(9.0–10.4)*	*(9.4–10.9)*	*(8.6–10.0)*	*(7.8–9.0)*	*(8.4–9.7)*	*(10.0–11.5)*	*(9.9–10.4)*
Females									
15–19	15.4	15.9	13.0	14.5	12.1	13.9	13.1	14.8	14.1
20–24	10.5	10.4	10.6	11.3	9.0	10.1	8.3	8.0	9.7
15–24 ASR[a]	*13.0*	*13.2*	*11.8*	*13.0*	*10.6*	*12.0*	*10.7*	*11.5*	*11.9*
(95% CI)	*(11.1–15.1)*	*(11.3–15.3)*	*(10.0–13.8)*	*(11.1–15.1)*	*(9.0–12.5)*	*(10.3–14.0)*	*(9.1–12.6)*	*(9.8–13.4)*	*(11.3–12.6)*
25–29	10.5	9.1	7.4	8.1	6.9	7.0	7.3	8.5	8.1
30–34	9.6	7.6	5.7	7.2	8.1	5.6	6.1	5.9	7.0
35–39	5.6	6.1	3.6	6.0	4.9	4.0	6.4	4.7	5.2
25–39 ASR[b]	*8.5*	*7.6*	*5.5*	*7.1*	*6.6*	*5.5*	*6.6*	*6.3*	*6.7*
(95% CI)	*(7.3–9.8)*	*(6.5–8.8)*	*(4.6–6.6)*	*(6.0–8.3)*	*(5.6–7.8)*	*(4.6–6.6)*	*(5.6–7.8)*	*(5.3–7.5)*	*(6.3–7.1)*
40–49	4.2	4.2	3.1	2.3	2.7	3.4	3.0	4.2	3.4
50–59	4.4	5.2	2.9	2.9	2.8	2.0	2.4	4.0	3.3
60–69	8.8	7.0	2.6	3.0	2.3	2.2	2.1	2.9	3.7
70–79	6.0	10.2	4.2	2.9	1.9	1.9	1.8	2.4	3.9
80+	7.9	9.6	6.5	4.6	2.1	2.0	2.4	1.9	4.4
40+ ASR[b]	*5.6*	*6.2*	*3.3*	*2.8*	*2.5*	*2.5*	*2.5*	*3.5*	*3.6*
(95% CI)	*(4.9–6.3)*	*(5.5–7.0)*	*(2.8–3.9)*	*(2.4–3.3)*	*(2.1–3.0)*	*(2.1–3.0)*	*(2.1–3.0)*	*(3.0–4.1)*	*(3.4–3.8)*
15+ ASR[b]	*7.7*	*7.8*	*5.4*	*5.8*	*5.1*	*5.0*	*5.1*	*5.7*	*5.9*
(95% CI)	*(7.1–8.3)*	*(5.4–10.3)*	*(3.3–7.7)*	*(3.5–8.2)*	*(3.0–7.3)*	*(2.9–7.3)*	*(3.0–7.2)*	*(3.6–7.9)*	*(5.1–6.7)*

(continued)

Table C4.2 (continued): Incidence (rate) of Type 1 diabetes among people aged 15 years and over: sex and age, by year of first insulin use, 2000–2007

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000–2007[a]
					Number per 100,000 population				
Persons									
15–19	16.5	16.9	16.0	17.4	16.0	17.1	16.6	17.4	16.8
20–24	12.9	14.3	13.0	13.9	12.2	12.7	11.1	12.7	12.8
15–24 ASR[b]	*14.8*	*15.6*	*14.5*	*15.7*	*14.2*	*15.0*	*13.9*	*15.1*	*14.8*
(95% CI)	*(13.3–16.3)*	*(14.2–17.2)*	*(13.1–16.1)*	*(14.3–17.3)*	*(12.8–15.7)*	*(13.6–16.5)*	*(12.6–15.4)*	*(13.7–16.6)*	*(14.3–15.3)*
25–29	13.5	12.9	10.7	13.5	11.3	10.6	10.3	13.9	12.1
30–34	13.0	11.3	9.8	9.5	10.3	9.6	10.2	10.3	10.5
35–39	9.0	9.2	5.7	8.6	8.6	5.7	7.3	8.5	7.8
25–39 ASR[b]	*11.8*	*11.1*	*8.7*	*10.5*	*10.1*	*8.6*	*9.2*	*10.9*	*10.1*
(95% CI)	*(10.8–12.9)*	*(10.1–12.1)*	*(7.8–9.6)*	*(9.5–11.5)*	*(9.1–11.0)*	*(7.7–9.5)*	*(8.3–10.1)*	*(9.9–11.9)*	*(9.8–10.4)*
40–49	6.9	5.5	5.2	4.4	4.4	4.4	4.6	5.4	5.1
50–59	6.4	6.1	3.8	4.2	3.5	2.6	3.9	5.2	4.4
60–69	9.5	9.6	4.2	3.5	3.0	2.8	3.2	3.7	4.8
70–79	7.8	11.0	5.1	3.3	2.2	1.8	2.7	3.0	4.6
80+	9.6	10.4	6.6	5.9	3.0	2.3	2.1	3.8	5.2
40+ ASR[b]	*7.6*	*7.5*	*4.7*	*4.1*	*3.5*	*3.1*	*3.7*	*4.6*	*4.8*
(95% CI)	*(7.0–8.2)*	*(6.9–8.1)*	*(4.3–5.2)*	*(3.7–4.6)*	*(3.1–3.9)*	*(2.7–3.5)*	*(3.3–4.1)*	*(4.2–5.1)*	*(4.6–4.9)*
15+ ASR[b]	**10.0**	**9.9**	**7.5**	**7.9**	**7.2**	**6.7**	**7.0**	**8.2**	**8.0**
(95% CI)	**(9.5–10.5)**	**(9.4–10.4)**	**(7.1–8.0)**	**(7.5–8.4)**	**(6.8–7.6)**	**(6.3–7.1)**	**(6.6–7.5)**	**(7.8–8.6)**	**(7.9–8.2)**

(a) Average annual rate for 2000–2007.

