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, target priority population groups, track the impact of environmental change and of prevention and control strategies, and to make decisions for cost-effective allocation of resources (AIHW: Dixon & Webbie 2006).

This is the third statistical profile report from the NDR, which now has seven years of data on over 76,000 people and is an important resource for research. The main aims of this report are to describe the NDR, provide general statistics such as the demographic features of the NDR population, provide incidence estimates and trends, and present the findings of mortality analyses.

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 eight chapters. Following this introduction, Chapter 2 provides general statistics to describe the demographic features of the NDR population. Chapter 3 focuses on people with Type 1 diabetes and Chapter 4 covers people with other types of insulin-treated diabetes. Chapter 5 examines the mortality of NDR registrants and Chapter 6 details statistical notes relevant to the analyses performed for this report. Chapter 7 provides details for researchers wanting to access the NDR data for diabetes research, and Chapter 8 provides information for people wishing to register on the NDR. The Appendix contains 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 (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, and other types of diabetes (see Box 2.1). The NDR aims at recording all new cases of people who use insulin to treat their diabetes, meaning the NDR 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 (GDM) cases require insulin treatment so those that do not are excluded from the NDR.

The NDR was established in 1999 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 largely funded by the Australian Government Department of Health and Ageing (DoHA).

Objectives

The main objectives of the NDR are to assist in national diabetes monitoring and to facilitate research. The collection of information about new cases of insulin-treated diabetes helps the NDR focus on specific objectives, which are to:

- 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 Commonwealth, state and local levels
- provide assistance in monitoring national diabetes indicators
- assess the feasibility and cost of estimating the prevalence of insulin-treated diabetes.

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 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 has two data sources:

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

The NDSS is an initiative of the Australian Government and subsidises the supply of insulin syringes, insulin infusion pump consumables and diagnostic reagents (blood and urine testing strips) to registered persons 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 APEG is the professional body in Australia which represents those involved in management and research of children with disorders of the endocrine system including diabetes mellitus. APEG's state-based databases collect diagnosis information on children and adolescents with Type 1 diabetes.

See the Data Sources section in the Appendix for further detail on NDSS and APEG.

Change to NDSS NDR 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. So the AIHW, Diabetes Australia and DoHA worked together to improve the NDSS registration form. As a result, 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. In other words, 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 important to be able 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 15–39 year olds with Type 1 diabetes (Section 3.3) the results from the NDR were adjusted to account for missing cases using information from the de-identified NDSS dataset (see page 75 for a description of the de-identified NDSS dataset). Incidence estimates for 0–14 year olds with Type 1 diabetes were not adjusted in this way as the coverage rate across the two data sources for this age group is over 96% (Table 3.1).

2 Profile of NDR registrants

This chapter provides a general profile of NDR registrants by describing the demographic features of the NDR population—people who began using insulin to treat their diabetes during the period 1999–2005. Summary data are presented for registrants' age, sex, geographical location, deaths, Indigenous status, country of birth, and diabetes type.

2.1 Current age and sex

The age distribution of the NDR shows a pattern of greater numbers with age, particularly after 55 years. More than 70% of registrants are aged 40 years and over, compared with 6% aged less than 15 years (Table 2.1).

Overall, there is a slightly higher proportion of females on the NDR (51%) compared with males (49%). However, these proportions vary considerably with age (Figure 2.1). For the younger age groups, the proportion of male to female records is similar. In the 25–44 year age groups, females strongly outnumber males, reflecting the effect of gestational diabetes in women from these age groups. There are more males than females in the older age groups—the 45–74 year age groups are made up of 58% males and 42% females. This may be a reflection of the higher rates of overweight and obesity in older males compared with females. Overweight and obesity are major risk factors for Type 2 diabetes and in the 45–74 year age groups a much higher proportion of males than females are estimated to be overweight or obese based on data from the 2004–05 National Health Survey (ABS 2006a). The proportion of males and females becomes evenly distributed again after 75 years. This may reflect the substantially lower number of males in this age group owing to the higher female life expectancy.

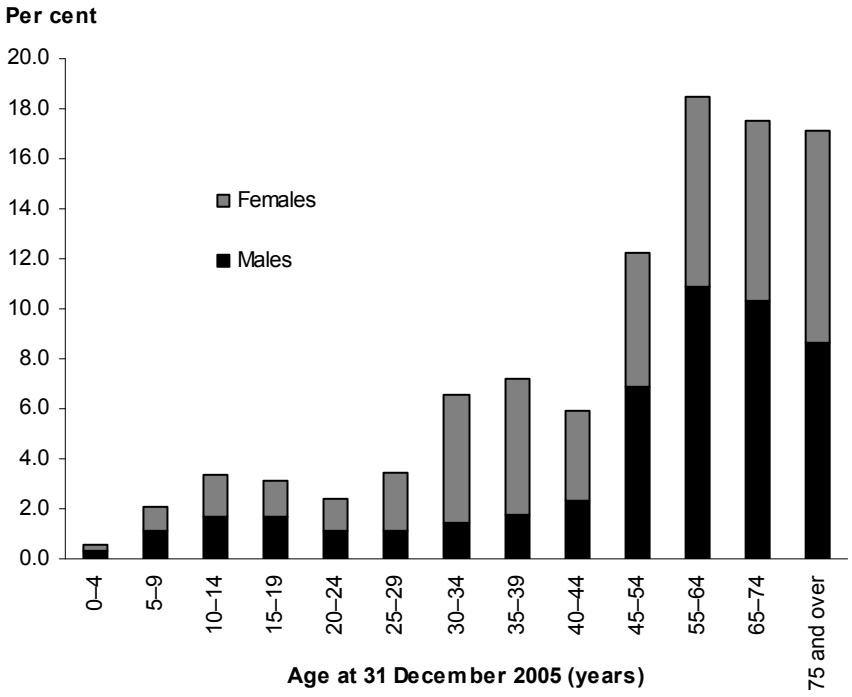
Table 2.1: NDR registrants[a]: current age and sex, 1999–2005

Age at 31 December 2005 (years)	Males		Females		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
0–4	238	0.3	180	0.2	418	0.5
5–9	841	1.1	772	1.0	1,613	2.1
10–14	1,261	1.7	1,267	1.7	2,528	3.3
15–19	1,283	1.7	1,064	1.4	2,347	3.1
20-24	847	1.1	976	1.3	1,823	2.4
25–29	824	1.1	1,820	2.4	2,644	3.5
30-34	1,089	1.4	3,930	5.2	5,019	6.6
35–39	1,312	1.7	4,179	5.5	5,491	7.2
40-44	1,739	2.3	2,748	3.6	4,487	5.9
45–54	5,239	6.9	4,071	5.3	9,310	12.2
55–64	8,262	10.9	5,781	7.6	14,043	18.4
65–74	7,826	10.3	5,517	7.2	13,343	17.5
75 and over	6,572	8.6	6,485	8.5	13,057	17.2
Total[b]	**37,334**	**49.0**	**38,790**	**51.0**	**76,124**	**100.0**

(a) Data are for all NDR registrants from 1 January 1999 to 31 December 2005.

(b) Total includes record for 1 male where age was not stated.

Source: National Diabetes Register (data extracted April 2007).



Source: National Diabetes Register for Australia, 1999–2005.

Figure 2.1: NDR registrants: distribution by age and sex, 1999–2005

2.2 Geographical location

The distribution of registrants from different remoteness areas varies between the states and territories (Table 2.2). Based on the ABS Australian Standard Geographic Classification (see Section 6.7 for further details), the majority of registrants (66%) live in major cities. New South Wales and Victoria account for the majority of these registrants, 19,555 and 14,013 respectively. One-fifth (21%) of registrants live in inner regional areas and smaller numbers of registrants live in outer regional (10%) or remote/very remote geographical locations (3%). This is similar to the geographic distribution of the Australian population in 2005 where there were 66% living in major cities, 21% in inner regional, 10% in outer regional and 3% in remote/very remote locations (AIHW population database).

Table 2.2: NDR registrants: area of usual residence by remoteness areas and state/territory[a], 1999–2005

State/ territory of usual residence	Major cities	Inner regional	Outer regional	Remote/ very remote	Unknown	Total
			Number			
NSW	19,555	5,308	1,944	215	—	27,022
Vic	14,013	3,813	949	20	—	18,795
Qld	7,710	3,954	2,696	711	1	15,073
WA	5,143	1,157	755	481	—	7,536
SA	3,027	639	642	146	1	4,454
Tas	—	1,115	663	33	—	1,811
ACT[b]	960	—	—	—	—	960
NT	—	—	199	272	—	471
Total[c]	**50,408**	**15,986**	**7,848**	**1,878**	**4**	**76,124**
			Per cent			
NSW	72.4	19.6	7.2	0.8	—	100.0
Vic	74.6	20.3	5.0	0.1	—	100.0
Qld	51.2	26.2	17.9	4.7	—	100.0
WA	68.2	15.4	10.0	6.4	—	100.0
SA	68.0	14.3	14.4	3.3	—	100.0
Tas	—	61.6	36.6	1.8	—	100.0
ACT[b]	100.0	—	—	—	—	100.0
NT	—	—	42.3	57.7	—	100.0
Total	**66.2**	**21.0**	**10.3**	**2.5**	**0.0**	**100.0**

(a) Using postcode of usual residence, registrants are classified using the Australian Standard Geographical Classification (ASGC) Remoteness Areas (AIHW population database).

(b) A small number of NDR registrants live in areas of the Australian Capital Territory that are designated as partially inner regional. However, for confidentiality reasons these registrants have all been included in the Australian Capital Territory major cities category.

(c) Total includes records where state or territory of usual residence was unknown.

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

Source: National Diabetes Register (data extracted April 2007).

2.3 Deaths

NDR records were matched with the National Death Index (NDI) to determine which registrants had died by the end of 2005 (see Appendix for details). Around 7,550 registrants, or 10%, who started using insulin between the years 1999 and 2005 were identified as having died as at 31 December 2005 (Table 2.3).

Proportions of deceased registrants varied among states and territories, ranging from 7% in the Northern Territory to 12% in Tasmania. More detailed analyses on deaths are presented in Chapter 5.

Table 2.3: NDR registrants: vital status, by states and territories[(a)], 1999–2005

Vital status	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia[(b)]
					Number				
Alive	24,508	16,676	13,639	6,815	4,022	1,587	890	439	68,577
Deceased	2,514	2,119	1,434	721	432	224	70	32	7,547
Total	**27,022**	**18,795**	**15,073**	**7,536**	**4,454**	**1,811**	**960**	**471**	**76,124**
					Per cent				
Alive	90.7	88.7	90.5	90.4	90.3	87.6	92.7	93.2	90.1
Deceased	9.3	11.3	9.5	9.6	9.7	12.4	7.3	6.8	9.9
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) State/territory of usual residence.

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

Source: National Diabetes Register (data extracted April 2007).

2.4 Aboriginal and Torres Strait Islander peoples

Data on the Indigenous status of NDR registrants are presented only for 2005 because of how these data were captured in the NDSS database before 2005. Before 2005 the NDSS database defaulted to 'non-Indigenous' for the Indigenous status variable, meaning that if registrants did not complete this section then they were recorded as non-Indigenous, and as such all data collected for this variable before 2005 may overstate the true number of non-Indigenous registrants and underestimate the number of Indigenous Australians registered on the NDR. In early 2005 the NDSS database was amended to add an extra value to the Indigenous status variable of 'Inadequate/Not stated' and this was made the default, in accordance with the *National health data dictionary* (HDSC 2006).

For 2005, 3% of people on the NDR reported being of Aboriginal and/or Torres Strait Islander origin (Table 2.4). This percentage is slightly higher than the proportion of Indigenous people in the Australian population (2% in 2001) (ABS & AIHW 2005).

Proportions of Indigenous registrants differed among states and territories, the highest being in the Northern Territory (42%) and the lowest in Victoria (0.1%). The proportion of registrants not reporting their Indigenous status was 7% overall and it varied considerably between the states and territories. Excluding the Northern Territory where all registrants reported their Indigenous status, the proportion of 'not stated' was lowest for Western Australia at 2% and highest for Victoria and Tasmania at 16% and 17%, respectively. The remaining states and territories ranged between 3% and 7%.

It is important to note that the NDR numbers do not reflect the extent of the difference in the prevalence or incidence of diabetes in Indigenous Australians compared with other Australians. Prevalence of diabetes (mainly Type 2) is considerably higher among Aboriginal and Torres Strait Islander peoples than for the whole Australian community (de Courten et al. 1998). Previous studies have shown that Aboriginal and Torres Strait Islander peoples are more than three times as likely as other Australians to report some form of diabetes (ABS 2006c). The apparently smaller number of Indigenous people on the NDR than expected may be due to lower rates of registration and/or some Indigenous people being included in the 'Not stated' group. However, it is important to remember that this is based on only one year of data, so this should be further investigated when there are more years of better quality data available.

