Incidence of Type 1 diabetes in Australian children 2000–2008

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Please note that there is the potential for minor revisions of data in this report. Please check the online version at <www.aihw.gov.au> for any amendments.

Contents

Acknowledgments

Abbreviations

AIHW   Australian Institute of Health and Welfare

APEG   Australasian Paediatric Endocrine Group

NDR   National Diabetes Register

NDSS   National Diabetes Services Scheme

OECD   Organisation for Economic Co-operation and Development

Summary

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

The report focuses on children with Type 1 diabetes who were aged 0–14 years when they began using insulin. It includes information on the incidence of the disease by various demographic factors, as well as trends over the 9-year period from 2000 to 2008.

The picture

- The incidence of Type 1 diabetes in Australian children increased significantly over the first part of the decade (2000–2004), but since 2005 there has been little change in the rate of new cases.

- On average, every day there are two new cases of Type 1 diabetes in Australian children.

Some numbers behind the picture

- Australia remains in the top 10 countries with the highest rates of Type 1 diabetes in children.
- There were over 8,000 new cases of Type 1 diabetes in Australian children during the period 2000–2008.
- The incidence of Type 1 diabetes in children increased from 19 to 24 new cases per 100,000 population between 2000 and 2004, at an average rate of 6.2% a year, but did not change significantly between 2005 and 2008.
- The incidence rate was higher among boys aged 0–4 years than among girls of the same age. However, there were no differences between boys and girls in the older age groups.
- Incidence rates were twice as high among 10–14 year olds as for 0–4 year olds (29.3 per 100,000 compared with 14.3 over the 9-year period), with the rate for 5–9 year olds sitting in between (24.1).

Introduction

Diabetes has a major impact on quality of life and life expectancy. The National Diabetes Register (NDR) was set up as an important part of Australia's monitoring system for diabetes. This monitoring is essential to improve Australia's ability to plan preventive and treatment services, identify and focus on priority population groups, track the effects of environmental change and prevention and control strategies, and decide the cost-effective allocation of resources (AIHW: Dixon & Webbie 2006).

The NDR now has 10 years of data on over 21,300 cases of people with Type 1 diabetes diagnosed over the period 1999–2008. Almost 9,000 children (aged 0–14 years) on the NDR have Type 1 diabetes.

This report focuses on new cases of Type 1 diabetes in Australian children, that is, children who were aged 0–14 years when they began using insulin to treat their diabetes. This report only includes data for 2000–2008 because of lower coverage rates in 1999 (see Table 1). Specifically, it provides incidence estimates for Type 1 diabetes in children aged 0–14 years by age, sex, year of first insulin use, Indigenous status and state or territory of current residence for the period 2000–2008. It also provides trends in incidence over the 9-year period. ('Incidence' refers to the number of new cases of an illness occurring during a given period.)

> For the most recent statistics on Australians of all ages with all types of insulin-treated diabetes, refer to our recent publication *Insulin-treated diabetes in Australia 2000–2007*.
>
> For a full list of NDR publications see our website <www.aihw.gov.au/diabetes/publications.cfm>.

National Diabetes Register

The NDR 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 and other types of diabetes. The register was set up in 1999 as a result of a recommendation of the National Diabetes Strategy and Implementation Plan (Colagiuri et al. 1998). The NDR aims to record all new cases of people who use insulin to treat their diabetes. This means that it should cover all new cases of Type 1 diabetes because they all need insulin treatment. The register is based on insulin treatment rather than type of diabetes 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 2000. As the register now has 10 years of data, it can also be used to estimate the prevalence of Type 1 diabetes in Australian children aged 0–9 years. The Australian Institute of Health and Welfare (AIHW) will publish a report on this shortly.

The NDR is managed by staff of the National Centre for Monitoring Diabetes at the AIHW, and is largely funded by the Australian Government Department of Health and Ageing.

Diabetes

Diabetes is a serious illness. It is associated with many other illnesses and, if not properly managed, can cause considerable morbidity and mortality. People with diabetes may suffer many complications and reduced quality of life. They need lifelong treatment and continual monitoring by health professionals.

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 cannot make enough 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. Diabetes can also cause many serious health complications, some of which may occur within months of diagnosis while others may develop over several years.

Some of the short-term complications of diabetes include diabetic ketoacidosis (resulting from a severe lack of insulin), hypoglycaemia (resulting from too much insulin or insufficient intake of glucose), increased susceptibility to infections and reduced ability to heal. Longer term complications include diseases 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). 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 the community. In 2003, diabetes accounted for more than 5% of the disease burden in Australia (Begg et al. 2007). The burden increases to 8% 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.

Diabetes is one of the most prevalent chronic diseases in Australia and many other countries, and is sometimes described as an epidemic. It is estimated that, if preventive programs are not put in place, 1 in 13 adults, or 438 million people worldwide, will have diabetes by 2030 (IDF 2009).

Types of diabetes

There are three main types of diabetes mellitus: 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. Each type of diabetes has different causes and requires different treatment (see Box 1).

Box 1: Types of diabetes

Type 1 diabetes commonly arises in children or young adults, although 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 the destruction of the insulin-producing cells in the pancreas by the body's immune system.

Type 2 diabetes is the most common form of diabetes. Although it occurs mostly in people aged 40 years and over, recent trends have shown 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 need medications as well, usually oral glucose-lowering drugs, although non-insulin injectable medications are now also available. Many others require insulin as well as the other treatments, particularly when the disease has been long-lasting. Only insulin-treated cases of Type 2 diabetes are included on the NDR.