(b) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Table C4.3: Incidence (number) of Type 1 diabetes among people aged 15 years and over: year of first insulin use, by state/territory of current residence, 2000–2007

Year of first insulin use	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
2000	544	297	278	165	137	63	23	10	1,521
2001	509	391	238	185	122	37	28	12	1,528
2002	385	288	200	144	100	36	14	3	1,175
2003	370	312	259	142	101	30	19	14	1,251
2004	318	314	229	138	90	29	10	15	1,143
2005	304	273	237	124	82	26	22	13	1,081
2006	329	290	219	163	92	28	18	11	1,151
2007	501	316	277	125	90	36	14	10	1,369
Total 2000–2007	**3,260**	**2,481**	**1,937**	**1,186**	**814**	**285**	**148**	**88**	**10,219**

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Table C4.4: Incidence (number) of Type 1 diabetes among people aged 15 years and over: sex and age, by states and territories of current residence, 2000–2007

Sex and age at first insulin use (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
Males									
15–19	364	272	199	131	74	27	22	6	1,095
20–24	249	211	214	103	65	18	21	11	893
15–24	*613*	*483*	*413*	*234*	*139*	*45*	*43*	*17*	*1,988*
25–29	277	209	212	98	54	30	10	11	901
30–34	247	207	183	101	52	20	8	13	832
35–39	179	147	136	84	59	10	8	3	628
25–39	*703*	*563*	*531*	*283*	*165*	*60*	*26*	*27*	*2,361*
40–49	246	173	158	112	60	26	9	7	792
50–59	192	132	66	75	55	18	4	6	548
60–69	149	91	45	44	39	10	2	3	383
70–79	104	64	11	19	25	8	1	0	234
80+	41	43	10	12	15	2	0	0	126
40+	*732*	*503*	*290*	*262*	*194*	*64*	*16*	*16*	*2,083*
Total males 15+	*2,048*	*1,549*	*1,234*	*779*	*498*	*169*	*85*	*60*	*6,432*
Females									
15–19	214	178	177	90	60	25	13	4	761
20–24	171	113	127	49	35	13	17	5	531
15–24	*385*	*291*	*304*	*139*	*95*	*38*	*30*	*9*	*1,292*
25–29	142	108	95	57	27	7	11	6	453
30–34	121	105	87	37	42	15	7	4	418
35–39	96	76	58	36	29	8	5	2	311
25–39	*359*	*289*	*240*	*130*	*98*	*30*	*23*	*12*	*1,182*
40–49	128	88	72	54	33	15	6	2	400
50–59	112	91	46	35	28	8	0	2	323
60–69	95	64	27	22	23	11	1	2	246
70–79	81	55	9	18	20	8	1	1	195
80+	52	54	5	9	19	6	2	0	149
40+	*468*	*352*	*159*	*138*	*123*	*48*	*10*	*7*	*1,313*
Total females 15+	*1,212*	*932*	*703*	*407*	*316*	*116*	*63*	*28*	*3,787*

(continued)

Table C4.4 (continued): Incidence (number) of Type 1 diabetes among people aged 15 years and over: sex and age, by states and territories of current residence, 2000–2007

Sex and age at first insulin use (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
Persons									
15–19	578	450	376	221	134	52	35	10	1,856
20–24	420	324	341	152	100	31	38	16	1,424
15–24	*998*	*774*	*717*	*373*	*234*	*83*	*73*	*26*	*3,280*
25–29	419	317	307	155	81	37	21	17	1,354
30–34	368	312	270	138	94	35	15	17	1,250
35–39	275	223	194	120	88	18	13	5	939
25–39	*1,062*	*852*	*771*	*413*	*263*	*90*	*49*	*39*	*3,543*
40–49	374	261	230	166	93	41	15	9	1,192
50–59	304	223	112	110	83	26	4	8	871
60–69	244	155	72	66	62	21	3	5	629
70–79	185	119	20	37	45	16	2	1	429
80+	93	97	15	21	34	8	2	0	275
40+	*1,200*	*855*	*449*	*400*	*317*	*112*	*26*	*23*	*3,396*
Total persons 15+	**3,260**	**2,481**	**1,937**	**1,186**	**814**	**285**	**148**	**88**	**10,219**

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Table C4.5: Incidence (rate) of Type 1 diabetes among people aged 15 years and over: sex and age, by states and territories of current residence, 2000–2007