Table 2.4: NDR registrants: Indigenous status by states and territories[a], 2005

Indigenous status	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia[b]
					Number				
Indigenous	123	4	204	86	21	5	5	37	485
Non-Indigenous	5,945	3,230	2,990	1,085	1,019	246	197	52	14,764
Not stated	290	617	114	25	41	50	16	—	1,154
Total persons	**6,358**	**3,851**	**3,308**	**1,196**	**1,081**	**301**	**218**	**89**	**16,403**
					Per cent				
Indigenous	1.9	0.1	6.2	7.2	1.9	1.7	2.3	41.6	3.0
Non-Indigenous	93.5	83.9	90.4	90.7	94.3	81.7	90.4	58.4	90.0
Not stated	4.6	16.0	3.4	2.1	3.8	16.6	7.3	—	7.0
Total persons	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) State/territory of usual residence.

(b) Totals include record where state or territory of usual residence was unknown.

Source: National Diabetes Register (data extracted April 2007).

2.5 Country of birth

Among NDR registrants who began using insulin between 1999 and 2005, 46% were recorded as being born in Australia (Table 2.5). For other registrants, 'North-West Europe' and 'Southern and Eastern Europe' were the most common regions of birth with around 9% of registrants each. However, over 20% of registrants did not report a country of birth. Of the registrants who reported a country of birth (59,524), 58% were born in Australia and 42% were born overseas. This is much higher than the proportion of the general Australian population born overseas—in 2005, 24% of the Australian population were born overseas (ABS 2006b). This finding would still be true even if all the people with an unknown country of birth were born in Australia, in which case 32% of registrants would have been born overseas. It is likely that the bias of the 'not stated' is to underestimate the proportion of overseas-born people.

The overrepresentation of overseas-born people on the NDR is consistent with previous findings showing a higher proportion of overseas-born people than Australian-born people reporting having diabetes (note that these findings included non-insulin-treated diabetes) (ABS 2006c; AIHW: Holdenson et al. 2003).

Table 2.5: NDR registrants: country of birth and sex, 1999–2005

	Males		Females		Persons	
Country of birth[(a)]	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Australia	17,176	46.0	17,633	45.5	34,809	45.7
New Zealand	624	1.7	725	1.9	1,349	1.8
Other Oceania and Antarctica (excluding Australia)	367	1.0	646	1.7	1,013	1.3
North-West Europe	3,743	10.0	2,995	7.7	6,738	8.9
Southern and Eastern Europe	3,664	9.8	3,071	7.9	6,735	8.8
North Africa and the Middle East	1,033	2.8	1,178	3.0	2,211	2.9
South-East Asia	757	2.0	1,377	3.5	2,134	2.8
North-East Asia	384	1.0	766	2.0	1,150	1.5
Southern and Central Asia	709	1.9	1,064	2.7	1,773	2.3
Americas	386	1.0	485	1.3	871	1.1
Sub-Saharan Africa	353	0.9	388	1.0	741	1.0
Not stated/unknown	8,138	21.8	8,462	21.8	16,600	21.8
Total persons	**37,334**	**100.0**	**38,790**	**100.0**	**76,124**	**100.0**

(a) Country of birth refers to ABS Standard Australian Classification of Countries—major groups (ABS 1998).

Source: National Diabetes Register (data extracted April 2007).

Box 2.1: Types of diabetes

Type 1 diabetes *mostly arises in children or young adults, though it can occur at any age. It is marked by 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.*

Type 2 diabetes *is the most common form of diabetes, and occurs mostly in people aged 40 years or over (however, recent trends have indicated an increase in diagnosis in younger people). 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 drugs as well, namely oral glucose-lowering drugs that work on the pancreas. Many others require insulin in addition to the other treatments (only insulin-treated cases of Type 2 diabetes are included on the NDR).*

Gestational diabetes *is a form of diabetes that develops during pregnancy in some women. It involves high blood sugar 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 persons being treated with insulin for these types of diabetes are included on the NDR.

2.6 Type of diabetes

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 in Box 2.1 and the Glossary.

It is well known that self-reported diabetes type is not reliable, particularly with people reporting Type 1 diabetes when they actually have Type 2 (described in more detail in Section 6.3). Thus, in order to obtain a more accurate measure of type of diabetes, an algorithm (method of calculation) has been developed which assesses and classifies registrants with reported Type 1 diabetes based on age at diagnosis and the period of time between diagnosis and date of first insulin use (for more information on algorithms to derive diabetes type, see Section 6.3). A different algorithm is used to assess and reclassify women with gestational diabetes who are aged over 50 years at diagnosis (see Section 6.3 for more information).

Table 2.6 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 in the age groups of 45–54 years the number of registrants with reported Type 1 diabetes is 1,413 but the derived type of diabetes shows only 685. That is, it is estimated that almost 50% of people on the NDR aged 45–54 years at diagnosis with reported Type 1 diabetes probably have Type 2 diabetes.

In total, the algorithm reclassified 3,934 people who were originally reported as having Type 1 diabetes and 25 women with reported GDM. Of these people, 2,877 were reclassified as having Type 2 diabetes. For the remaining 1,082 people, a type of diabetes could not be derived either because of missing information, such as age at diagnosis and/or date of first insulin use, or because they were aged under 15 years at diagnosis and the time between diagnosis and first insulin use was greater than one year. Note that no assumptions are made about diabetes type for the small group of registrants who are aged under 15 at diagnosis and have more then one year between their date of diagnosis and first insulin use—there are just over 100 of these registrants where a diabetes type was unable to be derived. The vast majority of registrants for which a type of diabetes could not be derived were missing an age at diagnosis (977 of the 1,082).

Clearly, the algorithm helps to reduce the misrepresentation of the level of Type 1 diabetes and some cases of GDM 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. However, note that even with the algorithm there will be some level of misclassification.

Table 2.6: NDR registrants: reported and derived diabetes type, by age, 1999–2005

Age at diagnosis (years)	Reported diabetes type				Derived diabetes type					
	Type 1	Type 2	GDM	Other[a]	Type 1	Type 2	GDM	Other[a]	Not derived[b]	Total
0–4	1,323	21	—	22	1,292	21	—	22	31	1,366
5–9	2,171	34	—	18	2,138	34	—	18	33	2,223
10–14	2,681	117	2	49	2,640	117	2	49	41	2,849
15–24	2,543	793	662	92	2,387	949	662	92	—	4,090
25–34	2,248	3,504	4,983	81	1,885	3,867	4,983	81	—	10,816
35–44	1,726	7,412	2,573	94	1,195	7,943	2,573	94	—	11,805
45–54	1,413	10,668	46	137	685	11,401	41	137	—	12,264
55–64	1,212	9,623	5	136	602	10,238	—	136	—	10,976
65–74	755	5,891	3	74	407	6,242	—	74	—	6,723
75 and over	507	2,733	4	36	383	2,861	—	36	—	3,280
Not stated	969	8,708	8	47	—	8,708	—	47	977	9,732
Total—number	**17,548**	**49,504**	**8,286**	**786**	**13,614**	**52,381**	**8,261**	**786**	**1,082**	**76,124**
Total—per cent	**23.1**	**65.0**	**10.9**	**1.0**	**17.9**	**68.8**	**10.9**	**1.0**	**1.4**	**100.0**

(a) See Glossary for 'Other types of diabetes'.

(b) See Section 6.3 for more details on derived diabetes type.

Source: National Diabetes Register (data extracted April 2007).

Age and sex

The NDR contains 76,124 records for people who started using insulin between 1 January 1999 and 31 December 2005 (Tables 2.6 and 2.7). Almost 70% of cases are of Type 2 diabetes; Type 1 diabetes accounts for 18% and gestational diabetes 11%. There are 37,334 males and 38,790 females. Using derived type of diabetes, males accounted for 58% of Type 1 cases and 54% of Type 2 cases.

For registrants with Type 1 diabetes, 45% were aged 0–14 years at diagnosis, 18% were aged 15–24, 23% were aged 25–44 and 15% were aged 45 years and over (derived from Table 2.6).

For registrants with Type 2 diabetes, less than 1% were aged 0–14 at diagnosis, almost 2% were aged 15–24, 23% were aged 25–44 and 59% were aged 45 years and over; 17% had missing data for age at diagnosis.

For registrants with gestational diabetes, less than 1% were aged 0–14 at diagnosis, 8% were aged 15–24, 91% were aged 25–44 and less than 1% were aged 45 years and over.

For registrants with other types of diabetes, 11% were aged 0–14 at diagnosis, 12% were aged 15–24, 22% were aged 25–44, and 49% were aged 45 years and over; 17% had missing data for age at diagnosis.

Table 2.7: NDR registrants: derived diabetes type, by sex, 1999–2005

Type of diabetes	Males		Females		Persons	
	Number	Per cent	Number	Per cent	Number	Per cent
Type 1	7,861	21.1	5,753	14.8	13,614	17.9
Type 2	28,468	76.3	23,913	61.6	52,381	68.8
Gestational	n.a.	n.a.	8,261	21.3	8,261	10.9
Other types[(a)]	439	1.2	347	0.9	786	1.0
Not derived[(b)]	566	1.5	516	1.3	1,082	1.4
Total	**37,334**	**100.0**	**38,790**	**100.0**	**76,124**	**100.0**

(a) See Glossary for 'Other types of diabetes'.

(b) See Section 6.3 for more details on derived diabetes type.

Source: National Diabetes Register (data extracted April 2007).

3 Type 1 diabetes in people aged 0–39 years

This chapter has three sections which present data for people with Type 1 diabetes aged under 40 years at their first insulin use. Section 3.1 presents information about 0–14 year olds, including the coverage of cases on the NDR as well as the profile and incidence estimates for this age group. Section 3.2 provides data about the coverage and profile of 15–39 year olds with Type 1 diabetes on the NDR, and Section 3.3 presents incidence estimates for this age group by adjusting NDR results to account for NDSS registrations that are not included on the NDR. The incidence estimates for both age groups are shown by sex, age and geographic location.

3.1 Type 1 diabetes in 0–14 year olds

This section presents data for 0–14 year olds on the NDR with Type 1 diabetes. The coverage of cases is presented in Table 3.1, the profile and incidence estimates for this age group are shown in Tables 3.2–3.6, and international comparisons are made in Table 3.7.

3.1.1 Coverage

Based on NDR data, a total of 6,066 people aged 0–14 years with Type 1 diabetes began using insulin between 1999 and 2005. Using the capture–recapture method (LaPorte et al. 1993) with the two independent data sources NDSS and APEG, coverage of 0–14 year olds with Type 1 diabetes on the NDR over the 7-year period was estimated to be 96.3% (Table 3.1). Based on this estimate it is expected that 233 cases were missed by both sources over the 7 years. The coverage rate has generally improved over the period. Although the rate for 2005 was slightly lower than that for 2004, it may increase if further late registrations are received for that year. Care should be taken when comparing 1999 with other years as the coverage was substantially lower in that year.

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, 1999–2005

	Males			Females			Persons		
Year of first insulin use	NDR regis-trants	Missing cases[(a)]	Coverage rate[(b)] (%)	NDR regis-trants	Missing cases[(a)]	Coverage rate[(b)] (%)	NDR regis-trants	Missing cases[(a)]	Coverage rate[(b)] (%)
1999	361	37	90.7	354	29	92.5	715	66	91.6
2000	396	16	96.1	364	9	97.5	760	25	96.8
2001	451	16	96.6	395	14	96.7	846	29	96.6
2002	457	17	96.5	443	10	97.8	900	27	97.1
2003	493	13	97.5	477	14	97.2	970	27	97.3
2004	512	12	97.6	462	10	97.9	974	22	97.8
2005	472	14	97.1	429	23	95.0	901	37	96.1
Total	**3,142**	**125**	**96.2**	**2,924**	**108**	**96.5**	**6,066**	**233**	**96.3**

(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 owing to rounding.

Source: National Diabetes Register and AIHW analysis of de-identified NDSS data (data extracted April 2007).

3.1.2 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 0–14 year olds on the NDR is considered high—based on capture–recapture estimates which show that coverage has been estimated at higher than 96% since 2000 (Table 3.1)—thus producing reliable estimates of Type 1 diabetes incidence.