Gestational diabetes mellitus is a form of diabetes that may develop during pregnancy. 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, but 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 and insulin action (formerly referred to as maturity-onset diabetes of the young)
- 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 (ADA 2010).

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

Type 1 diabetes

Type 1 diabetes, also known as juvenile-onset diabetes, accounts for about 13% of all diabetes in Australia but more than 90% of diabetes in children aged 0–14 years. It can occur at any age, although more than half of cases arise in childhood or adolescence. Type 1 diabetes is characterised by progressive destruction of the insulin-producing cells in the pancreas.

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 unplanned weight loss. The excess of ketones makes the blood acidic (ketoacidosis), and without urgent medical

intervention this can lead to coma and death. While the process may develop gradually over months or years, patients with this type of diabetes usually present at a health service with symptoms that have rapidly worsened over several weeks, when only small numbers of insulin-producing cells remain.

Treatment is with insulin, given either by injection several times a day or continuously by an insulin pump, with frequent monitoring of blood glucose levels. This usually involves pricking a small needle into the tip of the finger and placing a drop of blood on a reagent strip, which gives a reading to guide the patient on the insulin dose the body needs. A well-balanced and healthy diet, and continued monitoring of the diabetes by a multidisciplinary health team are essential for maintaining good 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 possible environmental risk factors being investigated include viruses; diet, such as early consumption of cow's milk; and low levels of vitamin D (Greer et al. 2007; Littorin et al. 2006; Vaarala 2005; Yoon et al. 1999).

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

This chapter presents estimates of the incidence of Type 1 diabetes in children aged 0–14 years at their first insulin use. It covers the period 2000–2008, and updates results previously published in *Insulin-treated diabetes in Australia 2000–2007* (AIHW 2009) and 'Australia's national trends in the incidence of Type 1 diabetes in 0–14-year-olds, 2000–2006' (Catanzariti et al. 2009). It therefore contains the most up-to-date NDR statistics on the incidence of Type 1 diabetes in Australian children between 2000 and 2008. Information is presented by age, sex, year of first insulin use, state or territory of current residence and Indigenous status. As well, results from Australia are compared with results from other countries.

Coverage

NDR data show that 8,259 children aged 0–14 years with Type 1 diabetes began using insulin between 2000 and 2008. 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 9-year period was estimated to be 97.7% (Table 1). Based on this estimate, 197 cases could have been missed by both sources over the 9 years. The coverage rate has remained consistently high during the period 2000–2008. Coverage in 1999 was lower and has therefore been excluded from the analyses presented in this report. (See Appendix B.6 for more information on this method and Appendix A for more information on the NDR data sources.)

Table 1: Coverage of Type 1 diabetes on the National Diabetes Register among children aged 0–14 years at their first insulin use, by year of first insulin use, 1999 to 2008

Year of first insulin use	Males			Females			Persons		
	NDR registrants (number)	Missing cases[a] (number)	Coverage rate[b] (per cent)	NDR registrants (number)	Missing cases[a] (number)	Coverage rate[b] (per cent)	NDR registrants (number)	Missing cases[a] (number)	Coverage rate[b] (per cent)
1999	366	38	90.7	350	28	92.6	716	65	91.6
2000	394	13	96.7	363	7	98.1	757	20	97.4
2001	453	15	96.8	397	14	96.6	850	29	96.7
2002	461	14	97.0	441	9	97.9	902	24	97.4
2003	499	12	97.6	481	12	97.5	980	25	97.5
2004	513	11	97.9	465	10	97.9	978	21	97.9
2005	468	11	97.8	435	20	95.5	903	31	96.7
2006	496	12	97.6	424	3	99.3	920	15	98.4
2007	526	11	97.9	463	8	98.3	989	19	98.1
2008	503	9	98.3	477	4	99.1	980	13	98.7
Total 2000–2008	**4,313**	**109**	**97.5**	**3,946**	**89**	**97.8**	**8,259**	**197**	**97.7**

(a)   Estimated number of missing cases using the capture–recapture method with the two independent data sources the National Diabetes Services Scheme and the Australasian Paediatric Endocrine Group.

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

Notes

1.   Columns and rows may not add to totals due to rounding.

2.   The total coverage shown here includes only 2000–2008. Data from 1999 are not included in any calculations in this report.

Source: National Diabetes Register (data extracted January 2010).

Age and sex

Between 2000 and 2008, 8,259 new cases of Type 1 diabetes among children aged 0–14 years were registered on the NDR—4,313 boys and 3,946 girls (tables 1 and C1). The total number of new cases equates to 2–3 new cases each day over the 9-year period.

The average age-standardised rate of new cases a year for the 9-year period was 23.2 per 100,000 population for boys and 22.4 for girls (Figure 1; Table 2). No significant differences in incidence were found between boys and girls. This is consistent with the findings of a Western Australian study by Haynes and colleagues (2004) and a Victorian study by Chong and colleagues (2007), but in contrast to a New South Wales study by Taplin and colleagues (2005).

Between 2000 and 2008, the age-standardised incidence rate for Type 1 diabetes among children aged 0–14 years increased significantly, from 19.1 to 23.9 per 100,000, at an estimated average increase of 1.7% each year. However, most of the increase occurred between 2000 and 2004, when the rate increased by an average of 6.2% a year. Since 2005 there has been no significant change in the overall incidence rate for 0–14 year olds (Table 3). (See Appendix B.4 for more information about the methodology used to estimate the average annual change.)