Sex and age at first insulin use (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
	Average annual rate (number per 100,000 population)								
Males									
15–19	19.6	19.8	17.9	22.2	17.3	19.5	21.8	9.6	19.3
20–24	13.5	15.0	19.4	17.9	15.6	15.0	18.3	16.1	15.8
15–24 ASR[(a)]	*16.6*	*17.4*	*18.6*	*20.1*	*16.5*	*17.3*	*20.1*	*12.8*	*17.6*
(95% CI)	*(15.3–18.0)*	*(15.9–19.0)*	*(16.9–20.5)*	*(17.6–22.8)*	*(13.9–19.5)*	*(12.6–23.2)*	*(14.5–27.1)*	*(7.4–20.5)*	*(16.8–18.4)*
25–29	14.7	14.8	19.8	17.6	13.5	27.2	9.4	15.0	16.1
30–34	12.5	13.8	16.3	17.1	12.2	16.5	7.7	17.5	14.1
35–39	9.0	9.9	12.1	13.9	13.2	7.7	8.1	4.2	10.6
25–39 ASR[(a)]	*12.0*	*12.8*	*16.0*	*16.2*	*12.9*	*16.9*	*8.4*	*12.1*	*13.5*
(95% CI)	*(11.1–12.9)*	*(11.8–13.9)*	*(14.6–17.4)*	*(14.3–18.2)*	*(11.0–15.1)*	*(12.9–21.8)*	*(5.5–12.3)*	*(8.0–17.7)*	*(13.0–14.1)*
40–49	6.3	6.0	7.1	9.4	6.6	9.2	4.8	5.5	6.8
50–59	5.9	5.5	3.4	7.5	7.0	7.1	2.5	6.2	5.5
60–69	6.8	5.7	3.6	7.1	7.4	5.7	2.3	6.8	5.9
70–79	6.9	5.8	1.4	4.9	6.5	6.9	2.0	0.0	5.4
80+	6.1	8.8	2.9	7.4	8.4	4.0	0.0	0.0	6.6
40+ ASR[(a)]	*6.3*	*6.0*	*4.4*	*7.7*	*7.0*	*7.3*	*3.0*	*4.8*	*6.1*
(95% CI)	*(5.9–6.8)*	*(5.5–6.5)*	*(3.9–4.9)*	*(6.8–8.7)*	*(6.0–8.0)*	*(5.6–9.4)*	*(1.7–4.9)*	*(2.7–7.8)*	*(5.8–6.3)*
15+ ASR[(a)]	*9.7*	*9.9*	*10.1*	*12.2*	*10.3*	*11.8*	*7.5*	*8.3*	*10.2*
(95% CI)	*(9.3–10.2)*	*(9.4–10.4)*	*(9.5–10.7)*	*(11.4–13.1)*	*(9.4–11.3)*	*(10.0–13.7)*	*(5.9–9.2)*	*(6.3–10.7)*	*(9.9–10.4)*
Females									
15–19	12.1	13.5	16.6	16.2	14.7	18.8	13.6	6.9	14.1
20–24	9.6	8.3	11.8	9.0	8.8	11.1	15.3	7.9	9.7
15–24 ASR[(a)]	*10.9*	*10.9*	*14.3*	*12.7*	*11.8*	*15.0*	*14.4*	*7.4*	*11.9*
(95% CI)	*(9.8–12.0)*	*(9.7–12.2)*	*(12.7–15.9)*	*(10.6–15.0)*	*(9.6–14.5)*	*(10.6–20.6)*	*(9.7–20.6)*	*(3.4–14.0)*	*(11.3–12.6)*
25–29	7.5	7.6	8.9	10.6	7.0	6.2	10.4	8.5	8.1
30–34	6.0	6.8	7.6	6.4	10.0	11.7	6.7	5.5	7.0
35–39	4.8	5.0	5.0	6.0	6.5	5.8	4.9	3.0	5.2
25–39 ASR[(a)]	*6.1*	*6.5*	*7.1*	*7.6*	*7.8*	*7.9*	*7.3*	*5.6*	*6.7*
(95% CI)	*(5.5–6.8)*	*(5.7–7.3)*	*(6.3–8.1)*	*(6.4–9.0)*	*(6.4–9.6)*	*(5.3–11.3)*	*(4.6–10.9)*	*(2.9–9.8)*	*(6.3–7.1)*
40–49	3.3	3.0	3.2	4.5	3.6	5.2	3.0	1.7	3.4
50–59	3.4	3.7	2.4	3.6	3.5	3.2	0.0	2.5	3.3
60–69	4.3	3.9	2.2	3.6	4.2	6.2	1.1	6.0	3.7
70–79	4.6	4.2	1.0	4.2	4.4	6.0	1.7	7.5	3.9
80+	4.4	6.2	0.9	3.2	5.9	6.6	5.6	0.0	4.4
40+ ASR[(a)]	*3.8*	*3.8*	*2.3*	*4.0*	*3.9*	*5.0*	*1.8*	*3.4*	*3.6*
(95% CI)	*(3.4–4.1)*	*(3.4–4.2)*	*(2.0–2.7)*	*(3.3–4.7)*	*(3.3–4.7)*	*(3.7–6.7)*	*(0.9–3.4)*	*(1.1–7.4)*	*(3.4–3.8)*
15+ ASR[(a)]	*5.6*	*5.8*	*5.7*	*6.5*	*6.4*	*7.6*	*5.5*	*4.7*	*5.9*
(95% CI)	*(5.3–6.0)*	*(5.4–6.1)*	*(5.3–6.2)*	*(5.9–7.2)*	*(5.7–7.2)*	*(6.2–9.1)*	*(4.3–7.1)*	*(2.9–7.0)*	*(5.7–6.1)*

(continued)

Table C4.5 (continued): Incidence (rate) of Type 1 diabetes among people aged 15 years and over: sex and age, by states and territories of current residence, 2000–2007

Sex and age at first insulin use (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
	Average annual rate (number per 100,000 population)								
Persons									
15–19	16.0	16.7	17.2	19.3	16.1	19.2	17.8	8.3	16.8
20–24	11.6	11.7	15.7	13.6	12.3	13.0	16.8	12.1	12.8
15–24 ASR[(a)]	*13.8*	*14.2*	*16.5*	*16.5*	*14.2*	*16.2*	*17.3*	*10.2*	*14.8*
(95% CI)	*(13.0–14.7)*	*(13.2–15.3)*	*(15.3–17.7)*	*(14.9–18.2)*	*(12.5–16.2)*	*(12.9–20.0)*	*(13.6–21.8)*	*(6.6–14.9)*	*(14.3–15.3)*
25–29	11.1	11.2	14.4	14.2	10.3	16.6	9.9	11.8	12.1
30–34	9.2	10.3	11.9	11.8	11.1	14.0	7.2	11.6	10.5
35–39	6.9	7.4	8.5	10.0	9.8	6.7	6.5	3.6	7.8
25–39 ASR[(a)]	*9.0*	*9.6*	*11.5*	*11.9*	*10.4*	*12.4*	*7.8*	*8.9*	*10.1*
(95% CI)	*(8.5–9.6)*	*(9.0–10.3)*	*(10.7–12.4)*	*(10.8–13.1)*	*(9.2–11.8)*	*(12.9–20.0)*	*(5.8–10.4)*	*(6.4–12.2)*	*(9.8–10.4)*
40–49	4.8	4.5	5.1	6.9	5.1	7.2	3.8	3.7	5.1
50–59	4.7	4.6	2.9	5.6	5.2	5.1	1.2	4.5	4.4
60–69	5.5	4.8	2.9	5.3	5.6	6.0	1.7	6.4	4.8
70–79	5.7	5.0	1.2	4.5	5.4	6.5	1.9	3.5	4.6
80+	5.0	7.1	1.6	4.7	6.8	5.7	3.6	0.0	5.2
40+ ASR[(a)]	*5.0*	*4.8*	*3.3*	*5.8*	*5.4*	*6.2*	*2.4*	*4.1*	*4.8*
(95% CI)	*(4.7–5.3)*	*(4.5–5.2)*	*(3.0–3.6)*	*(5.2–6.4)*	*(4.8–6.0)*	*(5.1–7.5)*	*(1.6–3.6)*	*(2.5–6.4)*	*(4.6–4.9)*
15+ ASR[(a)]	**7.7**	**7.8**	**7.9**	**9.4**	**8.3**	**9.7**	**6.5**	**6.5**	**8.0**
(95% CI)	**(7.4–7.9)**	**(7.5–8.1)**	**(7.6–8.3)**	**(8.8–9.9)**	**(7.8–8.9)**	**(8.6–10.9)**	**(5.5–7.7)**	**(5.2–8.1)**	**(7.9–8.2)**