Over the 7-year period from 1999 to 2005, there were 3,142 new cases of Type 1 diabetes among males and 2,924 new cases of Type 1 diabetes among females aged 0–14 years registered on the NDR (Table 3.1). The average age-standardised rate of new cases (per 100,000 population) each year was 22.0 for males and 21.5 for females (Table 3.2). Between 2000 and 2004, the age-standardised incidence rate for Type 1 diabetes among 0–14 year olds increased significantly from 19.2 to 24.4 (per 100,000). Although the 2005 rate (22.6) is slightly lower than the 2004 rate, it is still significantly higher than in 2000 and it may increase if further late registrations are received. No significant differences were found between boys and girls, 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).

The Type 1 diabetes incidence rate increased with increasing age in the 0–14 year age group (Table 3.2). Between 1999 and 2005, the average annual rate was lowest in the 0–4 year age group (14.5 per 100,000) and highest in the 10–14 year age group (27.7 per 100,000), with the 5–9 year age group sitting in between at 22.8 per 100,000. For both sexes in all years the rate was lowest in the youngest age group (0–4 years) and highest in the older age group (10–14 years).

Among 0–4 year olds, the annual age-standardised rate increased from 12.2 per 100,000 in 2000 to 15.9 in 2005, and was highest in 2003 at 16.9 per 100,000 (Table 3.2). In the two older

age groups, the incidence rate per 100,000 increased between 2000 and 2004, from 20.7 to 26.2 for 5–9 year olds and from 24.2 to 31.4 for 10–14 year olds.

Table 3.2: Incidence (number and rate) of Type 1 diabetes among 0–14 year olds: sex and age by year of first insulin use, 1999–2005

Sex and age at first insulin use (years)	1999[a]	2000	2001	2002	2003	2004	2005	1999 –2005[b]
				Number				
Males								
0–4	81	85	106	107	123	107	109	718
5–9	111	140	143	155	155	174	156	1,034
10–14	169	171	202	195	215	231	207	1,390
Total males 0–14	*361*	*396*	*451*	*457*	*493*	*512*	*472*	*3,142*
Females								
0–4	71	71	75	86	91	84	92	570
5–9	141	140	154	160	182	174	154	1,105
10–14	142	153	166	197	204	204	183	1,249
Total females 0–14	*354*	*364*	*395*	*443*	*477*	*462*	*429*	*2,924*
Persons								
0–4	152	156	181	193	214	191	201	1,288
5–9	252	280	297	315	337	348	310	2,139
10–14	311	324	368	392	419	435	390	2,639
Total persons 0–14	**715**	**760**	**846**	**900**	**970**	**974**	**901**	**6,066**
				Age–specific rate (number per 100,000 population)				
Males								
0–4	12.3	13.0	16.1	16.4	19.0	16.5	16.8	15.7
5–9	16.1	20.2	20.6	22.4	22.6	25.5	23.0	21.5
10–14	24.9	25.0	29.1	27.9	30.4	32.4	29.0	28.4
Total males 0–14	*17.8*	*19.5*	*22.1*	*22.4*	*24.1*	*25.1*	*23.1*	*22.0*
Males 0–14 ASR[c]	*17.9*	*19.5*	*22.1*	*22.3*	*24.1*	*25.0*	*23.0*	*22.0*
(95% CI)	*(16.1–19.8)*	*(17.6–21.5)*	*(20.1–24.2)*	*(20.3–24.5)*	*(22.0–26.3)*	*(22.9–27.2)*	*(21.0–25.2)*	*(21.2–22.8)*
Females								
0–4	11.4	11.4	12.0	13.9	14.8	13.7	14.9	13.1
5–9	21.6	21.3	23.4	24.4	28.0	26.9	23.9	24.2
10–14	21.9	23.4	25.1	29.5	30.3	30.2	27.0	26.8
Total females 0–14	*18.4*	*18.8*	*20.3*	*22.8*	*24.6*	*23.8*	*22.1*	*21.6*
Females 0–14 ASR[c]	*18.4*	*18.8*	*20.3*	*22.8*	*24.5*	*23.8*	*22.1*	*21.5*
(95% CI)	*(16.5–20.4)*	*(17.0–20.9)*	*(18.3–22.3)*	*(20.7–25.0)*	*(22.4–26.8)*	*(21.6–26.0)*	*(20.0–24.3)*	*(20.8–22.3)*
Persons								
0–4	11.8	12.2	14.1	15.2	16.9	15.1	15.9	14.5
5–9	18.8	20.7	22.0	23.4	25.2	26.2	23.5	22.8
10–14	23.5	24.2	27.2	28.7	30.4	31.4	28.0	27.7
Total persons 0–14	**18.1**	**19.2**	**21.2**	**22.6**	**24.4**	**24.5**	**22.6**	**21.8**
Persons 0–14 ASR(c) (95% CI)	**18.1 (16.8–19.5)**	**19.2 (17.8–20.6)**	**21.2 (19.8–22.7)**	**22.5 (21.1–24.1)**	**24.3 (22.8–25.9)**	**24.4 (22.9–26.0)**	**22.6 (21.1–24.1)**	**21.8 (21.2–22.3)**

(a) Care should be taken when comparing 1999 with other years as the coverage was lower—see Table 3.1.

(b) The number is the total for 1999–2005 and the rate is the average annual rate for the seven years.

(c) Age-standardised to the 2001 Australian population—see Section 6.4.

Source: National Diabetes Register (data extracted April 2007).

Geographical location

A registrant's geographical location (state/territory, remoteness category, statistical division) is derived from postcode data (see Section 6.7 for further detail). This can be done using postcode of usual residence or postcode at diagnosis. The NDR data for postcode of usual residence are more complete than the data for postcode at diagnosis. Analyses by postcode of usual residence may be more useful for resource planning, whereas those done by postcode at diagnosis may be of particular interest for research into patterns of occurrance. Analyses for this section were done by both postcodes and it was found that there were few differences in the results; therefore, only tables based on postcode of usual residence (because there were fewer missing) have been presented here.

States and territories

In 1999–2005, the rate of new cases of Type 1 diabetes among 0–14 year olds differed between the states and territories (Table 3.3). On average, Tasmania had the highest incidence rate of Type 1 diabetes among 0–14 year olds with 27.3 per 100,000 population. The rate of new cases in Tasmania was significantly higher than the rate of new cases in New South Wales (20.5), Queensland (22.1) and Australia (21.8). The Northern Territory had the lowest rate with 10.2 per 100,000 population and was significantly lower than all other states and territories. 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 0–14 year olds with increasing age in all states and territories (Table 3.4b). Overall, there were no significant difference between males and females and this was also true in each state and territory.

Remoteness

The geographic distribution of NDR registrants aged 0–14 years with Type 1 diabetes was 62% in major cities, 25% in inner regional, 11% in outer regional and 2% in remote/very remote (calculated from Table 3.5). This is similar to the geographic distribution of the Australian population aged 0–14 years in 1999–2005 where there were 63% in major cities, 22% in inner regional, 11% in outer regional and 3% in remote/very remote locations (AIHW population database, 1999–2005).

Inner regional areas had the highest age-standardised rate of new cases per year at 24.2 per 100,000. This was significantly higher than the rates in all other areas.

Statistical divisions

A major area of research interest in diabetes is whether geographic location influences incidence patterns of diabetes. For the 0–14 year old age group, some statistical divisions did show differences in the average rate of yearly cases when compared with other areas within the same state, the overall state rate or the national total (Table 3.6).

The 'Hunter' division in New South Wales had a significantly higher rate of new cases (27.0 cases per 100,000 population) than the overall New South Wales rate (20.5) and the national rate (21.8). The 'Sydney' division in New South Wales had a significantly lower rate (18.3) than the New South Wales rate and the national rate. In Queensland, the 'South West, Central West, Far North, North West' division had a significantly lower rate (11.4 cases per 100,000) than the overall Queensland rate of 22.1 cases per 100,000 and the national rate. The 'South Eastern, Central, Pilbara, Kimberly' division in Western Australia also had a significantly lower rate (14.6 cases per 100,000) than the overall Western Australia rate of 21.8 cases per 100,000 and the national rate.

Table 3.3: Incidence (number and rate) of Type 1 diabetes among 0–14 year olds by year of first insulin use: state/territory of usual residence, 1999–2005

Year of first insulin use	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
					Number				
1999[(a)]	236	175	125	87	57	19	12	4	715
2000	248	185	157	69	72	15	8	6	760
2001	270	210	174	85	62	26	14	5	846
2002	286	231	163	99	76	27	15	3	900
2003	281	251	198	104	87	31	12	6	970
2004	317	227	198	94	79	32	19	8	974
2005	270	236	196	75	60	39	22	3	901
					Age-standardised rate (number per 100,000 population)[(b)]				
1999[(a)]	17.8	18.4	16.6	21.8	19.2	18.7	18.2	8.0	18.1
2000	18.7	19.3	20.6	17.2	24.4	14.9	12.2	12.0	19.2
2001	20.1	21.9	22.5	21.1	21.1	26.2	21.3	10.3	21.2
2002	21.4	24.0	20.8	24.6	26.1	27.6	22.9	6.1	22.5
2003	21.1	26.1	24.9	26.0	30.1	31.8	18.4	12.5	24.3
2004	23.9	23.6	24.7	23.3	27.6	32.7	30.0	16.5	24.4
2005	20.4	24.6	24.1	18.7	21.0	40.0	35.5	6.0	22.6
Average 99–05 (95% CI)	*20.5 (19.6–21.4)*	*22.6 (21.4–23.7)*	*22.1 (20.9–23.4)*	*21.8 (20.1–23.6)*	*24.2 (22.1–26.4)*	*27.3 (23.6–31.5)*	*22.5 (18.4–27.4)*	*10.2 (7.1–14.2)*	*21.8 (21.2–22.3)*

(a) Care should be taken when comparing 1999 with other years as the coverage was lower—see Table 3.1.

(b) Age-standardised to the 2001 Australian population—see Section 6.4.

Source: National Diabetes Register (data extracted April 2007).

Table 3.4a: Incidence (number) of Type 1 diabetes among 0–14 year olds: sex and age, states and territories of usual residence, 1999–2005

Sex and age at first insulin use (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
					Number				
Males									
0–4	204	164	169	78	59	29	11	4	718
5–9	308	267	216	112	74	31	22	4	1,034
10–14	464	347	243	130	130	46	21	9	1,390
Total males 0–14	*976*	*778*	*628*	*320*	*263*	*106*	*54*	*17*	*3,142*
Females									
0–4	201	144	110	49	42	16	7	1	570
5–9	329	279	213	125	103	34	16	6	1,105
10–14	402	314	260	119	85	33	25	11	1,249
Total females 0–14	*932*	*737*	*583*	*293*	*230*	*83*	*48*	*18*	*2,924*
Persons									
0–4	405	308	279	127	101	45	18	5	1,288
5–9	637	546	429	237	177	65	38	10	2,139
10–14	866	661	503	249	215	79	46	20	2,639
Total persons 0–14	**1,908**	**1,515**	**1,211**	**613**	**493**	**189**	**102**	**35**	**6,066**

Source: National Diabetes Register (data extracted April 2007).

Table 3.4b: Incidence (rate) of Type 1 diabetes among 0–14 year olds: sex and age, states and territories of usual residence, 1999–2005

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	13.2	14.9	18.9	17.3	18.1	26.2	15.0	6.3	15.7
5–9	19.2	23.0	22.7	23.2	21.1	26.1	28.6	6.5	21.5
10–14	28.6	29.6	25.2	25.9	35.8	37.2	26.4	15.4	28.4
Total males 0–14	*20.4*	*22.6*	*22.4*	*22.3*	*25.3*	*30.0*	*23.5*	*9.3*	*22.0*
Total males 0–14 ASR[(a)] (95% CI)	*20.4 (19.2–21.7)*	*22.6 (21.1–24.3)*	*22.3 (20.6–24.2)*	*22.2 (19.9–24.8)*	*25.1 (22.2–28.4)*	*29.9 (24.5–36.2)*	*23.5 (17.6–30.6)*	*9.5 (5.5–15.1)*	*22.0 (21.2–22.8)*
Females									
0–4	13.7	13.7	13.0	11.4	13.5	15.2	9.8	1.7	13.1
5–9	21.5	25.3	23.7	27.4	30.8	30.1	21.6	10.4	24.2
10–14	26.0	28.0	28.4	24.9	24.7	28.1	32.7	20.3	26.8
Total females 0–14	*20.5*	*22.5*	*21.9*	*21.5*	*23.3*	*24.7*	*21.7*	*10.5*	*21.6*
Total females 0–14 ASR[(a)] (95% CI)	*20.5 (19.2–21.9)*	*22.5 (20.9–24.2)*	*21.9 (20.1–23.7)*	*21.4 (19.0–24.0)*	*23.2 (20.3–26.4)*	*24.6 (19.6–30.5)*	*21.6 (15.9–28.6)*	*11.0 (6.5–17.4)*	*21.5 (20.8–22.3)*
Persons									
0–4	13.4	14.3	16.0	14.4	15.9	20.9	12.5	4.1	14.5
5–9	20.3	24.1	23.2	25.2	25.8	28.0	25.2	8.4	22.8
10–14	27.3	28.8	26.8	25.4	30.4	32.8	29.5	17.8	27.7
Total persons 0–14	**20.5**	**22.6**	**22.1**	**21.9**	**24.3**	**27.4**	**22.6**	**9.9**	**21.8**
Total persons 0–14 ASR[(a)] (95% CI)	**20.5 (19.6–21.4)**	**22.6 (21.4–23.7)**	**22.1 (20.9–23.4)**	**21.8 (20.1–23.6)**	**24.2 (22.1–26.4)**	**27.3 (23.6–31.5)**	**22.5 (18.4–27.4)**	**10.2 (7.1–14.2)**	**21.8 (21.2–22.3)**

(a) Age-standardised to the 2001 Australian population—see Section 6.4.