Similar trends were also observed in each of the three age groups. The rate of new cases increased significantly by an estimated 5.7% per year for 0–4 year olds (from 12.2 to 14.9 per 100,000), 6.4% for 5–9 year olds (from 20.6 to 26.2) and 6.5% for 10–14 year olds (from 24.2 to 31.4) between 2000 and 2004, but there were no significant changes in any age group between 2005 and 2008 (Figure 2; tables 2 and 3).

In every year, the Type 1 diabetes incidence rate increased significantly with increasing age group for both sexes (Figure 2; Table 2). Between 2000 and 2008, the average annual rate was lowest in the 0–4 year age group (14.6 per 100,000) and highest in the 10–14 year age group (29.3), with the 5–9 year age group sitting in between at 24.1 (Figure 1).

Comparing boys and girls in different age groups over the 9-year period, the incidence rate was significantly higher among boys aged 0–4 years (15.6 per 100,000) than girls of the same age (13.6) (Figure 1; Table 2). However, there were no differences in incidence rates between boys and girls aged 5–9 years or 10–14 years.

Compared with previously published NDR reports, the estimated average increase for the age-standardised incidence rates for Type 1 diabetes in children aged 0–14 years has dropped from 2.7% each year for 2000–2006 (AIHW 2008) to 2.2% a year for 2000–2007 (AIHW 2009) and to 1.7% a year for 2000–2008. The reduction in the estimated average increase (while still being a statistically significant increase) is most likely due to a plateau in the incidence rates from 2005 onwards. This contrasts with the increasing incidence in Finland and other parts of Europe (Harjutsalo et al. 2008; Schober et al. 2009).

Table 2: Incidence of Type 1 diabetes among children aged 0–14 years: sex and age, by year of first insulin use, 2000 to 2008 (number per 100,000 population)

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2008	Average 2000– 2008[a]
Males										
0–4	13.0	16.0	16.2	19.1	16.2	16.2	14.3	15.1	14.2	15.6
5–9	19.9	21.0	22.2	23.2	25.4	22.3	23.0	26.1	25.6	23.2
10–14	25.0	29.1	28.6	30.1	32.5	28.9	33.7	33.6	31.4	30.4
Males 0–14 ASR[b]	*19.4*	*22.2*	*22.5*	*24.3*	*24.8*	*22.6*	*23.8*	*25.1*	*23.9*	*23.2*
(95% CI)	*(17.5–21.4)*	*(20.2–24.3)*	*(20.5–24.6)*	*(22.2–26.5)*	*(22.7–27.1)*	*(20.6–24.7)*	*(21.8–26.0)*	*(23.0–27.4)*	*(21.9–26.1)*	*(22.5–23.9)*
Females										
0–4	11.4	12.3	14.0	14.6	13.5	14.7	12.5	14.9	13.9	13.6
5–9	21.3	23.7	24.4	28.5	27.0	24.0	23.4	25.5	26.8	25.0
10–14	23.3	24.8	29.0	30.3	30.2	27.4	28.0	29.2	30.5	28.1
Females 0–14 ASR[b]	*18.8*	*20.4*	*22.6*	*24.6*	*23.8*	*22.2*	*21.5*	*23.3*	*23.9*	*22.4*
(95% CI)	*(16.9–20.8)*	*(18.5–22.5)*	*(20.6–24.8)*	*(22.5–26.9)*	*(21.6–26.0)*	*(20.1–24.4)*	*(19.5–23.6)*	*(21.3–25.6)*	*(21.8–26.1)*	*(21.7–23.1)*
Persons										
0–4	12.2	14.2	15.1	16.9	14.9	15.5	13.4	15.0	14.0	14.6
5–9	20.6	22.3	23.3	25.8	26.2	23.1	23.2	25.8	26.2	24.1
10–14	24.2	27.0	28.8	30.2	31.4	28.2	30.9	31.5	30.9	29.3
Total persons 0–14 ASR[b]	**19.1**	**21.3**	**22.5**	**24.4**	**24.3**	**22.4**	**22.7**	**24.3**	**23.9**	**22.8**
(95% CI)	**(17.8–20.5)**	**(19.9–22.8)**	**(21.1–24.1)**	**(22.9–26.0)**	**(22.8–25.9)**	**(21.0–23.9)**	**(21.2–24.2)**	**(22.8–25.8)**	**(22.4–25.4)**	**(22.3–23.3)**

ASR   age-standardised rate

CI   confidence interval

(a)   The rate is the average annual rate for the 9 years.

(b)   Age-standardised to the 2001 Australian population (see Appendix B.3).

Source: National Diabetes Register (data extracted January 2010).