(a) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Table C4.6: Incidence (number and rate) of Type 1 diabetes among people aged 15 years and over at their first insulin use: geographical locations based on postcode of current residence[a], 2005–2007

Age at first insulin use (years)	Major cities	Inner regional	Outer regional	Remote/ Very remote	Australia[b]
			Number		
15–19	496	159	58	14	727
20–24	381	93	46	16	537
15–24	*877*	*253*	*105*	*30*	*1,264*
25–29	353	80	47	14	493
30–34	327	71	43	8	449
35–39	233	62	31	5	330
25–39	*913*	*212*	*120*	*27*	*1,272*
40–49	293	92	44	6	435
50–59	219	60	20	8	307
60–69	111	38	21	4	174
70–79	56	21	10	2	89
80+	38	11	9	1	60
40+	*717*	*221*	*104*	*22*	*1,065*
Total 15+	**2,506**	**685**	**330**	**79**	**3,601**
			Average annual rate (number per 100,000 population)		
15–19	18.8	15.2	13.3	10.2	17.1
20–24	12.5	10.8	12.9	11.8	12.2
15–24 ASR[c]	*15.7*	*13.1*	*13.1*	*11.0*	*14.7*
(95% CI)	*(14.7–16.8)*	*(11.7–14.9)*	*(10.7–15.8)*	*(7.4–15.7)*	*(13.8–15.4)*
25–29	12.0	10.2	12.9	9.7	11.7
30–34	10.9	7.8	10.4	5.4	10.0
35–39	7.9	6.2	6.8	2.9	7.2
25–39 ASR[c]	*10.2*	*8.0*	*10.0*	*5.9*	*9.6*
(95% CI)	*(9.6–10.9)*	*(6.9–9.1)*	*(8.1–11.7)*	*(3.8–8.5)*	*(9.1–10.1)*
40–49	5.2	4.3	4.4	2.1	4.8
50–59	4.6	3.1	2.3	3.2	3.9
60–69	3.5	2.7	3.3	2.7	3.3
70–79	2.6	2.3	2.5	2.3	2.5
80+	2.7	2.1	3.9	2.7	2.7
40+ ASR[c]	*4.2*	*3.3*	*3.3*	*2.6*	*3.8*
(95% CI)	*(3.9–4.5)*	*(2.8–3.7)*	*(2.7–4.0)*	*(1.6–3.9)*	*(3.6–4.0)*
15+ ASR[c]	**7.9**	**6.3**	**6.9**	**5.0**	**7.3**
(95% CI)	**(7.6–8.2)**	**(5.8–6.8)**	**(6.2–7.7)**	**(3.9–6.2)**	**(7.1–7.6)**

(a) Registrants are classified according to the Australian Standard Geographical Classification (ASGC) Remoteness Areas based on postcode of current residence (AIHW population database)—see Appendix B.9.

(b) Includes 1 record where postcode of current residence is unknown.

(c) Age-standardised to the 2001 Australian population—see Appendix B.4.

Note: Columns and rows may not add to totals due to rounding.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Table C4.7: Incidence (number and rate) of Type 1 diabetes among people aged 15 years and over at their first insulin use: socioeconomic status (SES) based on postcode of current residence[a], 2005–2007

Age at first insulin use (years)	Group 1 (lowest SES)	Group 4	Group 3	Group 2	Group 5 (highest SES)	Australia
			Number			
15–19	166	161	140	109	151	727
20–24	108	109	130	114	76	537
15–24	*274*	*270*	*270*	*223*	*227*	*1,264*
25–29	100	96	113	87	97	493
30–34	112	84	96	73	84	449
35–39	76	60	63	62	69	330
25–39	*288*	*240*	*272*	*222*	*250*	*1,272*
40–49	83	87	98	80	87	435
50–59	60	52	62	63	70	307
60–69	26	30	33	28	57	174
70–79	15	12	19	16	27	89
80+	17	5	12	14	11	60
40+	*201*	*186*	*224*	*201*	*252*	*1,065*
Total 15+	**763**	**696**	**766**	**646**	**729**	**3,601**
			Average annual rate (number per 100,000 population)			
15–19	19.3	18.8	16.8	13.0	17.9	17.2
20–24	11.6	11.7	14.6	14.2	9.2	12.3
15–24 ASR[b]	*15.5*	*15.3*	*15.7*	*13.5*	*13.7*	*14.8*
(95% CI)	*(13.7–17.4)*	*(13.6–17.3)*	*(13.9–17.7)*	*(11.8–15.4)*	*(11.9–15.6)*	*(14.0–15.6)*
25–29	11.5	10.6	12.9	11.3	12.3	11.7
30–34	12.1	8.6	10.4	8.9	10.2	10.0
35–39	8.0	6.1	6.8	7.3	8.1	7.2
25–39 ASR[b]	*10.5*	*8.4*	*10.0*	*9.1*	*10.1*	*9.6*
(95% CI)	*(9.2–11.7)*	*(7.4–9.5)*	*(8.8–11.2)*	*(8.0–10.4)*	*(8.9–11.5)*	*(9.1–10.2)*
40–49	4.4	4.6	5.4	4.6	5.0	4.8
50–59	3.6	3.3	4.1	4.0	4.5	3.9
60–69	2.5	3.0	3.2	2.4	5.0	3.2
70–79	2.3	1.9	2.7	2.0	3.4	2.5
80+	3.7	1.2	2.9	3.0	2.5	2.7
40+ ASR[b]	*3.5*	*3.4*	*4.1*	*3.5*	*4.5*	*3.8*
(95% CI)	*(3.0–4.0)*	*(2.9–3.9)*	*(3.6–4.7)*	*(3.1–4.1)*	*(4.0–5.1)*	*(3.6–4.0)*
15+ ASR[b]	**7.5**	**6.9**	**7.8**	**6.8**	**7.7**	**7.3**
(95% CI)	**(7.0–8.1)**	**(6.4–7.4)**	**(7.2–8.3)**	**(6.3–7.4)**	**(7.1–8.3)**	**(7.1–7.6)**

