

National Diabetes Register

Statistical profile, December 2001

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National Diabetes Register

Statistical Profile, December 2001

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Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
APEG	Australasian Paediatric Endocrine Group
DA	Diabetes Australia
DoHA	Department of Health and Ageing
GDM	Gestational diabetes mellitus
ICD-10	International Classification of Diseases, 10th revision
ITDM	Insulin-treated diabetes mellitus
MACOD	Ministerial Advisory Committee on Diabetes
Menzies Centre	Menzies Centre for Population Health in Tasmania
NDI	National Death Index
NDR	National Diabetes Register
NDSS	National Diabetes Services Scheme
Register	National Diabetes Register
TITDR	Tasmanian Insulin Treated Diabetes Register
WHO	World Health Organization

Symbols

..	Not available
n.a.	Not applicable
—	Rounded to zero

Executive summary

The *National Diabetes Register: Statistical Profile, December 2001* is the second annual statistical report on the National Diabetes Register (NDR).

The Register holds information on people with insulin-treated diabetes who started using insulin since January 1999. People who started using insulin before January 1999 and people with non-insulin-treated diabetes are not included in this Register.

The Register provides information that will assist planners of diabetes services as well as providing a reference point for diabetes researchers wishing to access the Register for epidemiological studies.

Between 1 January 1999 and 31 December 2001, the main features of the NDR were:

Insulin-treated diabetes in males and females

- 22,575 people began to use insulin, and consented to be on the register (Table 2.4).
- There were slightly more males than females on the Register (11,462 males and 11,113 females).
- The sex ratio varied with age. For ages less than 25 years the numbers for males and females were similar. For ages 25–44 there were more females than males, largely due to the number of women with gestational diabetes in that age group.

Diabetes type of persons with insulin-treated diabetes

- 60.3% of registrants were found to have Type 2 diabetes; 29.3% Type 1 diabetes and 7.3% gestational diabetes (Table 2.4).
- A fifth of all registrants (4,548) had Type 1 diabetes and were aged less than 40 years (Table 3.1).

Age distributions of registrants

- 61.8% of registrants were aged over 45 years; 4.9% were aged less than 10 years, 4.8% aged 10–14 and 28.5% 15–44 years (Table 2.1).

Commencement of insulin use

- 50.5% of those aged 0–39 years at diagnosis and reporting Type 1 diabetes began to use insulin before the age of 15 years (Table 3.1).
- The majority of those reporting Type 2 diabetes commenced insulin use after 50 years of age (78.4%) (Table 4.1).

Incidence of Type 1 diabetes among children 0–14 years

- In 2000 and 2001, 1,565 new cases of Type 1 diabetes among children 0–14 years were recorded on the register, an average annual rate of 20 new cases per 100,000 population for boys and 19 per 100,000 for girls (Table 3.4). Rates were similar across states and territories.
- In 2000, Australia was among the countries with moderate to high incidence of Type 1 diabetes for children aged 0–14 years (Table 3.6). The rate was similar to those experienced in Canada and the United Kingdom, well below Finland (45 cases per 100,000), but much higher than in Middle Eastern and Asian countries.

Deaths

- Of the 22,575 NDR registrants between 1999 and 2001, 1,229 (5.4%) were identified as having died during the period (Table 2.5).
- Deaths largely occurred among older persons—80.0% of male deaths and 83.2% of female deaths occurred in persons aged 60 years or more (Table 5.1).
- For registrants who died in their first year of insulin use, death rates were three and a half times that of the general community (Table 5.2). For registrants who died in their second or third year of insulin use, death rates decreased to just over two times higher than in the Australian community.
- Malignant neoplasms (cancers) were the most commonly reported underlying cause of death (44.5%) among persons with insulin-treated diabetes (Table 5.3).
- The next most common underlying cause of death was diseases of the circulatory system, responsible for 24.9% of male deaths and 26.3% of female deaths.
- Given the elderly age profile of the persons who died and the relatively short period of time between insulin commencement and deaths, the high rate of cancer and circulatory disease deaths suggests that these are persons with chronic illnesses which include diabetes, and insulin use is likely to be one of a number of treatments they are undergoing during the last 12 to 36 months before death.
- Diabetes mellitus was the underlying cause for 9.9% of male deaths and 12.0% of female deaths (Table 5.3). In 38.2% of male deaths and 46.9% of female deaths, diabetes was mentioned as either an underlying or secondary cause of death on the death certificate.

Geographical coverage

- There were 45.5 age-standardised NDR registrations per 100,000 population in remote areas during 1999–2001, compared with 37.4 per 100,000 population nationally, despite lower National Diabetes Services Scheme coverage in remote areas (Table 2.2).
- The age-standardised rate of registrations per 100,000 population in capital cities and small rural centres was 36.9 and 40.0 respectively.
- Among the states and territories, age-standardised registrations per 100,000 population were relatively low in South Australia in 2001 (24.3) because of low ascertainment and relatively high in Western Australia (43.9) because of high ascertainment.

Indigenous status

- Just over 2% of registrants reported being of Aboriginal or Torres Strait Islander origin (Table 2.6). This proportion is much higher in the Northern Territory at 39%. These proportions are likely to be under-estimated as Indigenous identification is incomplete in the Register.

1. Introduction

The National Diabetes Register (NDR) has been collecting information about people who have begun to use insulin to manage their diabetes since 1 January 1999. This is the second statistical profile on the Register. The NDR was established following the launch of the National Diabetes Strategy and Implementation Plan in June 1998 (Colagiuri et al. 1998). As part of this strategy, the Ministerial Advisory Committee on Diabetes (MACOD) recommended the establishment of a National Diabetes Register for people with insulin-treated diabetes.