Source: National Diabetes Register (data extracted April 2007).

Table 3.5: Incidence (number and rate) of Type 1 diabetes among 0–14 year olds: geographical locations based on postcode of usual residence[a], 1999–2005

Geographical location	Age at first insulin use (years)				
	0–4	5–9	10–14	Total 0–14	0–14 ASR[b] (95% CI)
			Number		
Major cities	823	1,345	1,616	3,784	. .
Inner regional	320	502	694	1,516	. .
Outer regional	120	244	286	650	. .
Remote/very remote	23	42	36	101	. .
Unknown	3	5	7	15	. .
Total Australia	**1,288**	**2,139**	**2,639**	**6,066**	. .
	Average annual age-specific rate (number per 100,000 population)				
Major cities	14.3	22.8	27.2	21.5	21.5 (20.9–22.2)
Inner regional	17.2	23.9	31.3	24.5	24.2 (23.0–25.5)
Outer regional	12.2	22.9	26.2	20.7	20.6 (19.0–22.2)
Remote/very remote	7.7	13.7	12.6	11.3	11.4 (9.3–13.9)
Unknown	. .	. .	. .	. .	. .
Total Australia	**14.5**	**22.8**	**27.7**	**21.8**	**21.8 (21.2–22.3)**

(a) Registrants are classified according to the Australian Standard Geographical Classification (ASGC) Remoteness Areas based on postcode of usual residence (AIHW population database)—see Section 6.7.

(b) Age-standardised to the 2001 Australian population—see Section 6.4.

Source: National Diabetes Register (data extracted April 2007).

Table 3.6: Incidence (number and rate) of Type 1 diabetes among 0–14 year olds: statistical divisions based on postcode of usual residence, 1999–2005

Statistical division[a]	NDR cases 1999–2005	Population 1999–2005	Average annual ASR[b] per 100,000 population	95% CI
New South Wales				
Sydney	1,036	5,685,427	18.3	17.2–19.5
Hunter	229	842,412	27.0	23.6–30.7
Illawarra, Central West, South Eastern, Murrumbidgee	324	1,384,631	23.2	20.7–25.9
Richmond-Tweed, Mid-north Coast, Northern	232	1,002,890	22.6	19.8–25.7
Murray, Far West, North Western	86	403,970	21.3	17.0–26.2
New South Wales	*1,908*	*9,319,330*	*20.5*	*19.6–21.4*
Victoria				
Melbourne	1,042	4,701,733	22.2	20.9–23.6
Barwon, Central Highlands	128	576,876	22.1	18.4–26.3
Western District, Wimmera, Mallee	79	372,896	21.0	16.5–26.0
Loddon, Goulburn	148	555,848	26.4	22.2–30.9
Ovens-Murray, East Gippsland, Gippsland	117	502,026	22.8	18.9–27.4
Victoria	*1,515*	*6,709,379*	*22.6*	*21.4–23.7*
Queensland				
Brisbane	562	2,428,765	23.1	21.3–25.1
Moreton	240	1,025,309	23.2	20.3–26.3
Wide Bay-Burnett, Darling Downs, Fitzroy	260	997,387	25.8	22.8–29.2
Mackay, Northern	94	526,321	17.8	14.3–21.7
South West, Central West, Far North, North West	56	493,143	11.4	8.6–14.8
Queensland	*1,211*	*5,470,925*	*22.1*	*20.9–23.4*

(continued)

Table 3.6 (continued): Incidence (number and rate) of Type 1 diabetes among 0–14 year olds: statistical divisions based on postcode of usual residence, 1999–2005

Statistical division[(a)]	NDR cases 1999–2005	Population 1999–2005	Average annual ASR[(b)] per 100,000 population	95% CI
Western Australia				
Perth	444	1,959,430	22.6	20.5–24.8
South West, Lower Great Southern, Upper Great Southern, Midlands	121	506,977	23.7	19.6–28.3
South Eastern, Central, Pilbara, Kimberley	48	333,036	14.6	10.8–19.4
Western Australia	*613*	*2,799,443*	*21.8*	*20.1–23.6*
South Australia				
Adelaide	358	1,423,187	25.1	22.5–27.8
Outer Adelaide, Yorke & Lower North, Murray Lands, South East, Eyre, Northern	134	605,948	21.9	18.3–25.9
South Australia[(c)]	*493*	*2,029,135*	*24.2*	*22.1–26.4*
Tasmania				
Greater Hobart	84	277,902	30.0	23.8–37.0
Southern, Northern, Mersey-Lyell	105	410,971	25.5	20.8–30.8
Tasmania	*189*	*688,873*	*27.3*	*23.6–31.5*
Australian Capital Territory				
Australian Capital Territory	*102*	*451,675*	*22.5*	*18.4–27.4*
Northern Territory				
Northern Territory	*35*	*354,534*	*10.2*	*7.1–14.2*
Australia	**6,066**	**27,828,736**	**21.8**	**21.2–22.3**

(a) Statistical Divisions are as at 30 June 2004 (AIHW population database)—see Section 6.7.

(b) Age-standardised to the 2001 Australian population—see Section 6.4.

(c) Includes 1 case which could not be mapped to a Statistical Division.

Source: National Diabetes Register (data extracted April 2007).

3.1.3 International comparison

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 of varying quality and are not always available for comparable time periods. A study which examined the worldwide incidence of Type 1 diabetes for 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). The study divided incidence rates into five groups: very low, low, intermediate, high and very high. In that study the incidence data reported for Australia (14.5 for New South Wales for 1990–1993) classified Australia as a high-incidence country. Table 3.7 presents more recent data from the *Diabetes atlas* together with the Australian rate from the NDR. The data periods for the countries shown range over the years from 1990 to 2003. In keeping with the study described above, this publication also found Australia to have a comparatively high incidence, being among the top 10 countries in incidence rates for Type 1 diabetes in children. 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 therefore should be interpreted cautiously and considered as general indicators only (IDF 2006).

Table 3.7: Incidence of Type 1 diabetes in 0–14 year olds: Australia compared with selected countries, various years

Region[a] and country	Time period	New cases per 100,000 (cases per 100,000 population per year)	Population 0–14 years ('000s)
Australia[b]	**2000–2003**	**21.8**	**3,476**
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	216
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	10,720
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 2000–03.

(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 and National Diabetes Register for Australia.

3.2 Type 1 diabetes in 15–39 year olds: NDR registrants

This section presents data for 15–39 year olds with Type 1 diabetes on the NDR. The coverage of cases is presented in Table 3.8 and the profile of these registrants is shown in Tables 3.9–3.11. These tables use data from the NDR only in order to present a profile of data that are held on the NDR.

3.2.1 Coverage

The coverage rate for 15–39 year olds with Type 1 diabetes on the NDR (the proportion of NDSS registrants consenting to be on the NDR) has steadily increased from 59% in 1999 to 94% in 2005 (Table 3.8). The recent increases are largely due to the 2003 NDSS registration form change as described in Chapter 1. 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 the report *National Diabetes Register: impact of changed consent arrangements on ascertainment from the National Diabetes Services Scheme* (AIHW 2006).

Table 3.8: Coverage of Type 1 diabetes on the NDR among people aged 15–39 at their first insulin use: by year of first insulin use, 1999–2005

	Males			Females			Persons		
Year of first insulin use	NDR registrants	Missing cases[(a)]	Coverage rate[(b)] (%)	NDR registrants	Missing cases[(a)]	Coverage rate[(b)] (%)	NDR registrants	Missing cases[(a)]	Coverage rate[(b)] (%)
1999	411	235	63.6	283	256	52.5	694	491	58.6
2000	454	96	82.5	263	89	74.7	717	185	79.5
2001	447	112	80.0	270	64	80.8	717	176	80.3
2002	391	101	79.5	218	60	78.4	609	161	79.1
2003	459	97	82.6	257	67	79.3	716	164	81.4
2004	505	33	93.9	266	15	94.7	771	48	94.1
2005	483	30	94.2	257	18	93.5	740	48	93.9
Total	**3,150**	**704**	**81.7**	**1,814**	**569**	**76.1**	**4,964**	**1,273**	**79.6**

(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 and AIHW analysis of de-identified NDSS data (data extracted April 2007).

3.2.2 Profile

Characteristics of NDR registrants aged 15–39 years with Type 1 diabetes were as follows:

- Of people registered on the NDR, there were 4,964 registrants with Type 1 diabetes who were aged 15–39 years at first insulin use and began using insulin between 1999 and 2005 (Table 3.9). This represents 37% of NDR registrants with Type 1 diabetes.
- Males accounted for 64% of 15–39 year olds with Type 1 diabetes, greatly outnumbering females in all age groups.
- The number of registrants was greatest in the 15–19 years age group and decreased with increasing age.
- Within most states and territories, the number of new cases each year did not vary greatly (Table 3.10).
- New South Wales, Victoria and Queensland, being the largest states, contributed the largest number of registrants (Table 3.10) (See Table 3.13 for the rates of new cases per year for each state and territory).
- The geographic distribution of NDR registrants with Type 1 diabetes aged 15–39 years was 67% in major cities, 20% in inner regional, 10% in outer regional and 3% in remote/very remote (Table 3.11). This can be compared with the geographic distribution of the Australian population aged 15–39 in 1999–2005 (average) where there were 69% in major cities, 19% in inner regional, 9% in outer regional and 3% in remote/very remote locations (AIHW population database, 1999–2005).

Table 3.9: NDR registrants with Type 1 diabetes among 15–39 year olds: sex and age by year of first insulin use, 1999–2005

Sex and age at first insulin use (years)	1999[(a)]	2000	2001	2002	2003	2004	2005	Total
				Number				
Males								
15–19	90	106	105	109	119	129	143	801
20–24	91	83	91	86	101	100	101	653
25–29	94	97	91	70	101	104	94	651
30–34	74	88	85	78	76	85	93	579
35–39	62	80	75	48	62	87	52	466
Total males 15–39—number	*411*	*454*	*447*	*391*	*459*	*505*	*483*	*3,150*
Total males 15–39—per cent	*59.2*	*63.3*	*62.3*	*64.2*	*64.1*	*65.5*	*65.3*	*63.5*
Females								
15–19	68	71	82	68	81	79	86	535
20–24	61	48	56	48	59	57	65	394
25–29	63	56	48	43	38	45	47	340
30–34	43	59	46	36	46	52	36	318
35–39	48	29	38	23	33	33	23	227
Total females 15–39—number	*283*	*263*	*270*	*218*	*257*	*266*	*257*	*1,814*
Total females 15–39—per cent	*40.8*	*36.7*	*37.7*	*35.8*	*35.9*	*34.5*	*34.7*	*36.5*
Persons								
15–19	158	177	187	177	200	208	229	1,336
20–24	152	131	147	134	160	157	166	1,047
25–29	157	153	139	113	139	149	141	991
30–34	117	147	131	114	122	137	129	897
35–39	110	109	113	71	95	120	75	693
Total persons 15–39—number	**694**	**717**	**717**	**609**	**716**	**771**	**740**	**4,964**
Total persons 15–39—per cent	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Care should be taken when comparing 1999 with other years because the coverage was low—see Table 3.8.

Source: National Diabetes Register (data extracted April 2007).

Table 3.10: NDR registrants with Type 1 diabetes aged 15–39 years at their first insulin use: state/territory of usual residence, 1999–2005

Year of first insulin use	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
					Number				
1999[(a)]	179	188	152	95	33	25	16	6	694
2000	220	159	153	90	47	30	15	3	717
2001	196	166	162	99	48	21	19	6	717
2002	191	147	122	82	41	15	7	4	609
2003	221	170	154	91	49	10	15	6	716
2004	223	194	174	95	52	12	10	11	771
2005	213	198	172	61	54	12	21	9	740
Total—number	**1,443**	**1,222**	**1,089**	**613**	**324**	**125**	**103**	**45**	**4,964**
Total—per cent	**29.1**	**24.6**	**21.9**	**12.3**	**6.5**	**2.5**	**2.1**	**0.9**	**100.0**

(a) Care should be taken when comparing 1999 with other years because the coverage was low—see table 3.8.