Number per 100,000 population
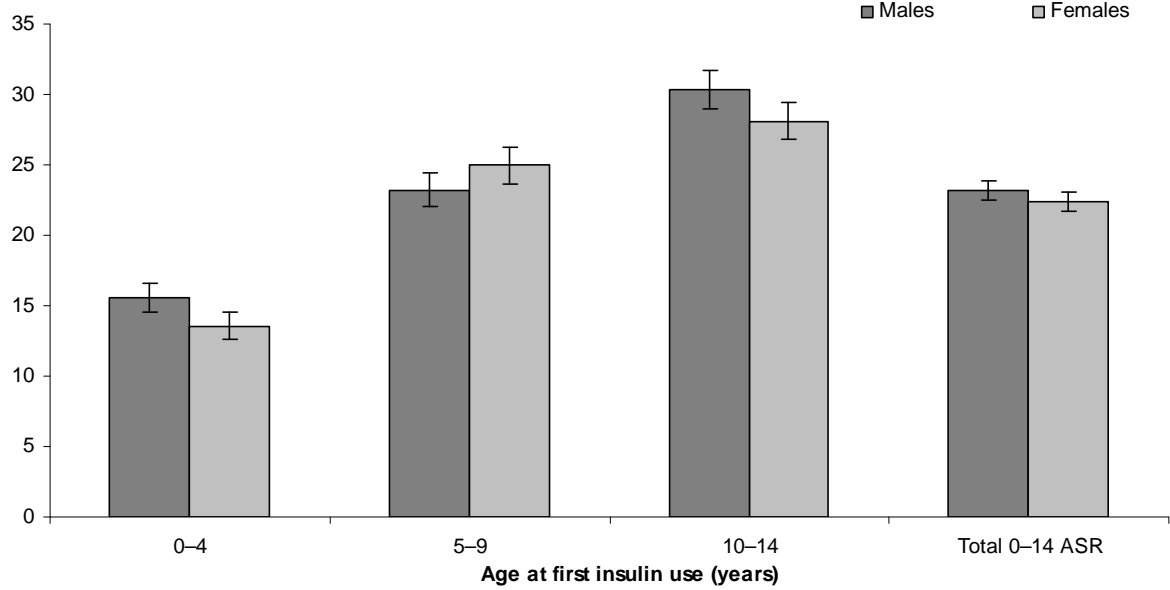
ASR   age-standardised rate

Note: The total rate for those aged 0–14 years is age-standardised to the 2001 Australian population (see Appendix B.3).

Source: National Diabetes Register (data extracted January 2010).

Figure 1: Incidence of Type 1 diabetes in children aged 0–14 years, by age and sex, 2000–2008

Number per 100,000 population
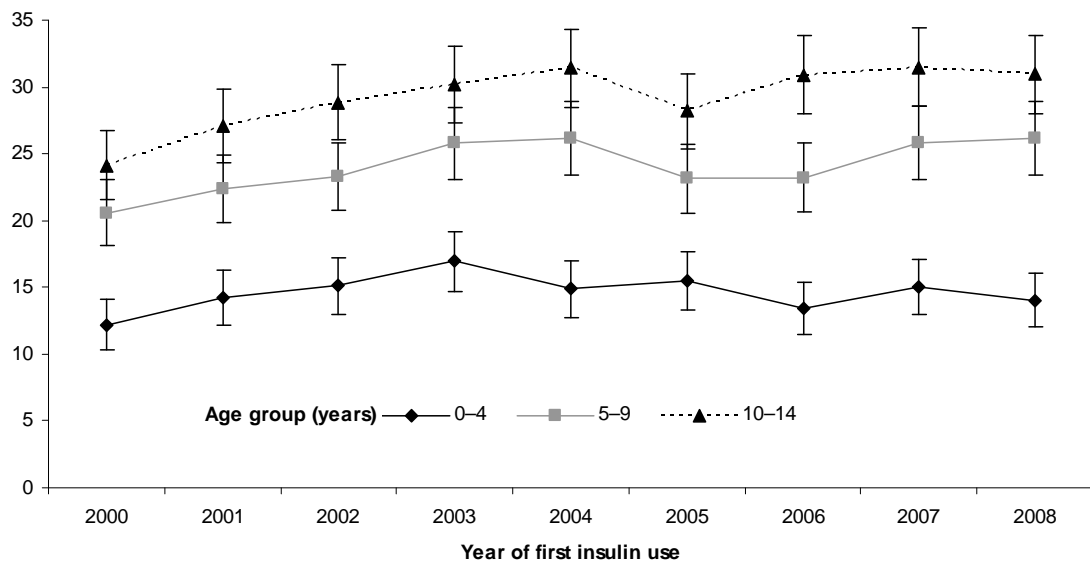
Source: National Diabetes Register (data extracted January 2010).

Figure 2: Incidence of Type 1 diabetes in children aged 0–14 years, by year of first insulin use, 2000 to 2008

Table 3: Average annual increase in the incidence of Type 1 diabetes among children aged 0–14 years, by year of first insulin use

Age at first insulin use (years)	2000–2004	2005–2008	2000–2008
0–4	5.7	–1.8	0.7
(95% CI)	(0.9–10.6)	(–7.8–4.7)	(–1.1–2.6)
5–9	6.4	4.9	2.2
(95% CI)	(2.7–10.1)	(0.0–10.1)	(0.8–3.6)
10–14	6.5	3.0	2.3
(95% CI)	(3.1–9.9)	(–1.3–7.5)	(1.0–3.6)
0–14	**6.2**	**2.0**	**1.7**
(95% CI)	**(3.9–8.5)**	**(–1.0–5.1)**	**(0.8–2.6)**

CI   confidence interval

Note: Estimate based on Poisson regression modelling (see Appendix B.4).

Source: National Diabetes Register (data extracted January 2010).

Indigenous status

Data on the Indigenous status of NDR registrants are presented only for 2005–2008 because of deficiencies in the way these data were captured in the NDSS database before 2005 (see Appendix B.7 for more information).

Although the proportion of registrants who did not state their Indigenous status has dropped since last reported in 2007 (when it was 20% for 2005–2007) (AIHW 2009), there were still 15% of registrants with 'not stated' Indigenous status (Table 4). The NDR may underestimate the number of Indigenous registrants with Type 1 diabetes. This could be because of low registration rates for the NDSS, particularly in certain geographical areas, or under-reporting of Indigenous status. This should be taken into account when interpreting the data.