In August 1998, the AIHW was contracted to operate the Register by the then Commonwealth Department of Health and Aged Care. The Register has two main data sources—the National Diabetes Services Scheme (NDSS) database, administered by Diabetes Australia, and the Australasian Paediatric Endocrine Group (APEG) state-based databases.

Registration on the National Diabetes Register is not determined by a person's type of diabetes, but by whether or not insulin is used to treat the diabetes. A person is eligible for the Register if insulin use commenced on or after 1 January 1999. Currently it includes new cases of insulin-treated diabetes mellitus from 1 January 1999 where consent has been provided for inclusion on the Register.

A person is not eligible for the Register if:

- insulin use commenced before 1 January 1999;
- insulin is not used to treat the person's diabetes; or
- consent is not provided.

Thus the Register includes people with all types of diabetes (Type 1, Type 2, gestational diabetes and other forms of diabetes) who are insulin-using and who have consented to be on the Register.

Structure and content of this report

This report has been divided into seven parts. Following this Introduction, Chapter 2 summarises the Register's holdings. Chapter 3 focuses on persons with Type 1 diabetes while Chapter 4 examines persons with other types of insulin-treated diabetes excluding Type 1. Chapter 5 looks at the mortality of the NDR registrants and Chapter 6 contains statistical notes relevant to the analyses performed on the NDR data to produce this report. Chapter 7 provides details for researchers wanting to access the NDR data for diabetes research.

2. Summary of Register data

The primary source of records of insulin-treated diabetes mellitus (ITDM) in Australia is the National Diabetes Services Scheme (NDSS). Secondary sources are the research databases of the Australasian Paediatric Endocrine Group (APEG) for 0–14 year olds and the Tasmanian Insulin Treated Diabetes Register which is held at the Menzies Centre for Population Health in Hobart.

2.1 Age and sex

The age distribution of the Register shows a pattern of increasing numbers with age, particularly after 45 years when numbers increase sharply. More than 60% of registrants are aged 45 years and over, compared with less than 10% aged under 15 years (Table 2.1).

There is a slightly higher proportion of male records on the Register (50.3%) compared to female records (49.7%). However, these proportions vary considerably with age. For the younger age groups, the ratio of male to female records is similar. In the 25–34 and 35–44 age groups, females strongly outnumber males, reflecting the effect of gestational diabetes in women from these age groups.

For older age groups (45–74 years), males strongly outnumber females, with 32% more male registrants than females. This may be attributed to lifestyle differences between males and females. The 1995 National Nutrition Survey showed that at every adult age, men were more likely than women to be overweight or obese, a major risk factor for diabetes (ABS 1998a). This survey also showed that mean waist-to-hip ratios were higher in men than women and increased with age. High waist-to-hip ratios indicate excessive abdominal fat which is associated with increased risk of diabetes.

For the ages 75 and over, there are 8% more females on the Register than males. This reflects the substantially lower proportion of males in the population in this age group due to the higher female life expectancy.

New cases of persons requiring insulin to treat their diabetes predominantly occur among middle-aged and older men with Type 2 diabetes, women in their twenties and thirties with gestational diabetes, and in older women with Type 2 diabetes.

Table 2.1: NDR registrants: current age and sex, 1999–2001

Age at 31 December 2001	Males	Females	Total	% Male
	Number			
0–4	184	138	322	57.1
5–9	379	357	736	51.5
10–14	518	514	1,032	50.2
15–24	655	597	1,252	52.3
25–34	751	1,635	2,386	31.5
35–44	966	1,466	2,432	39.7
45–54	1,708	1,243	2,951	57.9
55–64	2,246	1,620	3,866	58.1
65–74	2,078	1,695	3,773	55.1
75 and over	1,247	1,349	2,596	48.0
Total	10,732	10,614	21,346	50.3
	Per cent			
0–4	0.9	0.6	1.5	n.a.
5–9	1.8	1.7	3.4	n.a.
10–14	2.4	2.4	4.8	n.a.
15–24	3.1	2.8	5.9	n.a.
25–34	3.5	7.7	11.2	n.a.
35–44	4.5	6.9	11.4	n.a.
45–54	8.0	5.8	13.8	n.a.
55–64	10.5	7.6	18.1	n.a.
65–74	9.7	7.9	17.7	n.a.
75 and over	5.8	6.3	12.2	n.a.
Total	50.3	49.7	100.0	n.a.

Note: Deceased registrants have been excluded from this table.

2.2 Geographical location

The age-standardised registration rates (expressed as per 100,000 population) for 1999–2001 across metropolitan, rural and remote areas of Australia are similar for most states and territories (Table 2.2). The exceptions are South Australia and the Northern Territory, due to lower ascertainment—in remote areas of South Australia and the Northern Territory, diabetes products may be obtained from remote area pharmacy services which are not part of the NDSS. As a result the NDR does not receive data from these people.

Table 2.2: NDR registrants: geographical locations,^(a) states and territories, 1999–2001

state/ territory	Metropolitan		Rural			Remote	Total
	Capital city	Other metropolitan	Large rural centres	Small rural centres	Other rural areas		
Number							
NSW	4,563	1,036	340	590	881	79	7,488
Vic	4,196	218	378	378	744	21	5,935
Qld	1,954	597	592	264	684	270	4,362
WA	1,704	—	—	248	301	259	2,512
SA	817	—	26	94	216	18	1,170
Tas	245	—	124	83	171	4	627
ACT	376	—	—	—	—	—	376
NT	51	—	—	—	9	46	105
Total	13,904	1,852	1,460	1,657	3,006	696	22,575
Average annual age-standardised rate (per 100,000 population) ^{(b)(c)}							
NSW	36.2	38.6	34.5	36.8	36.9	44.6	36.1
Vic	38.7	42.2	52.9	42.6	35.9	47.4	39.1
Qld	40.2	38.5	39.7	35.5	38.8	48.6	39.7
WA	40.7	—	—	55.6	51.1	54.6	43.9
SA	23.8	—	35.3	35.4	23.8	22.0	24.3
Tas	39.9	—	46.3	43.2	40.0	51.1	41.4
ACT	42.6	—	—	—	—	—	42.6
NT	21.2	—	—	—	26.6	22.9	21.6
Total	36.9	39.0	41.1	40.0	36.6	45.5	37.4

(a) Registrants are classified into metropolitan, rural and remote zones according to the Rural, Remote and Metropolitan Areas Classification (DPIE & DSHS 1994).