Source: National Diabetes Register (data extracted April 2007).

Table 3.11: NDR registrants with Type 1 diabetes aged 15–39 years at their first insulin use: geographical locations based on postcode of usual residence[(a)], 1999–2005

	Age at first insulin use (years)					
Geographical location	**15–19**	**20–24**	**25–29**	**30–34**	**35–39**	**Total**
			Number			
Major cities	881	715	680	602	469	3,348
Inner regional	307	203	192	164	134	1,000
Outer regional	117	94	95	101	74	482
Remote/very remote	26	34	23	29	14	125
Unknown	5	1	1	1	1	9
Total Australia	**1,336**	**1,047**	**991**	**897**	**693**	**4,964**
			Per cent			
Major cities	66.0	68.3	68.7	67.1	67.7	67.4
Inner regional	23.0	19.4	19.3	18.3	19.4	20.2
Outer regional	8.8	9.0	9.6	11.3	10.7	9.7
Remote/very remote	1.9	3.2	2.3	3.2	2.1	2.5
Unknown	0.4	0.1	0.1	0.1	0.1	0.2
Total Australia	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

(a) Registrants are classified according to the Australian Standard Geographical Classification (ASGC) Remoteness Areas based on postcode of usual residence (AIHW population database)—see Section 6.7.

Source: National Diabetes Register (data extracted April 2007).

3.3 Type 1 diabetes in 15–39 year olds: incidence estimates

This section presents incidence estimates for 15–39 year olds with Type 1 diabetes. The tables in this section are produced using results from the NDR which 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.

On average there were 551 new cases per year of Type 1 diabetes among males aged 15–39 years and 340 new cases per year among females of the same age between 1999 and 2005 (derived from table 3.12a). For males aged 15–39 years the average number of new cases per 100,000 population per year (15.5) was significantly higher than the corresponding rate for females (9.7) (Table 3.12b).

Between 1999 and 2005, the age-standardised rate of new cases of Type 1 diabetes among 15–39 year olds decreased significantly from 16.9 to 10.9 per 100,000 (Table 3.12b). 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). This may indicate a shift to a younger age at onset but requires further investigation.

The rate of new cases of Type 1 diabetes decreased with increasing age in the 15–39 years age group (Table 3.12b). Between 1999–2005, the average annual rate was highest in the 15–19 year age group (17.0 per 100,000) and lowest in the 35–39 year age group (8.7 per 100,000).

Table 3.12a: Incidence (number) of Type 1 diabetes among 15–39 year olds: sex and age by year of first insulin use, 1999–2005

Sex and age at first insulin use (years)	1999	2000	2001	2002	2003	2004	2005	1999–2005
				Number				
Males								
15–19	134	120	124	133	142	139	150	942
20–24	133	102	119	103	113	107	112	789
25–29	158	119	116	96	128	108	96	821
30–34	113	114	110	103	91	94	101	726
35–39	108	95	90	57	82	90	54	576
Total males 15–39—number	*646*	*550*	*559*	*492*	*556*	*538*	*513*	*3,854*
Total males 15–39—per cent	*54.5*	*61.0*	*62.6*	*63.9*	*63.2*	*65.7*	*65.1*	*61.8*
Females								
15–19	104	101	102	86	96	82	93	664
20–24	97	65	67	70	76	60	70	505
25–29	117	76	63	52	53	46	48	455
30–34	113	68	55	43	56	59	38	432
35–39	108	42	47	27	43	34	26	327
Total females 15–39—number	*539*	*352*	*334*	*278*	*324*	*281*	*275*	*2,383*
Total females 15–39—per cent	*45.5*	*39.0*	*37.4*	*36.1*	*36.8*	*34.3*	*34.9*	*38.2*
Persons								
15–19	238	221	226	219	238	221	243	1,606
20–24	230	167	186	173	189	167	182	1,294
25–29	275	195	179	148	181	154	144	1,276
30–34	226	182	165	146	147	153	139	1,158
35–39	216	137	137	84	125	124	80	903
Total persons 15–39—number	**1,185**	**902**	**893**	**770**	**880**	**819**	**788**	**6,237**
Total persons 15–39—per cent	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

Sources: National Diabetes Register and AIHW analysis of de-identified NDSS data (data extracted April 2007).

Table 3.12b: Incidence (rate) of Type 1 diabetes among 15–39 year olds: sex and age by year of first insulin use, 1999–2005

Sex and age at first insulin use (years)	1999	2000	2001	2002	2003	2004	2005	1999–2005[a]
	Age-specific rate (number per 100,000 population)							
Males								
15–19	20.1	17.7	18.0	19.1	20.3	19.8	21.1	19.5
20–24	20.2	15.6	18.0	15.2	16.2	15.0	15.3	16.5
25–29	21.6	16.5	16.5	13.9	18.7	15.8	13.9	16.8
30–34	16.1	16.1	15.1	13.8	12.1	12.4	13.5	14.1
35–39	14.4	12.7	12.1	7.8	11.3	12.4	7.4	11.2
Total males 15–39	*18.4*	*15.7*	*15.9*	*13.9*	*15.6*	*15.0*	*14.2*	*15.5*
Total males 15–39 ASR[b] (95% CI)	*18.4 (17.0–19.8)*	*15.7 (14.4–17.0)*	*15.9 (14.6–17.2)*	*13.8 (12.6–15.1)*	*15.6 (14.3–17.0)*	*15.0 (13.8–16.3)*	*14.1 (12.9–15.3)*	*15.5 (15.0–16.0)*
Females								
15–19	16.3	15.6	15.4	13.0	14.4	12.3	13.7	14.4
20–24	15.1	10.2	10.4	10.7	11.4	8.8	10.0	10.9
25–29	16.0	10.5	8.9	7.6	7.8	6.8	7.1	9.3
30–34	15.9	9.5	7.4	5.7	7.3	7.7	5.0	8.3
35–39	14.2	5.6	6.3	3.6	5.8	4.6	3.5	6.3
Total females 15–39	*15.5*	*10.1*	*9.5*	*7.9*	*9.2*	*8.0*	*7.8*	*9.7*
Total females 15–39 ASR[b](95% CI)	*15.5 (14.2–16.9)*	*10.1 (9.1–11.3)*	*9.6 (8.6–10.7)*	*8.0 (7.1–9.0)*	*9.2 (8.2–10.3)*	*8.0 (7.1–9.0)*	*7.7 (6.8–8.7)*	*9.7 (9.3–10.1)*
Persons								
15–19	18.3	16.7	16.7	16.1	17.4	16.1	17.5	17.0
20–24	17.7	12.9	14.3	13.0	13.9	12.0	12.7	13.7
25–29	18.8	13.5	12.7	10.8	13.3	11.4	10.6	13.1
30–34	16.0	12.8	11.3	9.7	9.7	10.1	9.2	11.2
35–39	14.3	9.1	9.2	5.7	8.6	8.5	5.4	8.7
Total persons 15–39	**17.0**	**12.9**	**12.7**	**10.9**	**12.4**	**11.5**	**11.0**	**12.6**
Total persons 15–39 ASR[b] (95% CI)	**16.9 (16.0–17.9)**	**12.9 (12.1–13.8)**	**12.7 (11.9–13.6)**	**10.9 (10.2–11.7)**	**12.4 (11.6–13.3)**	**11.5 (10.7–12.3)**	**10.9 (10.2–11.7)**	**12.6 (12.3–12.9)**

(a) Average annual rate for 1999–2005.

(b) Age-standardised to the 2001 Australian population—see Section 6.4.

Sources: National Diabetes Register and AIHW analysis of de-identified NDSS data (data extracted April 2007).

Geographical location

A registrant's geographical location (state/territory, remoteness category, statistical division) is derived from postcode data (see Section 6.7 for further detail). This can be done using postcode of usual residence or postcode at diagnosis. The data for postcode of usual residence are more complete than the data for postcode at diagnosis. Analysis by postcode of usual residence may be most useful for resource planning, whereas that done by postcode at diagnosis may be of particular interest for research into patterns of occurrence. Analyses for this section were done by both postcodes and it was found that there were few differences in the results. Therefore, only tables based on postcode of usual residence (because there were fewer missing) have been presented here.

States and territories

The incidence rates of Type 1 diabetes in 15–39 year olds varied between the states and territories and year of first insulin use (Table 3.13). Tasmania had the highest incidence rate of Type 1 diabetes in 15–39 year olds with an average of 16.5 new cases per 100,000 population per year. This rate was significantly greater than the rate for New South Wales, South Australia, Victoria and the Northern Territory. The Northern Territory had the lowest rate, with 9.8 new cases per 100,000, significantly lower than Queensland, Western Australia and Tasmania.

For almost all states and territories, rates were highest in the younger age groups (15–19 years) and in all states and territories, rates were higher for males than females (Table 3.14b). Care should be taken, however, when interpreting these rates for the smaller states and territories because of the small numbers involved.

Remoteness

The geographical distribution of the estimated number of new cases of Type 1 diabetes among people aged 15–39 years was 68% in major cities, 20% in inner regional, 10% in outer regional and 3% in remote/very remote (calculated from Table 3.15). This is similar to the geographic distribution of the Australian population aged 15–39 in 1999–2005 where, on average, there were 69% in major cities, 19% in inner regional 9% in outer regional and 3% in remote/very remote locations (AIHW population database, 1999–2005).

The incidence rate of Type 1 diabetes in 15–39 year olds is similar across the different geographical location groups. Inner regional areas had the highest average annual rate at 13.3 per 100,000 and the remote/very remote group had the lowest rate at 12.1, though the differences between regions were not significant. The average annual rate generally decreased with increasing age in all areas in line with the national pattern. The highest rate was 17.4 in 15–19 year olds in inner regional areas.

Statistical divisions

No statistically significant differences were found between statistical divisions in the incidence of Type 1 diabetes among 15–39 year olds (Table 3.16). Although no differences were found at the aggregate level, that is, 15–39 year olds combined, more detailed analyses with finer age groups may yield different results. The statistical divisions with the highest rates per 100,000 population were 'Greater Hobart' (16.3) and 'Southern, Northern, Mersey-Lyell' (16.5) in Tasmania, 'Moreton' (15.2) in Queensland, and 'South West, Lower Great Southern, Upper Great Southern, Midlands' (15.2) in Western Australia (Table 3.16). The lowest rates were in the Northern Territory (9.8) and 'Sydney' (10.9) in New South Wales.

Table 3.13: Incidence (number and rate) of Type 1 diabetes among 15–39 year olds by year of first insulin use: state/territory of usual residence, 1999–2005

Year of first insulin use	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
					Number				
1999	375	279	234	125	99	40	23	10	1,185
2000	273	209	185	103	75	37	16	4	902
2001	263	202	202	115	57	25	20	9	893
2002	247	182	158	89	60	20	9	4	770
2003	263	216	190	96	68	20	17	10	880
2004	230	208	186	99	53	22	10	11	819
2005	228	204	175	75	58	17	21	10	788
Total 99–05	**1,879**	**1,500**	**1,330**	**702**	**470**	**181**	**116**	**58**	**6,237**
					Age-standardised rate (number per 100,000 population)[(a)]				
1999	16.0	16.1	17.8	17.9	18.7	25.1	17.9	11.5	16.9
2000	11.7	12.0	14.1	14.7	14.3	22.9	12.2	4.7	12.9
2001	11.2	11.5	15.3	16.3	10.9	15.9	15.6	10.7	12.7
2002	10.5	10.4	11.8	12.7	11.5	12.8	7.0	4.8	10.9
2003	11.2	12.3	13.9	13.6	13.1	13.4	12.7	11.6	12.4
2004	9.7	11.8	13.4	13.9	10.3	14.4	7.5	13.2	11.5
2005	9.6	11.4	12.4	10.3	11.1	10.3	16.5	11.9	10.9
Average 99–05 (95% CI)	*11.4 (10.9–11.9)*	*12.2 (11.6–12.8)*	*14.1 (13.3–14.9)*	*14.2 (13.2–15.3)*	*12.9 (11.8–14.1)*	*16.5 (14.2–19.1)*	*12.8 (10.5–15.3)*	*9.8 (7.4–12.6)*	*12.6 (12.3–12.9)*

(a) Age-standardised to the 2001 Australian population—see Section 6.4.

Sources: National Diabetes Register and AIHW analysis of de-identified NDSS data (data extracted April 2007).