During 2005–2008, 90 children recorded as of Aboriginal and/or Torres Strait Islander origin began to use insulin to treat Type 1 diabetes. This is 2.4% of all new cases of Type 1 diabetes in those aged 0–14 years (Table 4). When children who did not have their Indigenous status recorded were excluded from the analyses, the rate of new cases in the Indigenous population was, at a minimum, 11.6 per 100,000 population.

For all groups in Table 4—'Indigenous', 'non-Indigenous' and 'not stated'—the number of cases increased with age.

Table 4: New cases of insulin-treated Type 1 diabetes in children aged 0–14 years by Indigenous status, 2005–2008

Age at first insulin use (years)	Indigenous	Non-Indigenous	Not stated	Total persons
Number				
0–4	16	627	126	769
5–9	28	1,097	195	1,320
10–14	46	1,403	254	1,703
Total persons 0–14	**90**	**3,127**	**575**	**3,792**
Per cent				
0–4	2.1	81.5	16.4	100.0
5–9	2.1	83.1	14.8	100.0
10–14	2.7	82.4	14.9	100.0
Total persons 0–14	**2.4**	**82.5**	**15.2**	**100.0**

Source: National Diabetes Register (data extracted January 2010).

State and territory of current residence

It is useful to look at the incidence of Type 1 diabetes by state and territory of current residence as it provides a better understanding of where children with Type 1 diabetes live. Service providers and policy decision makers can then use this information to make decisions and plan appropriate services.

Coverage of the NDR over the 9-year period remained high across all states and territories; it was estimated to range from 96.4% in Tasmania to 100% in the Northern Territory (see Appendix B.6 for more information on the method used to calculate coverage).

Over 2000–2008, the rate of new cases of Type 1 diabetes among those aged 0–14 years differed among the states and territories (tables 5 and C2). As reported in *Insulin-treated diabetes in Australia 2000–2007* (AIHW 2009), Tasmania remains the state with the highest average incidence rate of Type 1 diabetes among those aged 0–14 years, at 28.3 per 100,000 population. The rate of new cases in Tasmania was significantly higher than that of Queensland (23.2), Western Australia (22.9), New South Wales (21.0), the Northern Territory (10.2) and the Australian average (22.8). The Northern Territory had the lowest rate reported through the NDR, significantly lower than in any other jurisdiction.

Between 2000 and 2008, the annual age-standardised rate increased significantly—by 2.0%—in both New South Wales and Victoria (based on Poisson regression modelling, see Appendix B.4). With the exception of the Australian Capital Territory, the age-standardised rate did not increase significantly over the 9-year period in any other jurisdiction, and this may reflect the smaller numbers involved. While the average annual increase in the Australian Capital Territory was statistically significant, the 95% confidence interval is too wide for the figure to be reliable. Because of the small numbers involved, it is advisable to disregard annual variations in the smaller states and territories.

In line with the national picture, the incidence of Type 1 diabetes among those aged 0–14 years increased with age in all states and territories (tables 6 and C2).

Table 5: Incidence of Type 1 diabetes among children aged 0–14 years: year of first insulin use, by state and territory of current residence, 2000 to 2008 (number per 100,000 population[a])

Year of first insulin use	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
2000	18.6	19.4	20.1	17.9	23.0	14.9	16.8	10.0	19.1
2001	20.1	22.1	22.9	20.9	21.5	26.2	19.8	10.3	21.3
2002	20.7	24.1	21.3	25.6	27.1	26.5	19.8	6.0	22.5
2003	20.1	27.1	25.7	26.4	31.0	29.7	21.4	10.3	24.4
2004	23.2	23.6	24.7	24.2	28.7	31.6	29.9	16.2	24.3
2005	19.8	24.8	23.1	20.7	21.1	41.0	30.4	5.8	22.4
2006	20.5	24.5	23.0	21.2	27.1	33.8	17.6	11.9	22.7
2007	21.4	26.7	25.9	26.6	19.7	21.8	44.4	10.0	24.3
2008	24.2	23.6	21.8	22.9	31.1	29.9	25.3	11.3	23.9
Average 2000–2008 (95% CI)	**21.0 (20.1–21.8)**	**24.0 (23.0–25.1)**	**23.2 (22.1–24.3)**	**22.9 (21.4–24.5)**	**25.6 (23.7–27.6)**	**28.3 (24.9–32.0)**	**25.0 (21.1–29.4)**	**10.2 (7.5–13.6)**	**22.8 (22.3–23.3)**

CI   confidence interval

(a)   Age-standardised to the 2001 Australian population (see Appendix B.3).

Source: National Diabetes Register (data extracted January 2010).

Table 6: Incidence of Type 1 diabetes among children aged 0–14 years: sex and age, by state and territory of current residence, 2000–2008 (number per 100,000 population)