(b) The population at 30 June 2000 by geographic location is used to derive the standardised rate (see Chapter 6).

(c) Age-standardised to the Australian population at 30 June 1991. The direct method of standardisation is used (see Chapter 6).

2.3 Type of diabetes

Type of diabetes is reported on the NDSS registration form by either a medical practitioner or an accredited diabetes educator. In the APEG collection, diabetes type is nearly always certified by a medical specialist. In making the NDR, the NDSS and APEG records are merged and deduplicated. When a difference in diabetes type is found, the certification by the health professional with the highest qualification is included in the Register. In age groups older than 14 years of age, where there is no source of secondary ascertainment, the diabetes type reported by the NDSS is accepted. However, it has been found that a concerning proportion of registrants on the NDR have been recorded as having Type 1 diabetes when they actually have Type 2 diabetes (AIHW 2001:13).

In order to obtain a more accurate measure of type of diabetes, an algorithm has been developed which re-classifies registrants with reported Type 1 diabetes over the age of 35

years. The algorithm is based on age at diagnosis and the period of time between diagnosis and date of first insulin use (for more information on the algorithm, see Section 6.2).

Table 2.3 shows data for the NDR registrants before (reported) and after (derived) the algorithm was applied. It can be seen that under the ages of 35 years the number of registrants with Type 1 diabetes remains the same regardless of whether the type of diabetes is reported or derived. This is because the algorithm does not apply to registrants under the age of 35. However, in each of the age groups 35 years and above, the number of registrants with Type 1 diabetes falls dramatically after the algorithm is applied. For example, in the age groups of 35–44 years the number of registrants with reported Type 1 diabetes is 906 but the derived type of diabetes shows only 633 with Type 1 diabetes in this age group.

In total the algorithm re-classified 1,824 people who were originally reported as having Type 1 diabetes. Of these people, 1,434 were re-classified as Type 2. For the remaining 390 people, a type of diabetes could not be derived due to missing information, such as date of first insulin use. Clearly, the algorithm helps to reduce the misrepresentation of the level of Type 1 diabetes on the register. 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, it should be noted that the algorithm cannot re-classify all records that have been misreported and thus the breakdown of diabetes type in this report may not reflect the true distribution of diabetes type among people with insulin-treated diabetes.

Table 2.3: NDR registrants: reported and derived^(a) diabetes type, by age, 1999–2001

Age at diagnosis	Reported diabetes type				Derived diabetes type			
	Type 1	Type 2	Gestational	Other	Type 1	Type 2	Gestational	Other
0–4	490	5	—	9	490	5	—	9
5–9	819	8	—	8	819	8	—	8
10–14	1,004	27	1	21	1,004	27	1	21
15–24	1,010	234	131	27	1,010	234	131	27
25–34	995	933	1,017	38	995	933	1,017	38
35–44	906	2,131	448	40	633	2,404	448	40
45–54	923	3,082	7	61	466	3,540	6	61
55–64	903	2,643	1	55	480	3,067	—	55
65–74	590	1,584	2	28	371	1,805	—	28
75 and over	356	690	1	13	294	753	—	13
Not stated	436	830	55	13	46	831	54	13
Total	8,432	12,167	1,663	313	6,608	13,607	1,657	313

(a) Type of diabetes could not be derived for 390 registrants due to missing information.

The Register contains 22,575 records for people who commenced using insulin between 1 January 1999 and 31 December 2001 (Table 2.4). There were 11,462 males and 11,113 females. Using derived type of diabetes, 33% of males had Type 1 diabetes compared with 25% of females; and 15.0% of females were reported to have gestational diabetes.

Table 2.4: NDR registrants: derived diabetes type, by sex, 1999–2001

	Males		Females		Persons	
	Number	Per cent	Number	Per cent	Number	Per cent
Type 1	3,780	33.0	2,828	25.4	6,608	29.3
Type 2	7,322	63.9	6,285	56.6	13,607	60.3
Gestational	1,657	14.9	1,657	7.3
Other types ^(a)	170	1.5	143	1.3	313	1.4
Not derived ^(b)	190	1.7	200	1.8	390	1.7
Total	11,462	100.0	11,113	100.0	22,575	100.0

(a) See Glossary for other types of diabetes.

(b) A derived diabetes type could not be calculated due to missing date of first injection or missing date of diagnosis.

2.4 Mortality

Register records were matched with the National Death Index (NDI). For the years 1999–2001, there were 1,229 registrants identified as having died, representing 5.4% of Register holdings (Table 2.5). Nineteen per cent of deaths were for registrants with Type 1 diabetes. The largest proportion of registrants recorded as deceased was in Tasmania (6.9%).

Table 2.5: NDR registrants: vital status and derived^(a) type of diabetes, by states and territories, 1999–2001

Vital status	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
Alive	7,087	5,584	4,129	2,399	1,101	584	358	104	21,346
Type 1	2,175	1,521	1,098	736	495	201	110	37	6,373
Other types	4,734	3,998	2,984	1,645	586	376	246	66	14,635
Deceased	401	351	233	113	69	43	18	1	1,229
Type 1	93	55	31	21	21	9	5	0	235
Other types	279	281	197	91	46	34	13	1	942
Total	7,488	5,935	4,362	2,512	1,170	627	376	105	22,575

(a) Type of diabetes could not be derived for 390 registrants due to missing information; however, they are included in the totals.