Table 3.14a: Incidence (number) of Type 1 diabetes among 15–39 year olds: sex and age by states and territories of usual residence, 1999–2005

Sex and age at first insulin use (years)	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
					Number				
Males									
15–19	310	241	172	108	61	22	21	6	942
20–24	224	197	171	93	53	20	21	10	789
25–29	234	210	192	92	50	24	11	8	821
30–34	216	177	149	91	49	25	8	11	726
35–39	165	131	132	68	58	12	7	3	576
Total males 15–39	*1,149*	*956*	*816*	*452*	*271*	*103*	*68*	*38*	*3,854*
Females									
15–19	179	159	148	78	59	23	12	6	664
20–24	160	106	121	44	38	18	15	3	505
25–29	147	106	98	56	23	11	9	5	455
30–34	134	106	85	36	45	17	4	5	432
35–39	110	67	62	36	34	9	8	1	327
Total females 15–39	*730*	*544*	*514*	*250*	*199*	*78*	*48*	*20*	*2,383*
Persons									
15–19	489	400	320	186	120	45	33	12	1,606
20–24	384	303	292	137	91	38	36	13	1,294
25–29	381	316	290	148	73	35	20	13	1,276
30–34	350	283	234	127	94	42	12	16	1,158
35–39	275	198	194	104	92	21	15	4	903
Total persons 15–39	**1,879**	**1,500**	**1,330**	**702**	**470**	**181**	**116**	**58**	**6,237**

Sources: National Diabetes Register and AIHW analysis of de-identified NDSS data (data extracted April 2007).

Table 3.14b: Incidence (rate) of Type 1 diabetes among 15–39 year olds: sex and age by states and territories of usual residence, 1999–2005

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	19.4	20.7	18.1	21.5	16.6	18.1	24.3	11.2	19.5
20–24	14.2	16.6	18.5	19.2	14.9	19.1	21.8	16.6	16.5
25–29	14.1	17.2	20.7	19.0	14.1	24.5	12.1	12.3	16.8
30–34	12.5	13.7	15.5	17.8	12.9	23.4	9.1	16.8	14.1
35–39	9.5	10.2	13.8	13.1	14.8	10.4	8.2	4.8	11.2
Total males 15–39	*13.8*	*15.5*	*17.3*	18.1	14.7	*18.9*	*15.2*	*12.4*	*15.5*
Total males 15–39 ASR[(a)] (95% CI)	*13.8 (13.0–14.6)*	*15.5 (14.6–16.5)*	*17.2 (16.1–18.5)*	*18.0 (16.4–19.8)*	*14.6 (13.0–16.5)*	*19.1 (15.5–23.1)*	*14.8 (11.5–18.8)*	*12.2 (8.7–16.8)*	*15.5 (15.0–16.0)*
Females									
15–19	11.8	14.2	16.3	16.4	16.9	19.7	14.5	12.1	14.4
20–24	10.5	9.1	13.5	9.6	11.3	17.9	16.1	5.7	10.9
25–29	8.9	8.6	10.6	11.9	6.8	10.9	9.9	8.2	9.3
30–34	7.6	7.9	8.7	7.1	12.1	15.0	4.4	8.0	8.3
35–39	6.3	5.1	6.3	6.9	8.7	7.4	9.1	1.8	6.3
Total females 15–39	*8.9*	*8.8*	*11.0*	10.3	11.1	*14.1*	*10.8*	*7.1*	*9.7*
Total females 15–39 ASR[(a)] (95% CI)	*8.9 (8.3–9.6)*	*8.9 (8.2–9.7)*	*10.9 (10.0–11.9)*	*10.3 (9.0–11.6)*	*11.1 (9.6–12.7)*	*14.0 (11.1–17.5)*	*10.6 (7.8–14.1)*	*7.1 (4.3–10.9)*	*9.7 (9.3–10.1)*
Persons									
15–19	15.7	17.5	17.2	19.0	16.7	18.9	19.5	11.6	17.0
20–24	12.4	12.9	16.0	14.5	13.2	18.5	19.0	11.5	13.7
25–29	11.5	12.8	15.7	15.5	10.6	17.6	11.0	10.3	13.1
30–34	10.0	10.7	12.1	12.5	12.5	19.1	6.7	12.5	11.2
35–39	7.9	7.6	10.0	10.0	11.7	8.9	8.7	3.4	8.7
Total persons 15–39	**11.4**	**12.2**	**14.1**	**14.2**	**12.9**	**16.5**	**13.0**	**9.8**	**12.6**
Total persons 15–39 ASR[(a)] (95% CI)	**11.4 (10.9–11.9)**	**12.2 (11.6–12.8)**	**14.1 (13.3–14.9)**	**14.2 (13.2–15.3)**	**12.9 (11.8–14.1)**	**16.5 (14.2–19.1)**	**12.8 (10.5–15.3)**	**9.8 (7.4–12.6)**	**12.6 (12.3–12.9)**

(a) Age-standardised to the 2001 Australian population—see Section 6.4.

Sources: National Diabetes Register and AIHW analysis of de-identified NDSS data (data extracted April 2007).

Table 3.15: Incidence (number and rate) of Type 1 diabetes among 15–39 year olds at their first insulin use: geographical locations based on postcode of usual residence[a], 1999–2005

Geographical location	Age at first insulin use (years)					Total 15–39	15–39 ASR[b] (95% CI)
	15–19	20–24	25–29	30–34	35–39		
				Number			
Major cities	1,057	894	883	787	625	4,246	. .
Inner regional	357	243	245	212	164	1,222	. .
Outer regional	149	116	114	123	94	595	. .
Remote/very remote	36	38	33	34	19	159	. .
Unknown	7	2	1	2	2	14	. .
Total Australia	**1,606**	**1,294**	**1,276**	**1,158**	**903**	**6,237**	. .
	Average annual age-specific rate (number per 100,000 population)						
Major cities	17.0	13.2	12.6	10.9	8.9	12.4	12.4 (12.0–12.8)
Inner regional	17.4	15.3	15.1	11.4	8.0	13.3	13.3 (12.6–14.1)
Outer regional	15.6	14.9	13.1	12.5	8.9	12.8	12.9 (11.9–14.0)
Remote/very remote	16.1	16.3	11.7	11.4	6.5	12.1	12.2 (10.4–14.2)
Unknown	. .	. .	. .	. .	. .	. .	. .
Total Australia	**17.0**	**13.7**	**13.1**	**11.2**	**8.7**	**12.6**	**12.6 (12.3–12.9)**

(a) Registrants are classified according to the Australian Standard Geographical Classification (ASGC) Remoteness Areas based on postcode of usual residence (AIHW population database)—see Section 6.7.

(b) Age-standardised to the 2001 Australian population—see Section 6.4.

Sources: National Diabetes Register and AIHW analysis of de-identified NDSS data (data extracted April 2007).

Table 3.16: Incidence (number and rate) of Type 1 diabetes among 15–39 year olds: statistical divisions based on postcode of usual residence, 1999–2005

Statistical division[a]	Number 1999–2005	Population 1999–2005	Average yearly ASR[b] per 100,000 population	95% CI
New South Wales				
Sydney	1,205	11,083,536	10.9	10.3–11.6
Hunter	177	1,369,761	12.8	11.0–14.8
Illawarra, Central West, South Eastern, Murrumbidgee	248	2,095,112	11.8	10.3–13.3
Richmond-Tweed, Mid-north Coast, Northern	166	1,384,824	11.9	10.1–13.8
Murray, Far West, North Western	83	566,905	14.6	11.6–18.1
New South Wales	*1,879*	*16,500,138*	*11.4*	*10.9–11.9*
Victoria				
Melbourne	1,117	9,342,504	12.0	11.3–12.8
Barwon, Central Highlands	115	935,162	12.3	10.1–14.7
Western District, Wimmera, Mallee	67	517,166	13.3	10.2–16.8
Loddon, Goulburn	112	804,435	14.0	11.5–16.8
Ovens-Murray, East Gippsland, Gippsland	89	721,918	12.4	9.9–15.2
Victoria	*1,500*	*12,321,185*	*12.2*	*11.6–12.8*
Queensland				
Brisbane	659	4,537,988	14.4	13.3–15.6
Moreton	264	1,742,652	15.2	13.4–17.2
Wide Bay-Burnett, Darling Downs, Fitzroy	193	1,464,613	13.0	11.2–14.9
Mackay, Northern	105	883,045	11.8	9.7–14.3
South West, Central West, Far North, North West	109	782,452	14.1	11.5–16.9
Queensland	*1,330*	*9,410,750*	*14.1*	*13.3–14.9*

(continued)

Table 3.16 (continued): Incidence of Type 1 diabetes among 15–39 year olds: Statistical Divisions based on postcode of usual residence, 1999–2005

Statistical division[a]	Number 1999–2005	Population 1999–2005	Average yearly ASR[b] per 100,000 population	95% CI
Western Australia				
Perth	531	3,683,223	14.4	13.2–15.6
South West, Lower Great Southern, Upper Great Southern, Midlands	109	720,807	15.2	12.5–18.4
South Eastern, Central, Pilbara, Kimberley	62	528,752	12.1	9.3–15.5
Western Australia	*702*	*4,932,782*	*14.2*	*13.2–15.3*
South Australia				
Adelaide	370	2,746,628	13.4	12.1–14.9
Outer Adelaide, Yorke & Lower North, Murray Lands, South East, Eyre, Northern	100	885,788	11.3	9.1–13.6
South Australia	*470*	*3,632,416*	*12.9*	*11.8–14.1*
Tasmania				
Greater Hobart	78	475,681	16.3	12.8–20.3
Southern, Northern, Mersey-Lyell	103	622,539	16.5	13.4–20.0
Tasmania	*181*	*1,098,220*	*16.5*	*14.2–19.1*
Australian Capital Territory				
Australian Capital Territory	*116*	*890,600*	*12.8*	*10.5–15.3*
Northern Territory				
Northern Territory	*58*	*589,286*	*9.8*	*7.4–12.6*
Australia[c]	**6,237**	**49,381,739**	**12.6**	**12.3–12.9**

(a) Statistical Divisions are as at 30 June 2004 (AIHW population database)—see Section 6.7.

(b) Age-standardised to the 2001 Australian population—see Section 6.4.

(c) Includes one case where state was missing.

Sources: National Diabetes Register and AIHW analysis of de-identified NDSS data (data extracted April 2007).

4 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, and other types such as diabetes caused by cystic fibrosis and diabetes caused by genetic defects of beta-cell function ('MODY') (see Glossary for further details). Section 4.1 presents data from the NDR only in order to show a profile of the data that are held on the NDR. Section 4.2 presents adjusted numbers for these groups by using results from the NDR which have been adjusted to account for missing cases using information from the de-identified NDSS data set. Adjusting the NDR results in this way gives more reliable incidence estimates. 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 report *National Diabetes Register: impact of changed consent arrangements on ascertainment from the National Diabetes Services Scheme* (AIHW 2006). It is important to be aware that the following tables present data on new cases of insulin-treated Type 2, gestational and other types of diabetes and do not include data for the many cases of these conditions where insulin is not used.

4.1 Other forms of insulin-treated diabetes: NDR registrants

This section presents data from the NDR only in order to show a profile of the data that are held on the NDR.

Age and sex

The age and sex distribution of NDR registrants with insulin-treated Type 2, gestational and other types of diabetes is shown in Table 4.1.

- There were 29,473 males and 33,037 females with insulin-treated diabetes other than Type 1, which represents just over 80% of all NDR registrants (Table 4.1). Eighty-four per cent of these cases were Type 2, 13% were gestational diabetes, and 1% were other types of diabetes (see Glossary).
- Over 75% of registrants with insulin-treated Type 2 diabetes were over 50 years of age at their first insulin use.
- There were more males than females among registrants aged 40–79 years with insulin-treated Type 2 diabetes.
- Gestational diabetes occurs during pregnancy, hence 85% of females with insulin-treated gestational diabetes first used insulin between the ages of 25 and 39 years.

Geographical location

The geographical distribution (based on postcode of usual residence) of NDR registrants with insulin-treated Type 2, gestational and other types of diabetes is shown in Table 4.2.

- Of NDR registrants with insulin-treated Type 2 diabetes, 64% lived in major cities, 22% in inner regional areas, 11% in outer regional areas, and 3% in remote/very remote areas.
- Of NDR registrants with insulin-treated gestational diabetes, 79% lived in major cities, 15% in inner regional areas, 5% in outer regional areas, and 1% in remote/very remote areas.
- Of NDR registrants with insulin-treated other types of diabetes, 66% lived in major cities, 23% in inner regional areas, 10% in outer regional areas, and 1% in remote/very remote areas.