(a) Registrants are classified according to the Index of Relative Socio-Economic Disadvantage (IRSD) based on postcode of current residence (AIHW population database)—see Appendix B.10.

(b) Age-standardised to the 2001 Australian population—see Appendix B.4.

Sources: National Diabetes Register; AIHW analysis of de-identified NDSS data (data extracted December 2008).

Chapter 5 appendix tables

Table C5.1: New cases of insulin-treated Type 2 diabetes: sex and age, by year of first insulin use, 2000–2007

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000–2007
					Number				
Males									
0–14	6	12	5	7	12	12	6	9	69
15–24	33	27	28	33	32	47	66	45	311
25–34	155	158	167	183	211	205	219	242	1,540
35–44	523	579	581	620	700	650	670	849	5,172
45–54	1,411	1,359	1,450	1,624	1,772	1,651	1,618	2,159	13,044
55–64	1,932	1,944	2,202	2,376	2,923	2,620	2,671	3,623	20,291
65–74	1,917	1,805	1,942	2,245	2,553	2,268	2,258	2,937	17,925
75–84	883	997	1,007	1,224	1,401	1,436	1,402	1,812	10,162
85+	123	152	174	169	219	243	280	312	1,672
Total males	*6,983*	*7,033*	*7,556*	*8,481*	*9,823*	*9,132*	*9,190*	*11,988*	*70,186*
Total males (per cent)	*53.1*	*52.9*	*54.2*	*54.0*	*55.4*	*54.9*	*55.2*	*56.1*	*54.6*
Females									
0–14	6	6	9	12	13	9	15	17	87
15–24	75	62	55	57	81	87	88	80	585
25–34	400	393	376	394	436	421	463	418	3,301
35–44	575	603	582	674	698	731	682	826	5,371
45–54	1,042	1,069	1,117	1,215	1,316	1,213	1,204	1,527	9,703
55–64	1,435	1,428	1,513	1,687	1,956	1,715	1,707	2,303	13,744
65–74	1,533	1,566	1,472	1,702	1,723	1,702	1,664	2,147	13,509
75–84	886	914	1,018	1,213	1,355	1,265	1,235	1,603	9,489
85+	209	212	238	273	315	360	397	464	2,468
Total females	*6,161*	*6,253*	*6,380*	*7,227*	*7,893*	*7,503*	*7,455*	*9,385*	*58,257*
Total females (per cent)	*46.9*	*47.1*	*45.8*	*46.0*	*44.6*	*45.1*	*44.8*	*43.9*	*45.4*
Persons									
0–14	12	18	14	19	25	21	21	26	156
15–24	108	89	83	90	113	134	154	125	896
25–34	555	551	543	577	647	626	682	660	4,841
35–44	1,098	1,182	1,163	1,294	1,398	1,381	1,352	1,675	10,543
45–54	2,453	2,428	2,567	2,839	3,088	2,864	2,822	3,686	22,747
55–64	3,367	3,372	3,715	4,063	4,879	4,335	4,378	5,926	34,035
65–74	3,450	3,371	3,414	3,947	4,276	3,970	3,922	5,084	31,434
75–84	1,769	1,911	2,025	2,437	2,756	2,701	2,637	3,415	19,651
85+	332	364	412	442	534	603	677	776	4,140
Total persons	**13,144**	**13,286**	**13,936**	**15,708**	**17,716**	**16,635**	**16,645**	**21,373**	**128,443**
Total persons (per cent)	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

Source: National Diabetes Register (data extracted December 2008)

Table C5.2: New cases of insulin-treated gestational diabetes among women aged 15–49 years: age, by year of first insulin use, 2000–2007

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000–2007
					Number				
15–19	8	11	11	12	11	21	30	28	132
20–24	56	67	85	76	112	173	203	308	1,080
25–29	202	286	338	263	370	572	720	1,012	3,763
30–34	322	390	513	419	702	1,048	1,287	1,751	6,432
35–39	195	261	348	364	506	857	1,024	1,469	5,024
40–44	57	66	104	102	151	206	292	404	1,382
45–49	4	4	12	4	10	20	18	37	109
Total	**844**	**1,085**	**1,411**	**1,240**	**1,862**	**2,897**	**3,574**	**5,009**	**17,922**

Source: National Diabetes Register (data extracted December 2008).

Table C5.3: New cases of insulin-treated other diabetes: sex and age, 2000–2007

Age at first insulin use (years)	Males	Females	Persons
	Number per 100,000 population		
0–14	0.4	0.5	0.4
15–24	0.6	0.7	0.6
25–34	0.7	0.7	0.7
35–44	0.8	0.6	0.7
45–54	1.5	0.8	1.1
55–64	2.0	1.1	1.5
65–74	1.9	1.4	1.7
75–84	1.7	0.8	1.2
85+	0.9	1.0	1.0
ASR[(a)] (95% CI)	**1.0 (0.9–1.0)**	**0.7 (0.7–0.8)**	**0.9 (0.8–0.9)**

(a) Age-standardised to the 2001 Australian population—see Appendix B.4.

Source: National Diabetes Register (data extracted December 2008).