2.5 Indigenous status

Just over 2% of records on the Register are for persons who report being of Aboriginal or Torres Strait Islander origin (Table 2.6). This percentage is consistent with the proportion of Indigenous people in the Australian population (2.2% in 2001). Although consistent with the population, the Register is likely to significantly under-report the true level of Indigenous people with insulin-treated diabetes because:

- the NDSS does not receive data from people who purchase diabetes products through remote area pharmacy services—many of these people are Indigenous people who inhabit remote areas; and

- the NDSS form is believed to obtain inadequate identification of Indigenous status. Incorrectly reporting Indigenous status particularly occurs if the personal details have been completed on the form by someone other than the registrant, e.g. a doctor or diabetes educator.

Proportions of Indigenous registrants differed among states and territories, the highest being in the Northern Territory (39.0%), the lowest in Victoria and the Australian Capital Territory (both 0.3%).

It is important to note that Register numbers do not reflect the higher prevalence or incidence of diabetes in Indigenous Australians. Prevalence of diabetes (mainly Type 2) is considerably higher among Aboriginal and Torres Strait Islander people than for the whole Australian community (AIHW 2002a). Available data suggest that overall prevalence lies between 10% and 30% of the Aboriginal and Torres Strait Islander peoples population and is therefore likely to be 2–4 times that of the non-Aboriginal community (De Courten et al. 1998).

Table 2.6: NDR registrants: Indigenous status, by age at first insulin use, states and territories, 1999–2001

	NSW	Vic	Qld	WA	SA	Tas	ACT	NT	Australia
Age at first insulin use									
<i>0–14</i>									
Indigenous	18	3	6	8	—	3	—	2	40
Non-Indigenous	722	228	367	241	182	57	40	11	1,848
Not stated	43	339	79	1	7	2	—	2	473
<i>15–34</i>									
Indigenous	22	3	38	27	2	4	—	13	109
Non-Indigenous	1,145	840	733	374	208	103	95	14	3,512
Not stated	63	18	6	10	4	9	1	—	111
<i>35–54</i>									
Indigenous	33	4	72	78	2	10	1	17	217
Non-Indigenous	1,750	1,350	1,045	623	260	123	111	15	5,277
Not stated	109	27	13	16	10	8	3	3	189
<i>55 and over</i>									
Indigenous	29	8	29	36	5	3	—	9	119
Non-Indigenous	3,366	3,054	1,962	1,066	461	279	123	17	10,328
Not stated	188	61	12	32	29	26	2	2	352
Total persons	7,488	5,935	4,362	2,512	1,170	627	376	105	22,575

2.6 Country of birth

There is substantial variation in the registration rate by birthplace (Table 2.7). The number of registrants per 100,000 population is highest among those born in North Africa and the Middle East and Southern and Central Asia. Both these groups have registration rates substantially higher than those of the Australian-born registrants, being more than 50%

higher for males and more than double for females. All other birthplace groups show similar registration rates to those for the Australian-born population.

The median age at diagnosis ranged between 41 and 47 for most countries of birth, with the exceptions of North-West Europe and Southern and Eastern Europe groups, which have a median age at diagnosis in the mid-50s.

Table 2.7: NDR registrants aged 15 years and over at diagnosis: country of birth, sex and median age at diagnosis, 1999–2001

Country of birth ^(a)	Males		Females		Median age at diagnosis (years)
	Number	Average annual rate ^(b) per 100,000 population	Number	Average annual rate ^(b)	
Australia	6,713	43.5	6,629	39.5	47.2
Oceania and Antarctica (excluding Australia)	244	41.9	326	53.4	40.6
North-West Europe	909	31.7	757	29.3	55.1
Southern and Eastern Europe	1,344	56.3	1,050	50.3	56.4
North Africa and the Middle East	267	73.4	276	88.0	47.2
South-East Asia	223	49.8	337	52.4	45.4
North-East Asia	134	39.6	213	50.9	45.5
Southern and Central Asia	200	72.7	242	92.5	41.3
Americas	98	42.7	82	38.6	44.3
Sub-Saharan Africa	86	49.8	75	39.2	43.5

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

(b) Age-standardised to the Australian population at 30 June 1991.

3. Persons with Type 1 diabetes

This chapter focuses on data for registrants with Type 1 diabetes aged under 40 years. In the previous statistical profile, AIHW reported on difficulties in the accurate classification of diabetes types (AIHW 2001). Correct classification of diabetes type for those aged 40 years and over is clinically difficult and inaccuracies may be reflected in the NDR data.

For those aged 0–14 years, dual ascertainment and certification from a specialist is considered sufficient to provide accurate classification of diabetes type. Because of this, and because coverage is believed to be close to 100%, the younger age groups have reliable estimates of Type 1 diabetes incidence.

Dual ascertainment is not available for those aged 15–39, and misclassification of diabetes type can occur, particularly by non-specialist practitioners who may wrongly assume that requirement for insulin in this age group means that the person has Type 1 diabetes. However, advice from the NDR Management Committee suggests that almost all Type 1 registrants in this age group are correctly classified and the high costs that would be incurred in investigating this matter further by checking against medical records are not justified.

3.1 New cases of Type 1 diabetes under 40 years of age

Features of NDR registrants aged 0–39 years with Type 1 diabetes were as follows:

- There were 4,548 new cases for the three years 1999–2001—2,587 (56.9%) were males and 1,961 (43.1%) were females (Table 3.1). This represents 69% of NDR registrants with Type 1 diabetes; the remaining 31% (2,060) were aged 40 and over (derived from Table 2.3).
- Tasmanians reported the highest average rate of new cases per year (18.1 per 100,000 population) (Table 3.2).
- The geographic distribution of new cases with Type 1 diabetes aged 0–39 years was 61.3% in capital cities, 8.2% in other metropolitan areas, 6.6% in large rural centres, 7.1% in small rural centres, and 16.7% in other rural areas and remote areas (Table 3.3). However, remote areas are known to be relatively under-represented because of distribution of diabetes services products through remote area pharmacy services rather than through the NDSS.