Table 4.1: NDR registrants with insulin-treated Type 2, gestational and other types of diabetes: age at first insulin use and sex, 1999–2005

Age at first insulin use (years)	Type 2		Gestational		Other[a]		Total[b]	
	No.	%	No.	%	No.	%	No.	%
Males								
0–14	50	0.2	n.a.	n.a.	39	8.9	129	0.4
15–24	168	0.6	n.a.	n.a.	42	9.6	252	0.9
25–39	1,786	6.3	n.a.	n.a.	73	16.6	1,970	6.7
40–49	3,936	13.8	n.a.	n.a.	68	15.5	4,062	13.8
50–59	7,222	25.4	n.a.	n.a.	95	21.6	7,401	25.1
60–69	7,719	27.1	n.a.	n.a.	70	15.9	7,890	26.8
70–79	5,697	20.0	n.a.	n.a.	43	9.8	5,830	19.8
80 and over	1,889	6.6	n.a.	n.a.	9	2.1	1,938	6.6
Not stated	1	—	n.a.	n.a.	—	—	1	—
Total males	*28,468*	*100.0*	*n.a.*	*n.a.*	*439*	*100.0*	*29,473*	*100.0*
Females								
0–14	53	0.2	1	—	51	14.7	140	0.4
15–24	311	1.3	569	6.9	48	13.8	968	2.9
25–39	2,908	12.2	7,058	85.4	51	14.7	10,105	30.6
40–49	2,978	12.5	626	7.6	42	12.1	3,689	11.2
50–59	5,275	22.1	—	—	46	13.3	5,398	16.3
60–69	5,404	22.6	—	—	63	18.2	5,524	16.7
70–79	4,726	19.8	—	—	31	8.9	4,841	14.7
80 and over	2,258	9.4	—	—	15	4.3	2,365	7.2
Not stated	—	—	7	—	—	—	7	—
Total females	*23,913*	*100.0*	*8,261*	*100.0*	*347*	*100.0*	*33,037*	*100.0*
Persons								
0–14	103	0.2	1	—	90	11.5	269	0.4
15–24	479	0.9	569	6.9	90	11.5	1,220	2.0
25–39	4,694	9.0	7,058	85.4	124	15.8	12,075	19.3
40–49	6,914	13.2	626	7.6	110	14.0	7,751	12.4
50–59	12,497	23.9	—	—	141	17.9	12,799	20.5
60–69	13,123	25.1	—	—	133	16.9	13,414	21.5
70–79	10,423	19.9	—	—	74	9.4	10,671	17.1
80 and over	4,147	7.9	—	—	24	3.1	4,303	6.9
Not stated	1	—	7	0.1	—	—	8	—
Total persons	**52,381**	**100.0**	**8,261**	**100.0**	**786**	**100.0**	**62,510**	**100.0**

(a) See Glossary for 'Other types of diabetes'.

(b) Total includes those where age at first insulin use was unknown and the 566 males and 516 females for whom a derived diabetes type could not be calculated (see Section 6.3 for more details) and therefore sub-components do not add to totals.

Source: National Diabetes Register (data extracted April 2007).

Table 4.2: NDR registrants with insulin-treated Type 2, gestational and other types of diabetes: by age and geographical location[a] based on postcode of usual residence, 1999–2005

Age at first insulin use (years)	Type 2	Gestational	Other[b]	Total[c]
Major cities				
0–39	3,427	5,998	194	9,875
40–59	12,285	521	178	13,141
60–79	15,302	—	128	15,649
80 and over	2,826	—	18	2,933
Total persons—number	*33,840*	*6,524*	*518*	*41,604*
Total persons—per cent	*64.6*	*79.0*	*65.9*	*66.6*
Inner regional				
0–39	992	1,168	72	2,291
40–59	4,095	73	50	4,279
60–79	5,300	—	52	5,425
80 and over	887	—	5	919
Total persons—number	*11,275*	*1,242*	*179*	*12,916*
Total persons—per cent	*21.5*	*15.0*	*22.8*	*20.7*
Outer regional				
0–39	583	365	33	1,006
40–59	2,332	27	22	2,413
60–79	2,516	—	23	2,574
80 and over	380	—	1	395
Total persons—number	*5,811*	*393*	*79*	*6,388*
Total persons—per cent	*11.1*	*4.8*	*10.1*	*10.2*
Remote/very remote				
0–39	274	97	5	390
40–59	698	5	1	715
60–79	428	—	4	438
80 and over	54	—	—	56
Total persons—number	*1,453*	*102*	*10*	*1,599*
Total persons—per cent	*2.8*	*1.2*	*1.3*	*2.6*
Total Australia				
0–39	5,276	7,628	304	13,564
40–59	19,411	626	251	20,550
60–79	23,546	—	207	24,085
80 and over	4,147	—	24	4,303
Total persons—number	**52,381**	**8,261**	**786**	**62,510**
Total persons—per cent	**100.0**	**100.0**	**100.0**	**100.0**

(a) Registrants are classified according to the Australian Standard Geographical Classification (ASGC) Remoteness Areas Classification based on postcode of usual residence (AIHW population database)—see Section 6.7.

(b) See Glossary for 'Other types of diabetes'.

(c) Total includes those where age at first insulin use was unknown and the 1,082 people for whom a derived diabetes type could not be calculated (see Section 6.3 for more details) and therefore sub-components do not add to totals.

Source: National Diabetes Register (data extracted April 2007).

4.2 Other forms of insulin-treated diabetes: estimated new cases

This section presents adjusted numbers for these types of diabetes by using results from the NDR which have been adjusted to account for missing cases using information from the de-identified NDSS data set. Adjusting the NDR results in this way gives more reliable incidence estimates.

Age and sex

The age and sex distribution of new cases of insulin-treated Type 2, gestational and other types of diabetes is shown in Table 4.3.

- Of the new cases of insulin-treated Type 2, gestational and other types of diabetes, there were 58,542 males and 60,719 females (Table 4.3). Eighty-four per cent of these cases were Type 2, 9% were gestational diabetes, and less than 1% were other types of diabetes (see Glossary).
- There were over 100,000 new cases of insulin-treated Type 2 diabetes over the last 7 years. Over 75% of new cases with insulin-treated Type 2 diabetes were over 50 years of age at their first insulin use, with the highest number occurring in the 60–69 years age group (26,416).
- There were more males than females among registrants aged 40 years and over with insulin-treated Type 2 diabetes.
- In line with recent evidence that people are developing Type 2 diabetes at younger ages (McMahon et al. 2004; Pinhas-Hamiel & Zeitler 2005; Craig et al. 2007), there were 149 cases of insulin-treated Type 2 diabetes in 0–14 year olds and 720 cases among 15–24 year olds (Table 4.3).
- Gestational diabetes occurs during pregnancy, hence 85% of females with insulin-treated gestational diabetes first used insulin between the ages of 25 and 39 years.

Geographical location

The geographical distribution (based on postcode of usual residence) of new cases of insulin-treated Type 2, gestational and other types of diabetes is shown in Table 4.4.

- Of the new cases of insulin-treated Type 2 diabetes, 65% were in major cities, 22% were in inner regional areas, 11% in outer regional areas, and 3% in remote/very remote areas.
- Of the new cases of insulin-treated gestational diabetes, 79% were in major cities, 15% in inner regional areas, 5% in outer regional areas, and 2% in remote/very remote areas.
- Of the new cases of insulin-treated other types of diabetes, 68% were in major cities, 22% in inner regional areas, 9% in outer regional areas, and 1% in remote/very remote areas.

Table 4.3: New cases of insulin-treated Type 2, gestational and other types of diabetes: age at first insulin use and sex, 1999–2005

Age at first insulin use (years)	Type 2		Gestational		Other[(a)]		Total[(b)]	
	No.	%	No.	%	No.	%	No.	%
Males								
0–14	74	0.1	n.a.	n.a.	45	7.7	222	0.4
15–24	231	0.4	n.a.	n.a.	49	8.4	411	0.7
25–39	2,764	5.1	n.a.	n.a.	100	17.1	3,251	5.6
40–49	6,757	12.5	n.a.	n.a.	93	15.9	7,313	12.5
50–59	13,606	25.1	n.a.	n.a.	122	20.8	14,485	24.7
60–69	15,323	28.3	n.a.	n.a.	98	16.7	16,307	27.9
70–79	11,598	21.4	n.a.	n.a.	63	10.8	12,409	21.2
80 and over	3,852	7.1	n.a.	n.a.	16	2.7	4,143	7.1
Not stated	1	—	n.a.	n.a.	—	—	1	—
Total males	*54,206*	*100.0*	*n.a.*	*n.a.*	*586*	*100.0*	*58,542*	*100.0*
Females								
0–14	75	0.2	1	—	62	13.7	256	0.4
15–24	489	1.1	718	6.8	56	12.3	1,452	2.4
25–39	4,671	10.1	8,997	85.4	78	17.2	14,320	23.6
40–49	5,306	11.5	806	7.7	53	11.7	6,603	10.9
50–59	10,091	21.8	1	—	61	13.4	10,732	17.7
60–69	11,093	24.0	—	—	77	17.0	11,808	19.4
70–79	9,979	21.6	—	—	44	9.7	10,643	17.5
80 and over	4,518	9.8	—	—	23	5.1	4,898	8.1
Not stated	—	—	7	0.1	—	—	7	—
Total females	*46,222*	*100.0*	*10,530*	*100.0*	*454*	*100.0*	*60,719*	*100.0*
Persons								
0–14	149	0.1	1	—	107	10.3	478	0.4
15–24	720	0.7	718	6.8	105	10.1	1,863	1.6
25–39	7,435	7.4	8,997	85.4	178	17.1	17,571	14.7
40–49	12,063	12.0	806	7.7	146	14.0	13,916	11.7
50–59	23,697	23.6	1	—	183	17.6	25,217	21.1
60–69	26,416	26.3	—	—	175	16.8	28,115	23.6
70–79	21,577	21.5	—	—	107	10.3	23,052	19.3
80 and over	8,370	8.3	—	—	39	3.8	9,041	7.6
Not stated	1	—	7	0.1	—	—	8	—
Total persons	**100,428**	**100.0**	**10,530**	**100.0**	**1,040**	**100.0**	**119,261**	**100.0**

(a) See Glossary for 'Other types of diabetes'.

(b) Total includes those where age at first insulin use was unknown and the 3,750 males and 3,513 females for whom a derived diabetes type could not be calculated (see Section 6.3 for more details) and therefore sub-components do not add to totals.

Source: National Diabetes Register and AIHW analysis of de-identified NDSS data (data extracted April 2007).

Table 4.4: New cases of insulin-treated Type 2, gestational and other types of diabetes: by age and geographical location[a] based on postcode of usual residence, 1999–2005

Age at first insulin use (years)	Type 2	Gestational	Other[b]	Total[c]
Major cities				
0–39	5,421	7,634	259	14,329
40–59	22,814	677	239	25,128
60–79	31,253	—	178	33,231
80 and over	5,666	—	27	6,113
Total persons—number	*65,154*	*8,317*	*703*	*78,807*
Total persons—per cent	*64.9*	*79.0*	*67.6*	*66.1*
Inner regional				
0–39	1,568	1,455	86	3,404
40–59	7,586	92	61	8,241
60–79	10,770	—	69	11,510
80 and over	1,830	—	11	1,969
Total persons—number	*21,755*	*1,547*	*226*	*25,126*
Total persons—per cent	*21.7*	*14.7*	*21.7*	*21.1*
Outer regional				
0–39	876	466	39	1,521
40–59	4,183	31	26	4,498
60–79	5,147	—	31	5,537
80 and over	775	—	1	853
Total persons—number	*10,980*	*497*	*98*	*12,410*
Total persons—per cent	*10.9*	*4.7*	*9.4*	*10.4*
Remote/very remote				
0–39	440	161	7	656
40–59	1,173	8	3	1,261
60–79	819	—	4	885
80 and over	97	—	—	104
Total persons—number	*2,528*	*168*	*13*	*2,906*
Total persons—per cent	*2.5*	*1.6*	*1.3*	*2.4*
Total Australia				
0–39	8,304	9,716	390	19,912
40–59	35,760	807	329	39,133
60–79	47,993	—	282	51,167
80 and over	8,370	—	39	9,041
Total persons—number	**100,428**	**10,530**	**1,040**	**119,261**
Total persons—per cent	**100.0**	**100.0**	**100.0**	**100.0**

(a) Registrants are classified according to the Australian Standard Geographical Classification (ASGC) Remoteness Areas based on postcode of usual residence (AIHW population database)—see Section 6.7.

(b) See Glossary for 'Other types of diabetes'.