Table C5.4: New cases of insulin-treated other diabetes: age, by year of first insulin use, 2000–2007

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2000 –2007[(a)]
					Number per 100,000 population				
Persons									
0–14	0.3	0.4	0.4	0.3	0.4	0.6	0.4	0.5	0.4
15–24	0.3	0.7	0.8	0.6	0.6	0.5	0.9	0.6	0.6
25–34	0.6	1.2	0.7	0.6	0.5	0.5	0.7	0.7	0.7
35–44	0.7	0.8	0.4	0.4	0.5	0.8	0.8	0.9	0.7
45–54	0.9	1.4	1.1	0.9	1.0	0.9	1.2	1.8	1.1
55–64	1.8	2.1	1.3	1.1	1.0	1.7	1.5	1.7	1.5
65–74	1.5	1.9	1.4	1.3	1.7	1.3	2.5	1.8	1.7
75–84	1.0	1.2	1.0	0.9	1.4	1.2	1.5	1.4	1.2
85+	1.2	0.4	0.7	1.1	0.7	1.3	0.9	1.5	1.0
ASR[(b)]	**0.8**	**1.1**	**0.8**	**0.7**	**0.7**	**0.8**	**1.0**	**1.0**	**0.9**
(95% CI)	**(0.6–0.9)**	**(0.9–1.2)**	**(0.7–0.9)**	**(0.6–0.8)**	**(0.6–0.9)**	**(0.7–1.0)**	**(0.9–1.1)**	**(0.9–1.2)**	**(0.8–0.9)**

(a) The rate for 2000–2007 is the average annual rate for the 8 years.

(b) Age-standardised to the 2001 Australian population—see Appendix B.4.

Source: National Diabetes Register (data extracted December 2008).

Chapter 7 appendix tables

Table C7.1: NDR registrants: current age and sex, 2000–2007

	Males		Females		Total	
Age (years)	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
0–4	204	0.4	193	0.3	397	0.4
5–9	959	1.8	830	1.4	1,789	1.6
10–14	1,477	2.8	1,482	2.5	2,959	2.7
15–19	1,657	3.2	1,406	2.4	3,063	2.8
20–24	1,159	2.2	1,377	2.4	2,536	2.3
25–29	1,086	2.1	3,089	5.3	4,175	3.8
30–34	1,369	2.6	6,071	10.4	7,440	6.7
35–39	1,800	3.4	7,623	13.1	9,423	8.5
40–44	2,304	4.4	4,661	8.0	6,965	6.3
45–54	7,414	14.1	5,899	10.1	13,313	12.0
55–64	11,960	22.8	8,258	14.2	20,218	18.3
65–74	11,125	21.2	7,810	13.4	18,935	17.1
75+	9,985	19.0	9,464	16.3	19,449	17.6
Total	**52,499**	**100.0**	**58,163**	**100.0**	**110,662**	**100.0**

Source: National Diabetes Register (data extracted December 2008).

Table C7.2: NDR registrants: state or territory of current residence, by remoteness areas, 2005–2007

State/territory of current residence	Major cities	Inner regional	Outer regional	Remote/ Very remote	Total[(a)]
			Number		
NSW	15,859	3,969	1,262	136	21,229
Vic	10,587	2,589	623	13	13,815
Qld	6,614	2,676	1,730	557	11,581
WA	2,814	611	384	255	4,064
SA	2,748	466	526	140	3,880
Tas	. .	777	476	23	1,276
ACT	740	2	. .	. .	742
NT	. .	. .	169	150	319
Total	**39,363**	**11,089**	**5,172**	**1,273**	**56,918**
			Per cent		
NSW	74.7	18.7	5.9	0.6	100.0
Vic	76.6	18.7	4.5	0.1	100.0
Qld	57.1	23.1	14.9	4.8	100.0
WA	69.2	15.0	9.5	6.3	100.0
SA	70.8	12.0	13.6	3.6	100.0
Tas	. .	60.9	37.3	1.8	100.0
ACT	99.8	0.2	. .	. .	100.0
NT	. .	. .	53.1	46.9	100.0
Total	**69.2**	**19.5**	**9.1**	**2.2**	**100.0**

(a) Total includes records where state or territory of current residence was unknown.

Source: National Diabetes Register (data extracted December 2008).

Table C7.3: NDR registrants: country of birth and sex, 2000–2007

	Males		Females		Persons	
Country of birth	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Australia	21,105	40.2	22,165	38.1	43,270	39.1
New Zealand	895	1.7	1,101	1.9	1,996	1.8
Other Oceania and Antarctica	517	1.0	1,011	1.7	1,528	1.4
North-West Europe	5,166	9.8	4,201	7.2	9,367	8.5
Southern and Eastern Europe	5,087	9.7	4,139	7.1	9,226	8.3
North Africa and the Middle East	1,516	2.9	1,833	3.2	3,349	3.0
South-East Asia	1,076	2.0	2,232	3.8	3,308	3.0
North-East Asia	571	1.1	1,287	2.2	1,858	1.7
Southern and Central Asia	1,048	2.0	1,914	3.3	2,962	2.7
Americas	549	1.0	769	1.3	1,318	1.2
Sub-Saharan Africa	500	1.0	624	1.1	1,124	1.0
Not stated/unknown	14,469	27.6	16,887	29.0	31,356	28.3
Total persons	**52,499**	**100.0**	**58,163**	**100.0**	**110,662**	**100.0**

Source: National Diabetes Register (data extracted December 2008).

Appendix D: Data held on the NDR

As described in Chapter 1, the NDR has two main data sources: the National Diabetes Services Scheme database (NDSS), and the Australasian Paediatric Endocrine Group's (APEG) state and territory databases. For details about NDSS and APEG, see the Data Sources section below.

Table D.1 lists the data items held on the NDR, the source of each data item, and a description of output categories available for each item. Identifiable information is used only for AIHW's management of the NDR and is not available as output. These items are marked accordingly.