Table 3.1: NDR registrants aged 0–39 years with derived^(a) Type 1 diabetes, by age and sex, 1999–2001

Age at first insulin use	Males		Females		Persons	
	Number	Per cent	Number	Per cent	Number	Per cent
0–14	1,207	46.7	1,092	55.7	2,299	50.5
15–24	570	22.0	389	19.8	959	21.1
25–39	810	31.3	480	24.5	1,290	28.4
Total	2,587	100.0	1,961	100.0	4,548	100.0

(a) There is no difference between reported and derived type of diabetes for registrants aged 0–35 years (see Table 2.3).

Table 3.2: NDR registrants aged 0–39 years with derived^(a) Type 1 diabetes: states and territories, 1999–2001

Year of first insulin use	NSW	Vic	Qld	SA	WA	Tas	NT	ACT	Australia
	Number								
1999	454	376	293	91	183	45	10	35	1,487
2000	504	323	290	123	160	46	7	25	1,478
2001	492	375	321	116	181	50	10	38	1,583
Total	1,450	1,074	904	330	524	141	27	98	4,548
	Number per 100,000 population aged 0–39 years^(b)								
1999	12.3	13.9	14.1	11.1	16.6	17.3	7.3	18.1	13.5
2000	13.6	11.9	14.0	15.0	14.5	17.7	5.1	12.9	13.4
2001	13.3	13.8	15.4	14.1	16.4	19.2	7.3	19.6	14.4
	Average annual number per 100,000 population aged 0–39 years^(b)								
1999–2001	13.1	13.2	14.5	13.4	15.8	18.1	6.5	16.9	13.8

(a) There is no difference between reported and derived type of diabetes for registrants aged 0–35 years (see Table 2.3).

(b) Population is at 30 June 2000.

Table 3.3: NDR registrants aged 0–39 years with derived^(a) Type 1 diabetes: geographical locations,^(b) 1999–2001

Geographical location	Age at first insulin use (years)			Total
	0–14	15–24	25–39	
	Number			
Capital city	1,361	617	810	2,788
Other metropolitan	203	68	102	372
Large rural centre	144	66	91	302
Small rural centre	175	57	93	325
Other rural and remote	416	150	195	762
Total Australia	2,299	959	1,290	4,548
	Per cent			
Capital city	59.2	64.3	62.8	61.3
Other metropolitan	8.8	7.1	7.9	8.2
Large rural centre	6.3	6.9	7.0	6.6
Small rural centre	7.6	6.0	7.2	7.1
Other rural and remote	18.1	15.7	15.1	16.7
Total Australia	100.0	100.0	100.0	100.0

(a) There is no difference between reported and derived type of diabetes for registrants aged 0–35 years (see Table 2.3).

(b) Registrants are classified according to the Rural, Remote and Metropolitan Areas Classification (DPIE & DSHS 1994).

3.2 Incidence estimates for 0–14 year olds

NDR records for 0–14 year olds were received from three data sources:

- Diabetes Australia;
- APEG; and
- Menzies Centre in Tasmania.

As a result, coverage of new cases of insulin-treated diabetes under 15 years of age is considered to be close to 100% for 2000 and 2001.

Features of the Type 1 diabetes incidence for 0–14 year olds were as follows:

- New cases of Type 1 diabetes for male children were on average 20.3 new registrations per 100,000 population per year; the corresponding number for female children was 18.9 (Table 3.4).
- For most states and territories, rates were lower in the younger age groups (0–4 years) than in the 5–9 or 10–14 year groups. Care should be taken when interpreting these rates for the smaller states and territories due to the small numbers involved.
- The numbers of new cases remained similar across 1999, 2000 and 2001 for most states and territories, with cases in 2001 showing a general increase (Table 3.5).
- Australia is among the moderate to high incidence countries, see next section.

Table 3.4: New cases of Type 1 diabetes among 0–14 year olds: sex and age, states and territories, 2000 and 2001

Sex and age at first insulin use	NSW	Vic	Qld	SA	WA	Tas	NT	ACT	Australia
Number									
Males									
0–4	55	45	39	13	22	7	—	6	187
5–9	89	69	58	23	25	10	1	4	279
10–14	137	73	73	34	29	9	4	6	365
<i>Total males 0–14</i>	<i>281</i>	<i>187</i>	<i>170</i>	<i>70</i>	<i>76</i>	<i>26</i>	<i>5</i>	<i>16</i>	<i>831</i>
Females									
0–4	50	34	32	8	13	2	1	3	143
5–9	87	75	49	26	31	8	—	4	280
10–14	100	80	59	28	33	7	—	4	311
<i>Total females 0–14</i>	<i>237</i>	<i>189</i>	<i>140</i>	<i>62</i>	<i>77</i>	<i>17</i>	<i>1</i>	<i>11</i>	<i>734</i>
Average annual rate per 100,000 population									
Males									
0–4	12.2	14.1	15.3	13.7	16.8	21.8	—	28.1	14.2
5–9	19.0	20.6	21.5	22.5	18.0	28.8	—	17.7	20.1
10–14	29.6	22.0	27.3	32.7	20.2	25.4	—	26.0	26.4
<i>Total males 0–14</i>	<i>20.4</i>	<i>19.0</i>	<i>21.5</i>	<i>23.2</i>	<i>18.4</i>	<i>25.5</i>	<i>—</i>	<i>23.9</i>	<i>20.3</i>
Females									
0–4	11.7	11.2	13.3	8.8	10.4	6.6	—	14.5	11.4
5–9	19.6	23.5	19.2	26.8	23.6	24.3	—	18.3	21.2
10–14	22.7	25.1	23.4	28.6	24.3	20.9	—	18.1	23.6
<i>Total females 0–14</i>	<i>18.1</i>	<i>20.1</i>	<i>18.7</i>	<i>21.7</i>	<i>19.7</i>	<i>17.5</i>	<i>—</i>	<i>17.0</i>	<i>18.9</i>