Sex and age at first insulin use (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
Males									
0–4	13.3	15.4	17.6	15.3	20.0	23.9	17.7	3.7	15.6
5–9	21.2	23.5	24.3	25.1	26.0	26.6	30.0	8.7	23.2
10–14	28.9	32.3	29.2	28.1	35.3	42.9	29.6	15.6	30.4
Total males 0–14 ASR[a] *(95% CI)*	*21.3* *(20.1–22.4)*	*23.9* *(22.5–25.4)*	*23.8* *(22.3–25.4)*	*23.0* *(20.9–25.2)*	*27.2* *(24.5–30.2)*	*31.3* *(26.3–36.8)*	*25.9* *(20.4–32.5)*	*9.4* *(5.9–14.3)*	*23.2* *(22.5–23.9)*
Females									
0–4	13.9	14.1	13.2	12.7	13.7	13.4	15.1	5.2	13.6
5–9	21.6	27.0	24.2	28.7	30.7	32.2	26.6	8.1	25.0
10–14	26.1	30.8	29.8	26.6	26.6	29.3	29.8	19.6	28.1
Total females 0–14 ASR[a] *(95% CI)*	*20.6* *(19.5–21.8)*	*24.1* *(22.7–25.7)*	*22.5* *(21.0–24.2)*	*22.9* *(20.7–25.2)*	*23.8* *(21.2–26.7)*	*25.2* *(20.7–30.4)*	*24.0* *(18.6–30.4)*	*11.0* *(7.1–16.4)*	*22.4* *(21.7–23.1)*
Persons									
0–4	13.6	14.8	15.4	14.0	16.9	18.8	16.5	4.4	14.6
5–9	21.4	25.2	24.2	26.9	28.3	29.3	28.4	8.4	24.1
10–14	27.5	31.6	29.5	27.4	31.0	36.3	29.7	17.5	29.3
Total persons 0–14 ASR[a] **(95% CI)**	**21.0** **(20.1–21.8)**	**24.0** **(23.0–25.1)**	**23.2** **(22.1–24.3)**	**22.9** **(21.4–24.5)**	**25.6** **(23.7–27.6)**	**28.3** **(24.9–32.0)**	**25.0** **(21.1–29.4)**	**10.2** **(7.5–13.6)**	**22.8** **(22.3–23.3)**

ASR age-standardised rate

CI confidence interval

(a) Age-standardised to the 2001 Australian population (see Appendix B.3).
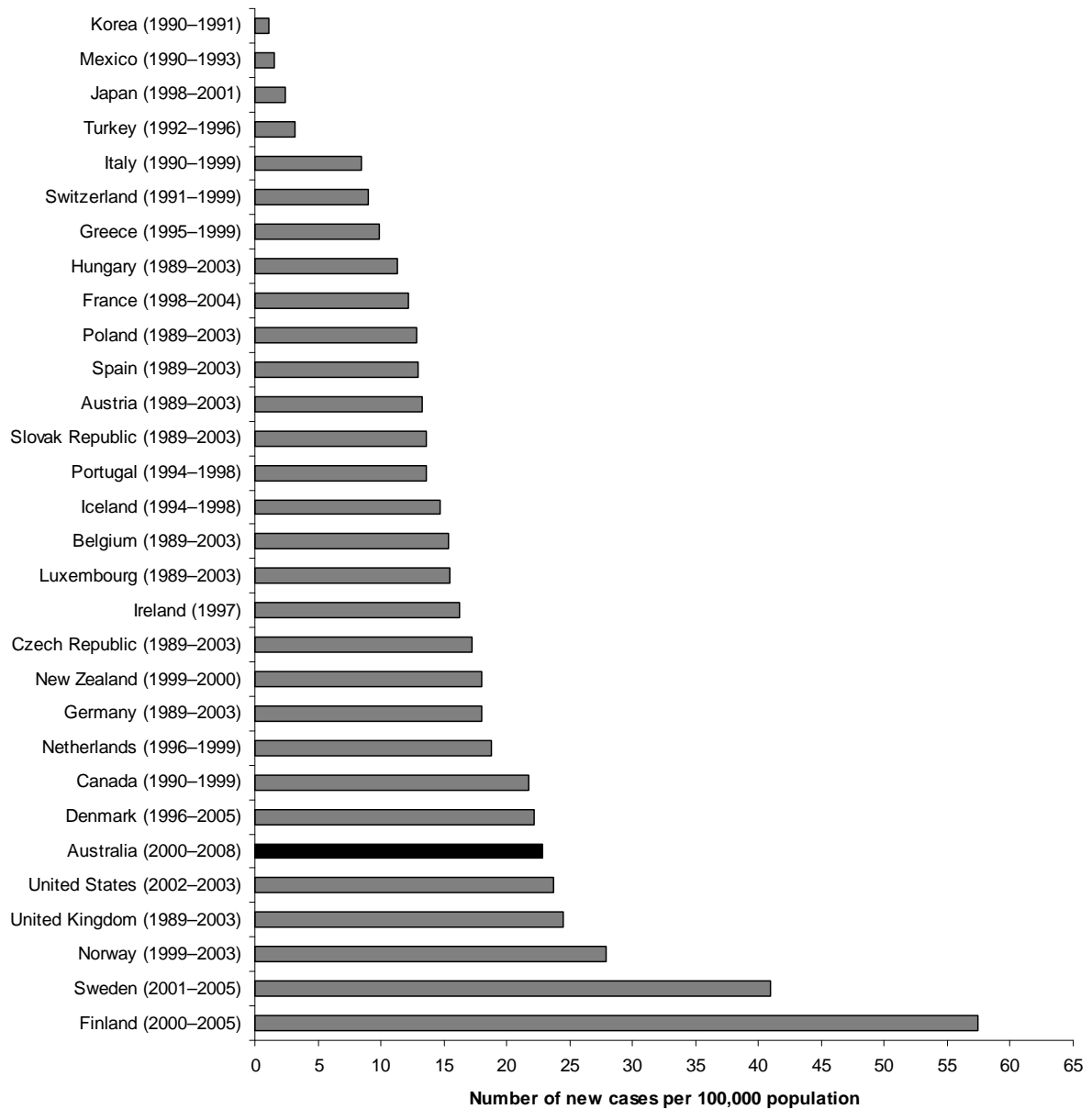
Source: National Diabetes Register (data extracted January 2010).