Table D.1: Data collected by the NDR: field by source and output categories

Field	Collected by NDSS	Collected by APEG	Derived item	Output categories	Comments
Registrant information					
Source			X	N—NDSS A—APEG B—Both O—Other	
Registration number	X	X		Not available	Unique registration for NDSS or APEG
State/territory of registration	X	X	X	1—NSW 2—Vic 3—Qld 4—SA 5—WA 6—Tas 7—NT 8—ACT	
NDR consent	X	X	X		Must consent to be included on NDR
Research consent	X	X		Yes No	
Title (Mr, Mrs, Dr etc.)	X			Not available	
Family name	X	X		Not available	
Given names	X	X		Not available	
Other name(s)	X			Not available	
Sex	X	X		Male Female	
Address 1	X	X		Not available	
Address 2	X	X		Not available	
Address 3	X	X		Not available	
State/territory of current residence			X	1—NSW 2—Vic 3—Qld 4—SA 5—WA 6—Tas 7—NT 8—ACT	Derived from postcode of current residence

(continued)

Table D.1 (continued): Data collected by the NDR: field, by source and output categories

Field	Collected by NDSS	Collected by APEG	Derived item	Output categories	Comments
Postcode of current residence	X	X			
Phone	X			Not available	
Date of birth	X	X		Not available	
Age			X	5-year age groups	Expressed as age at a particular point in time
Indigenous status	X	X		Indigenous Non-Indigenous Not stated	
Country of birth	X	X		Australian Standard Classification of Countries for Social Statistics ABS cat. no. 1269.0 (ABS 1998)	
Main language spoken at home	X			Diabetes Australia language code	
Postcode at diagnosis	X	X			
Diagnosis date	X			Year of diagnosis	For APEG diagnosis date is assumed to be the same date as date of first insulin use
Age at diagnosis			X	5-year age groups	Derived from date of birth and date of diagnosis
Time since diagnosis	X			Not recorded Last year 1–2 years ago 3–5 years ago More than 5 years	
Registration date	X	X		Year of registration	Year of registration with NDSS or APEG
Diabetes type—reported	X	X		1—Type 1 2—Type 2 3—Gestational 4—Other types of diabetes	
Diabetes type—derived			X	1—Type 1 2—Type 2 3—Gestational 4—Other types of diabetes 9—Not derived	See Appendix B.3 for more information
Date of first insulin injection	X	X		Year of first insulin use	
Time since first insulin injection	X			Not recorded Last year 1–2 years ago 3–5 years ago More than 5 years	
Age at first insulin use			X	5-year age groups	Derived from date of birth and date of first insulin injection
Insulin type—injection	X			No Yes	

(continued)

Table D.1 (continued): Data collected by the NDR: field, by source and output categories

Field	Collected by NDSS	Collected by APEG	Derived item	Output categories	Comments
Insulin type—pump	X			No Yes	
Insulin type—other therapy	X			No Yes	
Date of first syringe purchase	X			Year of first syringe purchase	
Vital status			X	1—Alive 2—Deceased	
Year of death			X	Year of death	
Underlying cause of death			X	ICD-10 coding	
Associated cause(s) of death			X	ICD-10 coding	
Form ID	X			Old—pre-2003 form change New—post-2003 form change	
Date last modified	X			Not available	No information on what was modified
Doctor's details					
Certifying doctor's name		X		Not available	
Doctor's address 1		X		Not available	
Doctor's address 2		X		Not available	
Doctor's address 3		X		Not available	
Doctor type		X		G—General practitioner E—Endocrinologist S—Specialist O—Other medical practitioner D—Diabetes educator	
Doctor's provider number		X		Not available	
Doctor's research involvement		X		Not available	
Certified by a doctor	X			No Yes (GP, specialist, endocrinologist)	
Certified by a Credentialed Diabetes Educator-Registered Nurse	X			No Yes	
Carer details					
Carer family name		X		Not available	
Carer given name		X		Not available	
Carer phone number		X		Not available	
Carer flag (carer details are present)	X			No Yes	
Flag—use carer's mailing address)	X			No Yes	

Appendix E: Concordance between NDSS and APEG

The overlap between the APEG and NDSS records on the NDR is summarised in tables E.1 and E.2, by year of first insulin use and state, respectively. The tables show that APEG records as a proportion of NDSS records ranged between 77% and 83% for the first 5 years. One possible reason for the drop off in the proportion in 2004 could be the introduction of the new NDSS registration form in late 2003, which changed the consent arrangement to an opt-out system, meaning the NDR now receives a higher proportion of total NDSS records than in the past. The lower coverage for the final year is likely to improve as more APEG records for that period are received.

The concordance varies greatly by state, from 47% in the Northern Territory to 104% in Western Australia (Table E.2).

Table E.1: Concordance between NDSS and APEG records for registrants first diagnosed in 1999–2007 and aged 0–14 years at time of diagnosis, by year

Year	Both APEG and NDSS	NDSS only	APEG only	Total	APEG as proportion of NDSS (per cent)
1999	392	221	118	731	83.2
2000	510	209	55	774	78.6
2001	577	213	80	870	83.2
2002	611	255	65	931	78.1
2003	657	281	64	1,002	76.9
2004	616	367	42	1,025	66.9
2005	531	369	55	955	65.1
2006	545	403	26	974	60.2
2007	537	480	28	1,045	55.6

Source: National Diabetes Register (data extracted December 2008).

Table E.2: Concordance between NDSS and APEG records for registrants first diagnosed in 1999–2007 and aged 0–14 years at time of diagnosis, by state/territory of residence

State/territory of residence	Both APEG and NDSS	NDSS only	APEG only	Total	APEG as proportion of NDSS (per cent)
NSW	1,457	899	178	2,534	69.4
Vic	1,187	828	106	2,121	64.2
Qld	866	756	76	1,698	58.1
WA	764	36	67	867	103.9
SA	447	146	59	652	85.3
Tas	160	47	34	241	93.7
ACT[(a)]	78	59	9	146	63.5
NT[(b)]	17	26	3	46	46.5
Australia[(c)]	**4,976**	**2,798**	**533**	**8,307**	**70.9**

(a) APEG records for the Australian Capital Territory are collected by the New South Wales APEG register.

(b) APEG records for the Northern Territory are collected by the Queensland and South Australian APEG registers.

(c) Columns may not add to the Australian totals as these include records were state/territory of residence was unknown.

Source: National Diabetes Register (data extracted December 2008).