Table 3.5: New cases of Type 1 diabetes among 0–14 year olds: states and territories, 1999, 2000, 2001

Year	NSW	Vic	Qld	SA	WA	Tas	NT	ACT	Australia
1999	237	172	135	57	84	18	4	13	720
2000	247	174	150	73	69	16	1	13	743
2001	271	202	160	59	84	27	5	14	822

International comparison

Australia is among the countries with a moderate to high incidence for children diagnosed with Type 1 diabetes. However, it is important to note that international data on diabetes are of varying quality and variations within regions and countries can exist. In 1993, Karvonen et al. reported that incidence rates in Europe varied from 4.6 per 100,000 in the northern regions of Greece to 30.2 per 100,000 in Sardinia. Authors of the Diabetes Atlas from which data for Table 3.6 were extracted note that data are compiled from multiple studies about childhood

onset diabetes (IDF 2000). Therefore data should be interpreted cautiously and considered general indicators only.

Table 3.6: Incidence of Type 1 diabetes in 0–14 year olds: selected countries, 2000

Region ^(a) and country	New cases per 100,000	Population 0–14 years ('000s)
Australia	18.7	3,979
New Zealand	15.0	862
Europe	10.3	140,720
Albania (lowest rate in Europe)	3.0	1,152
Germany	13.0	13,889
United Kingdom	18.0	11,513
Finland (highest rate in Europe)	45.0	993
North America	12.2	109,010
Mexico (lowest rate in North America)	0.6	37,646
United States of America	16.0	59,909
Canada (highest rate in North America)	20.0	6,454
Eastern Mediterranean and Middle East	5.6	197,311
Pakistan	5.0	70,880
Egypt	7.0	26,732
Africa	1.5	242,277
Tanzania (lowest rate in Africa)	0.8	16,240
Zimbabwe (highest rate in Africa)	2.0	5,581
South and Central America	5.7	136,142
Peru (lowest rate in South and Central America)	1.0	9,468
Puerto Rico (highest rate in South and Central America)	18.0	1,339
Asia	5.0	422,324
Republic of Korea (lowest rate in Asia)	0.7	11,363
Bangladesh (highest rate in Asia)	5.0	54,708

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

Sources: Diabetes Atlas 2000 (IDF 2000) and National Diabetes Register for Australia.

Geographical location

A major area of research interest in diabetes is whether geographic influences manifest themselves in a change in incidence patterns of diabetes. Although three years of data are not sufficient to produce statistically significant findings for most areas, some Statistical Divisions did show differences in yearly cases when compared to other rates within the same state, the overall state rate or the national rate (Table 3.7):

- Hunter Statistical Division had a significantly higher rate (27.2 cases per 100,000 population) than the overall New South Wales rate of 19.1 cases per 100,000 population and the national rate of 19.4.
- The Sydney incidence (16.7 per 100,000 population) was significantly below the national incidence rate (19.4 per 100,000 population).

Incidence estimates for the Northern Territory and outback Queensland and Western Australia are low but should be treated cautiously as levels of ascertainment are considered low and may affect results.

Table 3.7: New cases of Type 1 diabetes among 0–14 year olds: Statistical Divisions, 1999–2001

Statistical Division ^(a)	NDR cases	Population ^(b)	Yearly cases (per 100,000 population)	95% CI
New South Wales				
Sydney	402	802,675	16.7	15.1–18.3
Hunter	97	119,442	27.2	21.8–32.5
Illawarra, Central West, South Eastern, Murrumbidgee	127	194,787	21.8	18.0–25.5
Richmond-Tweed, Mid-north Coast, Northern	86	142,186	20.2	16.0–24.5
Murray, Far West, North Western	42	57,621	24.2	16.9–31.5
<i>New South Wales</i>	<i>755</i>	<i>1,316,711</i>	<i>19.1</i>	<i>17.7–20.5</i>
Victoria				
Melbourne	366	663,699	18.4	16.5–20.3
Barwon, Central Highlands	49	80,712	20.3	14.6–26.0
Western District, Wimmera, Mallee	30	52,890	18.8	12.0–25.5
Loddon, Goulburn	54	77,972	22.9	16.8–29.1
Ovens-Murray, East Gippsland, Gippsland	50	71,951	23.1	16.7–29.5
<i>Victoria</i>	<i>548</i>	<i>947,224</i>	<i>19.3</i>	<i>17.7–20.9</i>
Queensland				
Brisbane	202	331,855	20.3	17.5–23.1
Moreton	81	137,211	19.7	15.4–24.0
Wide Bay-Burnett, Darling Downs, Fitzroy	102	140,110	24.3	19.6–29.0
Mackay, Northern	36	74,856	15.9	10.7–21.2
South West, Central West, Far North, North West	24	69,402	11.6	7.0–16.2
<i>Queensland</i>	<i>445</i>	<i>753,434</i>	<i>19.7</i>	<i>17.9–21.5</i>

(continued)

Table 3.7 (continued): New cases of Type 1 diabetes among 0–14 year olds: Statistical Divisions, 1999–2001