(c) Total includes those where age at first insulin use was unknown and the 3,750 males and 3,513 females for whom a derived diabetes type could not be calculated (see Section 6.3 for more details) and therefore sub-components do not add to totals.

Source: National Diabetes Register and AIHW analysis of de-identified NDSS data (data extracted April 2007).

5 Mortality of NDR registrants

5.1 Number of deaths

All NDR records for people who began using insulin in 1999–2005 were matched against the AIHW National Death Index. Of these 76,124 registrants, 7,547 were identified as having died, that is 10% of all NDR registrants in that period (Table 5.1).

More than 90% of deaths occurred in registrants aged 50 years and over, suggesting that the majority of deaths were for people with Type 2 diabetes. There were 11 deaths in registrants aged 0–14 years and 155 deaths in registrants aged 15–39 years, 0.1% and 2% of all registrant deaths, respectively.

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) and thus the number of deaths in people with insulin-treated diabetes is likely to be higher than shown here.

Table 5.1: NDR registrants: deaths, 1999–2005

	Males		Females		Persons	
Age at death (years)	Number	Per cent	Number	Per cent	Number	Per cent
0–14	6	0.1	5	0.2	11	0.1
15–19	8	0.2	9	0.3	17	0.2
20–24	13	0.3	10	0.3	23	0.3
25–29	8	0.2	7	0.2	15	0.2
30–34	23	0.5	9	0.3	32	0.4
35–39	44	1.0	24	0.8	68	0.9
40–44	51	1.1	40	1.3	91	1.2
45–49	118	2.6	73	2.4	191	2.5
50–54	203	4.5	115	3.8	318	4.2
55–59	371	8.3	154	5.0	525	7.0
60–64	460	10.2	231	7.6	691	9.2
65–69	574	12.8	322	10.5	896	11.9
70–74	731	16.3	392	12.8	1,123	14.9
75–79	784	17.4	551	18.0	1,335	17.7
80+	1,099	24.5	1,112	36.4	2,211	29.3
All ages	**4,493**	**100.0**	**3,054**	**100.0**	**7,547**	**100.0**

Source: National Diabetes Register (data extracted April 2007).

5.2 Cause of death

Death certificate data provide an underlying cause of death and up to 20 associated causes of death for each death. The underlying cause of death 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).

Features of the underlying cause of death data for NDR registrants (persons with insulin-treated diabetes only) who died in 1999–2005 were as follows (Table 5.2):

- At the broad group level, neoplasms—including cancers (malignant) 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 (38%) 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 19% of all deaths. This was followed by cancer of the pancreas causing 7% 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 (7%) than females (3%).
- A higher proportion of females died from diseases of the circulatory system (31%) than males (27%).

NDR registrants who died between 1999 and 2005 died at a significantly higher rate than expected based on the death rates of the Australian population over the same period (summarised using the Standardised Mortality Ratio or SMR). For deaths from all causes, there were nearly 3 times as many deaths as expected among both males and females on the NDR (Table 5.2). Not surprisingly, deaths from diabetes occurred at a rate that was more than 15 times as high as the rate in the general population. Deaths from cancer of the pancreas was almost 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 2.8 in this population group.

Note that it is not possible to directly compare the standardised mortality ratios (SMRs) for males with those for females because different standard populations have been used (see Section 6.5 for information about the methodology used to calculate the SMRs).

Table 5.2: NDR registrants: underlying causes of death for deceased registrants, 1999–2005

Underlying cause of death	Males			Females			Persons		
	No.	%	SMR[(a)] (95% CI)	No.	%	SMR[(a)] (95% CI)	No.	%	SMR[(a)] (95% CI)
Neoplasms	1,718	38.2	3.28 (3.13–3.44)	966	31.6	3.30 (3.10–3.52)	2,684	35.6	3.29 (3.17–3.42)
Cancer of the pancreas	*324*	*7.2*	*13.89 (12.42–15.49)*	*236*	*7.7*	*13.50 (11.83–15.34)*	*559*	*7.4*	*13.72 (12.61–14.91)*
Cancer of the bronchus and lung	*296*	*6.6*	*2.51 (2.24–2.82)*	*88*	*2.9*	*1.91 (1.53–2.35)*	*385*	*5.1*	*2.34 (2.11–2.59)*
Diseases of the circulatory system	1,231	27.4	2.29 (2.16–2.42)	951	31.1	2.30 (2.16–2.46)	2,182	28.9	2.30 (2.20–2.40)
Ischaemic heart disease	*839*	*18.7*	*2.70 (2.52–2.89)*	*556*	*18.2*	*2.87 (2.63–3.12)*	*1,395*	*18.5*	*2.76 (2.62–2.91)*
Cerebrovascular diseases	*171*	*3.8*	*1.51 (1.30–1.76)*	*190*	*6.2*	*1.61 (1.39–1.86)*	*361*	*4.8*	*1.57 (1.41–1.74)*
Diabetes mellitus	599	13.3	13.94 (12.85–15.11)	482	15.8	16.86 (15.39–18.44)	1,080	14.3	15.11 (14.22–16.04)
Diseases of the respiratory system	289	6.4	4.40 (3.91–4.94)	201	6.6	3.90 (3.38–4.48)	490	6.5	4.18 (3.82–4.57)
All other diseases	657	14.6	1.88 (1.74–2.03)	454	14.9	1.74 (1.58–1.90)	1,111	14.7	1.82 (1.71–1.93)
All causes	**4,493**	**100.0**	**2.96 (2.87–3.05)**	**3,054**	**100.0**	**2.92 (2.81–3.02)**	**7,547**	**100.0**	**2.94 (2.88–3.01)**

(a) Standardised mortality ratio—see Section 6.5.

Source: National Diabetes Register (data extracted June 2007).

5.3 Diabetes on the death certificate

Diabetes has been shown to be underreported on death certificates (Whittall et al. 1990). 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); and many people have other chronic diseases in addition to diabetes, so selecting a single underlying cause of death may be difficult in these people (AIHW: Mathur et al. 2000).

Just under half of the deceased NDR registrants—people known to have diabetes—had diabetes listed on their death certificate (Table 5.3). However, this has increased since 2000 from 42.6% (AHIW 2001). A higher proportion of females than males had diabetes listed on their death certificate, 52% 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.

At the broad group level, diabetes was listed on the death certificate in 54% of deaths with an underlying cause of 'diseases of the circulatory system', 49% of deaths with an underlying

cause of 'diseases of the respiratory system', and 30% of deaths with an underlying cause of neoplasms, which includes malignant (cancers) and benign tumours.

Table 5.3: NDR registrants: underlying causes of death[(a)] and proportion with diabetes listed on the death certificate, 1999–2005

	Males			Females			Persons		
Underlying cause of death	**No.**	**%**	**% with diabetes on death certificate**	**No.**	**%**	**% with diabetes on death certificate**	**No.**	**%**	**% with diabetes on death certificate**
Neoplasms	1,687	38.2	30.4	951	31.6	30.4	2,638	35.6	30.4
Cancer of the pancreas	*318*	*7.2*	*26.4*	*232*	*7.7*	*25.0*	*550*	*7.4*	*25.8*
Cancer of the bronchus and lung	*291*	*6.6*	*29.2*	*87*	*2.9*	*37.9*	*378*	*5.1*	*31.2*
Diseases of the circulatory system	1,209	27.4	53.3	936	31.1	55.4	2,145	28.9	54.2
Ischaemic heart disease	*824*	*18.7*	*56.6*	*547*	*18.2*	*56.1*	*1,371*	*18.5*	*56.4*
Cerebrovascular diseases	*168*	*3.8*	*49.4*	*187*	*6.2*	*55.6*	*355*	*4.8*	*52.7*
Diabetes mellitus	588	13.3	100.0	474	15.8	100.0	1,062	14.3	100.0
Diseases of the respiratory system	284	6.4	45.8	198	6.6	52.5	482	6.5	48.5
All other diseases	645	14.6	37.8	447	14.9	40.7	1,092	14.7	39.0
All causes[(b)]	**4,413**	**100.0**	**48.0**	**3,006**	**100.0**	**52.2**	**7,419**	**100.0**	**49.7**

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

(b) Excludes records with a missing underlying cause of death.

Source: National Diabetes Register (data extracted June 2007).

6 Statistical notes and methods

6.1 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 GDM 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 records*

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

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

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

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

*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).

6.2 Calculation of year of first insulin use

The method used to derive 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

6.3 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 (GDM)
- 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 our 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 (38% of people with Type 1 on the NDR were aged 25 or older at diagnosis, see Table 2.3), that many people diagnosed with Type 2 diabetes actually have Type 1 diabetes (but a slow onset form known as 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. For example, in the ABS 1995 National Health Survey (NHS), over one-third of respondents who reported having been told by a doctor or a nurse that they had diabetes were not able to report what type of diabetes they had.

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, GDM, and other types of diabetes. This means many people report having Type 1 diabetes because they use insulin when, in fact, they have another form of insulin-treated diabetes. A small survey conducted with registrants' certifying doctors in 2000 confirmed this misclassification (see AIHW (2001) pages 13 and 24 for details). 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 ABS NHS, the 1983 National Heart Foundation Risk Factor Prevalence Study, and the 1999–00 AusDiab 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 NHS 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 which 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) in an effort to more accurately describe the distribution of registrants' diabetes type—this has been in place since before the first statistical profile report. Owing to 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 targeted 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 NDDWG, and the

current algorithm is shown in Box 6.1. 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 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 re-classify all records that have been misreported.

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

For further background information on this algorithm, please see the *National Diabetes Register, statistical profile, December 2000* (AIHW 2001:13-14).

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 diabetes-associated autoantibodies are performed at diagnosis, 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 value is taken over the NDSS value.

Box 6.1 NDR algorithm to derive diabetes type

APEG only or APEG & 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:

- *and the reported diabetes type is Type 2 or 'Other', then the derived diabetes type equals the reported diabetes type.*
- *and the reported diabetes type is Type 1 and the age at diagnosis is missing, then the derived diabetes type is unable to be derived.*
- *and the reported diabetes type is Type 1 and the age at diagnosis is less than 15 years:*
  - *and the time between diagnosis and first insulin use is missing, then the derived diabetes type is unable to be derived*
  - *and the time between diagnosis and first insulin use is more than 1 year, then the derived diabetes type is unable to be derived*
  - *and 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.*
- *and the reported diabetes type is Type 1 and the age at diagnosis is greater than or equal to 15 years:*
  - *and the time between diagnosis and first insulin use is missing, then the derived diabetes type is unable to be derived*
  - *and the time between diagnosis and first insulin use is more than 1 year, then the derived diabetes type equals Type 2*
  - *and 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.*
- *and the reported diabetes type is GDM:*
  - *and the age at diagnosis is less than 50 years, then the derived diabetes type equals the reported diabetes type, that is, GDM*
  - *and the age at diagnosis is greater than or equal to 50 years, then the derived diabetes type equals Type 2*
  - *and the age at diagnosis is missing, then the derived diabetes type is unable to be derived.*

6.4 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 of time, 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 Chapter 3 and the indirect method was used as the basis for calculating the standardised mortality ratios in Chapter 5.

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.

6.5 Standardised mortality ratios

Comparisons between mortality rates for the NDR population compared with 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 128 deaths (80 in males and 48 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 (1999 to 2005) was estimated for each sex and 5-year age group.
4. The death rates for the comparison group (here the whole Australian population) for each sex, year and 5-year age group were calculated.
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 section 6.6.

6.6 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 SMRs 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 which 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.

6.7 Remoteness areas and statistical divisions

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 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).

Remoteness areas

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 Accessibility/Remoteness Index of Australia (ARIA) (DoHA 2001). This index is based on how distant a place is by road from urban centres of different sizes, and therefore provides a relative indication of how difficult it might be for residents to gain access to certain services such as health care and education.

Statistical divisions

The statistical division is a general-purpose spatial unit and is the largest and most stable spatial unit within each state and territory. The boundaries for statistical divisions are stable in that they do not change frequently. Statistical divisions consist of one or more statistical subdivisons. In aggregate, they cover Australia without gaps or overlaps and they aggregate to form state and territories (ABS 2001).

Postcodes of usual residence and of diagnosis for NDR registrants were mapped to statistical divisions by firstly mapping postcodes to statistical local areas (SLAs) and then mapping SLAs to statistical divisions. SLAs are based on the administrative areas of local government where these exist. The SLA is the base spatial unit used by the ABS to collect and disseminate statistics other than those collected in population censuses (ABS 2001).

7 Diabetes research using the NDR

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, alternatively, by contacting:

The Project Officer, National Diabetes Register
Cardiovascular Disease and Diabetes 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.

8 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 from you 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 a Commonwealth Government program 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, 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 at the following address, or email us at diabetes@aihw.gov.au

  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.