Appendix F: Data sources

AIHW population database

Population data held by the AIHW are sourced from the ABS Demography section and are updated as revised/new estimates become available. All population estimates currently produced by ABS are based on a current residence concept; that is, where people usually reside, and are referred to as Estimated Resident Populations.

De-identified NDSS data set

The de-identified NDSS data set is a file provided by Diabetes Australia Ltd that contains de-identified information on all NDSS registrations since 1987. This report analyses data on registrants in the scope of the NDR; that is, they use insulin to treat their diabetes, and their insulin use started on or after 1 January 1999.

National Death Index

The National Death Index is a database housed at the Australian Institute of Health and Welfare 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 index is designed to help epidemiological studies, and its use is strictly confined to medical research.

National Diabetes Register

The NDR has two sources of ascertainment: the National Diabetes Services Scheme database, and the Australasian Paediatric Endocrine Group's state and territory databases for children aged 0–14 years.

National Diabetes Services Scheme

The NDSS is an Australian Government initiative that subsidises the supply of insulin syringes, insulin infusion pump consumables and diagnostic reagents (blood and urine testing strips) to registered people with diabetes. The scheme was established in 1987, and is administered by Diabetes Australia Ltd, which coordinates the supply of products in all states and territories. The NDSS aims to enhance the capacity of people with diabetes to understand and manage their life with diabetes, and to ensure they have timely, reliable and affordable access to the supplies and services they need to effectively self-manage their condition (see Table D.1 for a list of the data items that the NDSS contributes to the NDR).

Australasian Paediatric Endocrine Group

APEG is the professional body in Australia and New Zealand that represents those involved in management and research of children with disorders of the endocrine system including diabetes mellitus.

APEG is actively involved in setting standards of care for children and adolescents with diabetes. One aspect of this care is APEG's state-based databases, which collect diagnosis information on children and adolescents with Type 1 diabetes. Each state has established its database independently, and at varying times since 1985, but all collect the same minimum data set (see Table D.1 for a list of the data items that APEG contributes to the NDR).

Glossary

Associated cause of death

Any condition, disease and injury—other than the underlying cause—considered to contribute to a death. Compare with *Underlying cause of death.* See also C*ause of death.*

Cause of death

From information reported on the medical certificate of cause of death, each death is classified by the underlying cause of death according to rules and conventions of the 10th revision of the International classification of diseases (ICD-10). See also U*nderlying cause of death* and *Associated cause of death.*

Derived diabetes type

Refers to how a classification of individuals on the NDR as Type 1, Type 2 and so on is derived from data in the NDR. The method of calculation (algorithm) is based on age of diagnosis and the period between the date of diagnosis and start of insulin use. For more information, see Appendix B.3.

Diabetes (diabetes mellitus)

A chronic condition in which the body cannot properly use its main energy source, the sugar glucose. This is due to either the pancreas not producing enough of the hormone insulin, or the body being unable to effectively use the insulin produced. Insulin 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 can have serious short- and long-term effects on many of the body's systems, especially the blood vessels and nerves.

For the different types of diabetes, see *Type 1 diabetes, Type 2 diabetes, Gestational diabetes mellitus* and *Other types of diabetes.*

Gestational diabetes mellitus

Develops during pregnancy in some women but usually disappears when the pregnancy is over. However, women who have had gestational diabetes are at greater risk of developing *Type 2 diabetes* later in life. Gestational diabetes increases the risk of perinatal morbidity and mortality. See Box 1.1.

Women who had their diabetes diagnosed before a pregnancy do not fall into this category.

Glucose

A simple sugar that is the major source of energy for the body and the sole source of energy for the brain. It is supplied through food and is also produced and released by the liver. Its proper use requires the hormone insulin.

Incidence

The number of new cases (of an illness or event) occurring during a given period. Compare with *Prevalence.*

Insulin

A hormone produced by the pancreas. Its main action is to enable body cells to absorb glucose from the blood and use it for energy.

Insulin-treated diabetes

All types of diabetes treated with insulin, includes Type 1, Type 2, gestational and other types of diabetes. It is a term used to describe those on the NDR, and is not a standard classification used in clinical practice.

Latent autoimmune diabetes in adults (LADA)

Adult patients with a slowly progressive form of autoimmune or Type 1 diabetes who could be treated initially without insulin injections.

Other types of diabetes

Other types of diabetes include certain conditions or syndromes, such as:

- genetic defects of beta-cell function (formerly referred to as maturity-onset diabetes of the young (MODY)
- genetic defects in insulin action
- diseases of the exocrine pancreas (for example, cystic fibrosis and cancer of the pancreas)
- endocrinopathies (for example, acromegaly and Cushing's Syndrome)
- drug- or chemical-induced diabetes (for example, steroid-induced diabetes)
- infections (for example, congenital rubella)
- uncommon but specific forms of immune-mediated diabetes mellitus
- other genetic syndromes sometimes associated with diabetes (WHO 1999).

These types of diabetes are relatively uncommon. Only those being treated with insulin for these types of diabetes are included on the National Diabetes Register. See Box 2.1 for more information.

Pancreas

The organ that lies behind the lower part of the stomach and produces insulin.

Prevalence

The number or proportion (of cases or instances) present in a population at a given time. Compare with *Incidence.*

Reported diabetes type

The type of diabetes recorded on the NDSS or APEG registration forms. Diabetes type is known to be misreported in many instances; for more information see Appendix B.3.

Type 1 diabetes

Mostly arises in childhood or young adults, though can occur at any age. It is marked by the inability to produce insulin. People with Type 1 diabetes need insulin replacement for survival. Most cases are caused by an autoimmune condition that destroys the pancreatic cells that produce insulin. See Box 1.1.

Type 2 diabetes

The most common form of diabetes, which occurs mostly in people aged 40 years and over. People with Type 2 diabetes produce insulin but may not produce enough or cannot use it effectively. Some cases may be managed with changes to diet, along with increased exercise and weight loss. Many require drugs as well, namely oral glucose-lowering drugs that work on the pancreas. Many others require insulin in addition to other treatments. See Box 1.1.

Underlying cause of death

The condition, disease or injury initiating the sequence of events leading directly to death; that is, the main cause. Compare with *Associated cause(s) of death.*

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