Statistical Division ^(a)	NDR cases	Population ^(b)	Yearly cases (per 100,000 population)	95% CI
South Australia				
Adelaide	135	203,238	22.1	18.4–25.9
Outer Adelaide, Yorke & Lower North, Murray Lands, South East, Eyre, Northern	54	88,226	20.2	14.8–25.7
<i>South Australia</i>	189	291,464	21.6	18.5–24.7
Western Australia				
Perth	174	276,095	21.0	17.9–24.1
South West, Lower Great Southern, Upper Great Southern, Midlands	46	73,076	21.0	14.9–27.0
South Eastern, Central, Pilbara, Kimberley	17	48,660	11.6	6.1–17.2
<i>Western Australia</i>	237	397,831	19.9	17.3–22.4
Tasmania				
Greater Hobart	31	39,311	26.0	16.8–35.2
Southern, Northern, Mersey-Lyell	30	59,469	17.0	11.0–23.1
<i>Tasmania</i>	61	98,780	20.6	15.4–25.8
Northern Territory				
<i>Northern Territory</i>	10	50,857	6.6	2.5–10.6
Australian Capital Territory				
<i>Australian Capital Territory</i>	40	64,067	20.8	14.4–27.3
Australia	2,285	3,922,183	19.4	18.6–20.2

(a) Statistical Divisions are as at 30 June 2000 (ABS 2001a–h).

(b) Australian population at 30 June 2000.

4. Persons with insulin-treated diabetes excluding Type 1

This chapter describes the characteristics of NDR registrants who have insulin-treated diabetes, excluding those with Type 1 diabetes. These include persons with insulin-treated diabetes in the following categories:

- Type 2
- Gestational
- Other types of diabetes excluding Type 1 (see Glossary).

It is important to note that these statistics may be somewhat unreliable due to consent rates of less than 80%.

4.1 Age and sex

Features of persons with insulin-treated diabetes, excluding Type 1, were as follows:

- There were 7,682 males and 8,285 females with insulin-treated diabetes other than Type 1, which represents just over 70% of all NDR registrants (Table 4.1).
- Males and females had a reported type of 'other' (see Glossary), in 2.2% and 1.7% of registrants, respectively.
- Almost 80% of registrants with Type 2 diabetes began to use insulin at or after 50 years of age.
- Gestational diabetes occurs during pregnancy, hence 86.6% of females with gestational diabetes first used insulin between the ages of 25 and 39 years.

Table 4.1: NDR registrants with insulin-treated diabetes, excluding Type 1: derived^(a) type, by age at first insulin use and sex, 1999–2001

Age at first insulin use	Type 2		Gestational		Other ^(b)		Total	
	No.	%	No.	%	No.	%	No.	%
Males								
0–14	13	0.2	n.a.	n.a.	14	8.2	27	0.4
15–24	38	0.5	n.a.	n.a.	10	5.9	48	0.6
25–39	398	5.4	n.a.	n.a.	32	18.8	435	5.7
40–49	974	13.3	n.a.	n.a.	31	18.2	1,026	13.4
50–59	1,849	25.3	n.a.	n.a.	35	20.6	1,922	25.0
60–69	2,057	28.1	n.a.	n.a.	30	17.6	2,135	27.8
70–79	1,526	20.8	n.a.	n.a.	13	7.6	1,596	20.8
80 and over	467	6.4	n.a.	n.a.	5	2.9	493	6.4
<i>Total males</i>	<i>7,322</i>	<i>100.0</i>	<i>n.a.</i>	<i>n.a.</i>	<i>170</i>	<i>100.0</i>	<i>7,682</i>	<i>100.0</i>
Females								
0–14	12	0.2	0	0.0	23	16.1	35	0.4
15–24	74	1.2	120	7.2	15	10.5	209	2.5
25–39	636	10.1	1,435	86.6	26	18.2	2,101	25.4
40–49	772	12.3	102	6.2	14	9.8	904	10.9
50–59	1,373	21.8	—	0.0	19	13.3	1,427	17.2
60–69	1,564	24.9	—	0.0	27	18.9	1,630	19.7
70–79	1,291	20.5	—	0.0	17	11.9	1,359	16.4
80 and over	563	9.0	—	0.0	2	1.4	620	7.5
<i>Total females</i>	<i>6,285</i>	<i>100.0</i>	<i>1,657</i>	<i>100.0</i>	<i>143</i>	<i>100.0</i>	<i>8,285</i>	<i>100.0</i>

(a) There were 190 males and 200 females for whom a derived diabetes type could not be calculated due to missing date of first injection or missing date of diagnosis. These are included in the total.

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

4.2 Geographical location

The geographical distribution of NDR registrants with insulin-treated diabetes excluding Type 1 is presented in Table 4.2.

Table 4.2: NDR registrants with derived^(a) insulin-treated diabetes (excluding Type 1): diabetes type, age at first insulin use and geographical location, 1999–2001