International comparisons

It is estimated that each year 76,000 children aged less than 15 years develop Type 1 diabetes worldwide, amounting to 480,000 children living with Type 1 diabetes (IDF 2009). In Australia, the average annual incidence of Type 1 diabetes over the period 2000–2008 was 22.8 per 100,000 population, which is high when compared with available data from other countries. Figure 3 presents data for OECD (Organisation for Economic Co-operation and Development) countries from the *Diabetes atlas* (IDF 2009), together with the Australian rate from the NDR. The data periods for the countries shown range from 1989 to 2008.

This worldwide research completed by the International Diabetes Federation found Australia to be in the top 10 countries for incidence of Type 1 diabetes in children (IDF 2009). Among OECD countries, Australia had the sixth highest rate of new cases of Type 1 diabetes at 22.8 per 100,000, behind Finland (57.4), Sweden (41.0), Norway (27.9), the United Kingdom (24.5) and the United States (23.7) (Table C4). Compared with the last *Diabetes atlas* (IDF 2006), Australia has remained in the same position at sixth. Note that the overseas data were compiled from multiple studies about childhood-onset diabetes, and so should be considered as a general indicator only.

There is considerable variation in the incidence of Type 1 diabetes in children worldwide, with the DIAMOND Project Group (2006) finding that the number of new cases over the period 1990–1999 varied from 0.1 per 100,000 a year in China and Venezuela to 40.9 per 100,000 a year in Finland. This variation 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 data from particular countries, especially those with very low gross domestic products and the largest child populations, such as Africa and South-East Asia (DIAMOND Project Group 2006).

Korea (1990–1991)
Mexico (1990–1993)
Japan (1998–2001)
Turkey (1992–1996)
Italy (1990–1999)
Switzerland (1991–1999)
Greece (1995–1999)
Hungary (1989–2003)
France (1998–2004)
Poland (1989–2003)
Spain (1989–2003)
Austria (1989–2003)
Slovak Republic (1989–2003)
Portugal (1994–1998)
Iceland (1994–1998)
Belgium (1989–2003)
Luxembourg (1989–2003)
Ireland (1997)
Czech Republic (1989–2003)
New Zealand (1999–2000)
Germany (1989–2003)
Netherlands (1996–1999)
Canada (1990–1999)
Denmark (1996–2005)
Australia (2000–2008)
United States (2002–2003)
United Kingdom (1989–2003)
Norway (1999–2003)
Sweden (2001–2005)
Finland (2000–2005)

Number of new cases per 100,000 population

Note: Incidence rate for Australia is the average annual age-standardised rate for 2000–2008 (calculated from the NDR; age-standardised to the 2001 Australian population).

Sources: IDF 2009; National Diabetes Register (for Australia).

Figure 3: Incidence of Type 1 diabetes in children aged 0–14 years: Australia compared with other OECD countries, various years

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Appendixes

Appendix A: Data sources

A.1   AIHW population database

Population data held by the AIHW are sourced from the Australian Bureau of Statistics' Demography section and are updated as revised or new estimates become available. All population estimates currently produced by the Australian Bureau of Statistics are based on a 'current residence' concept (that is, where people usually reside) and are referred to as 'Estimated Resident Populations'.

A.2   National Diabetes Register

The NDR has two sources of ascertainment: the NDSS database, and the APEG's state and territory databases for children aged 0–14 years.

National Diabetes Services Scheme

The NDSS is an Australian Government program 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 help 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 manage their condition.

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.

Appendix B: Statistical methods

B.1   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.

Box B1: Method used to derive the year of first insulin use

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.2   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).

As described in *Insulin-treated diabetes in Australia 2000–2007* (AIHW 2009), reported diabetes type may not be reliable, particularly with people reporting Type 1 diabetes when they actually have Type 2. To obtain a more accurate measure of type of diabetes, an algorithm (method of calculation, see Box B.2) has been developed to better 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 with, and agreement from, the National Diabetes Data Working Group. The current algorithm relevant for children aged 0–14 years is shown in Box B.2 (for the complete algorithm and more background information, see *Insulin-treated diabetes in Australia 2000–2007* (AIHW 2009)).

There were 173 registrants who were unable to be reclassified using the algorithm, either because there was insufficient information or 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 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.

Data collection

National Diabetes Services Scheme

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

Australasian Paediatric Endocrine Group

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. These serve 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.2: Algorithm used to derive diabetes type for children aged 0–14 years with reported Type 1 diabetes

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 time between diagnosis and first insulin use is missing, then the derived diabetes type cannot be derived
- if the time between diagnosis and first insulin use is more than 1 year, then the derived diabetes type cannot 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.

B.3   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).

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 is the age-standardised rate for the population being studied

r_i is the age-group specific rate for age group i in the population being studied

p_i is the population of age group i in the Australian standard population (persons) as at 30 June 2001.

B.4   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 2008

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 be calculated as:

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

B.5   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 and colleagues (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.

B.6   Assessing coverage of the National Diabetes Register using the capture–recapture method

The capture–recapture method as described by LaPorte and colleagues (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 this method, 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.7   Indigenous data limitations

Before 2005, if the response to the Indigenous status question was not completed on the NDSS 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). For this reason, data for Indigenous status in this report are presented for 2005–2008 only.

Note that the NDR may underestimate the number of Indigenous registrants with insulin-treated diabetes. This may be the result of such factors as 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 people 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 obtain Pharmaceutical Benefits Scheme medicines free of charge from the Aboriginal Health Services without a prescription, at the time of medical consultation. As supplies for diabetes are free under this arrangement, it is likely that most Aboriginal and Torres Strait Islander people in remote areas will use this channel rather than the NDSS, which requires a copayment. In addition, the NDSS is 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

Table C1: Incidence of Type 1 diabetes among children aged 0–14 years: sex and age, by year of first insulin use, 2000 to 2008 (number)

Sex and age at first insulin use (years)	2000	2001	2002	2003	2004	2005	2006	2007	2008	2000 −2008
Males										
0–4	85	105	106	125	106	107	96	104	100	934
5–9	138	146	154	160	174	153	158	180	177	1,440
10–14	171	202	201	214	233	208	242	242	226	1,939
Total males 0–14	*394*	*453*	*461*	*499*	*513*	*468*	*496*	*526*	*503*	*4,313*
Females										
0–4	71	77	87	91	84	92	80	97	93	772
5–9	140	156	160	186	176	156	153	167	176	1,470
10–14	152	164	194	204	205	187	191	199	208	1,704
Total females 0–14	*363*	*397*	*441*	*481*	*465*	*435*	*424*	*463*	*477*	*3,946*
Persons										
0–4	156	182	193	216	190	199	176	201	193	1,706
5–9	278	302	314	346	350	309	311	347	353	2,910
10–14	323	366	395	418	438	395	433	441	434	3,643
Total persons 0–14	**757**	**850**	**902**	**980**	**978**	**903**	**920**	**989**	**980**	**8,259**

Source: National Diabetes Register (data extracted January 2010).

Table C2: Incidence of Type 1 diabetes among children aged 0–14 years: year of first insulin use, by state and territory of current residence, 2000 to 2008 (number)

Year of first insulin use	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
2000	247	186	153	72	68	15	11	5	757
2001	270	212	177	84	63	26	13	5	850
2002	278	233	167	103	79	26	13	3	902
2003	269	262	205	106	90	29	14	5	980
2004	309	229	200	98	83	31	19	8	978
2005	264	241	191	84	61	40	19	3	903
2006	273	240	192	87	78	33	11	6	920
2007	284	262	220	111	57	21	28	5	989
2008	321	233	188	97	90	29	16	6	980
2000–2008	**2,515**	**2,098**	**1,693**	**842**	**669**	**250**	**144**	**46**	**8,259**

Note: Columns may not add to the Australian total, as two records have an unknown state of current residence.

Source: National Diabetes Register (data extracted January 2010).

Table C3: Incidence of Type 1 diabetes among children aged 0–14 years: sex and age, by state and territory of current residence, 2000–2008 (number)

Sex and age at first insulin use (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
Males									
0–4	267	224	212	92	84	34	17	3	934
5–9	435	351	304	158	116	40	29	7	1,440
10–14	606	496	376	185	165	68	30	12	1,939
Total males 0–14	*1,308*	*1,071*	*892*	*435*	*365*	*142*	*76*	*22*	*4,313*
Females									
0–4	265	194	150	72	55	18	14	4	772
5–9	422	383	287	170	131	46	25	6	1,470
10–14	520	450	364	165	118	44	29	14	1,704
Total females 0–14	*1,207*	*1,027*	*801*	*407*	*304*	*108*	*68*	*24*	*3,946*
Persons									
0–4	532	418	362	164	139	52	31	7	1,706
5–9	857	734	591	328	247	86	54	13	2,910
10–14	1,126	946	740	350	283	112	59	26	3,643
Total persons 0–14	**2,515**	**2,098**	**1,693**	**842**	**669**	**250**	**144**	**46**	**8,259**

Note: Columns may not add to the Australian total, as two records have an unknown state of current residence.

Source: National Diabetes Register (data extracted January 2010).

Table C4: Incidence of Type 1 diabetes in children aged 0–14 years: Australia compared with other OECD countries, various years

OECD countries (in descending order)	Period	New cases per 100,000 per year
Finland	2000–2005	57.4
Sweden	2001–2005	41.0
Norway	1999–2003	27.9
United Kingdom	1989–2003	24.5
United States	2002–2003	23.7
Australia[a]	**2000–2008**	**22.8**
Denmark	1996–2005	22.2
Canada	1990–1999	21.7
Netherlands	1996–1999	18.8
Germany	1989–2003	18.0
New Zealand	1999–2000	18.0
Czech Republic	1989–2003	17.2
Ireland	1997	16.3
Luxembourg	1989–2003	15.5
Belgium	1989–2003	15.4
Iceland	1994–1998	14.7
Portugal	1994–1998	13.6
Slovak Republic	1989–2003	13.6
Austria	1989–2003	13.3
Spain	1989–2003	13.0
Poland	1989–2003	12.9
France	1998–2004	12.2
Hungary	1989–2003	11.3
Greece	1995–1999	9.9
Switzerland	1991–1999	9.0
Italy	1990–1999	8.4
Turkey	1992–1996	3.2
Japan	1998–2001	2.4
Mexico	1990–1993	1.5
Korea	1990–1991	1.1

(a)   Incidence rate for Australia is the average annual age-standardised rate for 2000–2008 (calculated from the NDR; age-standardised to the 2001 Australian population).

Sources: IDF 2009; National Diabetes Register (for Australia).

Glossary

Derived diabetes type

Refers to the classification of individuals on the NDR as Type 1, Type 2 and so on 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.2.

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 Box 1.

Gestational diabetes mellitus

A type of diabetes (see Box 1).

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, which include 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.

Other types of diabetes

A category that includes less-common conditions or syndromes that cause diabetes (see Box 1).

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.2.

Type 1 diabetes

A type of diabetes (see Box 1).

Type 2 diabetes

A type of diabetes (see Box 1).

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