Age at first insulin use	Type 2	Gestational	Other	Total
Capital city				
0–39	726	1,104	78	1,914
40–59	3,038	87	64	3,244
60–79	3,887	—	49	4,035
80 and over	635	—	3	680
<i>Total persons—number</i>	<i>8,286</i>	<i>1,191</i>	<i>194</i>	<i>9,872</i>
<i>Total persons—per cent</i>	<i>83.9</i>	<i>12.1</i>	<i>2.0</i>	<i>100.0</i>
Other metropolitan				
0–39	84	130	10	225
40–59	351	3	9	376
60–79	595	—	8	621
80 and over	95	—	2	107
<i>Total persons—number</i>	<i>1,126</i>	<i>133</i>	<i>29</i>	<i>1,329</i>
<i>Total persons—per cent</i>	<i>84.7</i>	<i>10.0</i>	<i>2.1</i>	<i>100.0</i>
Large rural centres				
0–39	79	95	10	183
40–59	317	4	8	335
60–79	414	—	5	437
80 and over	78	—	1	80
<i>Total persons—number</i>	<i>888</i>	<i>99</i>	<i>24</i>	<i>1,035</i>
<i>Total persons—per cent</i>	<i>85.8</i>	<i>9.5</i>	<i>2.3</i>	<i>100.0</i>
Small rural centres				
0–39	81	59	7	148
40–59	364	—	8	383
60–79	505	—	9	535
80 and over	86	—	—	93
<i>Total persons—number</i>	<i>1,036</i>	<i>59</i>	<i>25</i>	<i>1,160</i>
<i>Total persons—per cent</i>	<i>89.3</i>	<i>5.1</i>	<i>2.1</i>	<i>100.0</i>
Other rural & remote				
0–39	201	168	15	385
40–59	897	8	11	941
60–79	1,037	—	15	1,091
80 and over	136	—	1	153
<i>Total persons—number</i>	<i>2,271</i>	<i>176</i>	<i>42</i>	<i>2,571</i>
<i>Total persons—per cent</i>	<i>88.3</i>	<i>6.8</i>	<i>1.6</i>	<i>100.0</i>

(continued)

Table 4.2 (continued): NDR registrants with derived^(a) insulin-treated diabetes (excluding Type 1): diabetes type, age at first insulin use and geographical location, 1999–2001

Age at first insulin use	Type 2	Gestational	Other	Total
Total Australia				
0–39	1,171	1,555	120	2,855
40–59	4,968	102	99	5,279
60–79	6,438	—	87	6,720
80 and over	1,030	—	7	1,113
<i>Total persons—number</i>	<i>13,607</i>	<i>1,657</i>	<i>313</i>	<i>15,967</i>
<i>Total persons—per cent</i>	<i>85.2</i>	<i>10.4</i>	<i>2.0</i>	<i>100.0</i>

(a) There were 190 males and 200 females for whom a derived diabetes type could not be calculated due to missing date of first injection or missing date of diagnosis; these are included in the totals and therefore sub-components do not add to totals.

5. Mortality

All NDR records for 1999 to 2001 were matched against the AIHW National Death Index (NDI). In the years 1999 to 2001, there were 1,229 registrants identified as having died (Table 5.1). This represents just over 5% of all registrants on the Register. 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.

When interpreting the mortality statistics in this chapter, it should be noted that consent for participation in the NDR is only about 70% in the age groups above 40 years and therefore the true number of deaths of persons with insulin-treated diabetes is significantly understated.

Table 5.1: NDR registrants: deaths, 1999–2001

Age at death	Males		Females		Persons	
	Number	Per cent	Number	Per cent	Number	Per cent
0–49	50	6.8	32	6.4	82	6.7
50–59	96	13.2	52	10.4	148	12.0
60–69	156	21.4	84	16.8	240	19.5
70–79	244	33.4	168	33.7	412	33.5
80 and over	184	25.2	163	32.7	347	28.2
All ages	730	100.0	499	100.0	1,229	100.0

5.1 Mortality rates

Age-standardised death rates were calculated for NDR registrants who died during 1999, 2000 and 2001 (Table 5.2). The main findings were as follows:

- For males who died during their first year of insulin use, the age-standardised death rates were 2,953 per 100,000 registrants in 1999; 2,591 in 2000 and 2,966 in 2001.
- This rate of mortality in the first year of insulin use was roughly 4 times higher than for males in the general population.
- For male registrants who were alive after the first year of insulin use, the age-standardised death rate dropped to around 2,000 per 100,000 registrants in both 2000 and 2001 for those in their second year of insulin use, about 2.8 times higher than for males in the general community.
- For male registrants alive after the second year of insulin use, the age-standardised death rate fell further in the third year of insulin use to about 1,500 per 100,000 registrants, in 2001.
- For female registrants, the age-standardised death rates were lower than for males. In the first year of insulin use, the age-standardised death rates for females were 1,458, 1,831 and 1,619 per 100,000 registrants in 1999, 2000 and 2001 respectively. This is between 3 and 4 times higher than for the general community.

- By the third year of insulin use, the age-standardised death rate for females had fallen to 1,131 per 100,000 registrants, 2.4 times higher than for the general population.

It is important to note that these data are based on only three years of collection and an ascertainment level in the older age groups of around 70%. Further analyses and confirmation of trends should be possible in the future as additional years of data are added and an improved level of ascertainment is achieved.

Table 5.2: NDR registrants: average annual age-standardised death rates,^(a) 1999–2001

Year commenced insulin use	1999		2000		2001	
	Age-standardised death rate per 100,000 registrants	Ratio ^(b)	Age-standardised death rate per 100,000 registrants	Ratio ^(c)	Age-standardised death rate per 100,000 registrants	Ratio ^(d)
Males						
1999	2,953	4.0	2,048	2.9	1,476	2.1
2000	2,591	3.6	1,944	2.7
2001	2,966	4.2
Females						
1999	1,458	3.0	1,599	3.4	1,131	2.4
2000	1,831	3.9	1,246	2.6
2001	1,619	3.4

(a) The indirect method of standardisation is used (see Chapter 6).

(b) 1999 Australian death rates used in calculation of standardised mortality ratio (AIHW National Mortality Database).

(c) 2000 Australian death rates used in calculation of standardised mortality ratio (AIHW National Mortality Database).

(d) 2000 Australian death rates used in calculation of standardised mortality ratio (AIHW National Mortality Database). Number of deaths for Australia for 2001 were not available until after production of this report.

5.2 Cause of death

Cause of death information is available for most deaths occurring in 1999 and 2000. As at June 2002, the National Death Index contained information on underlying causes (see Glossary) and associated causes of death recorded on the death certificate for calendar years up to 2000. Up to 20 causes of death can be coded on the certificate. Causes of death are classified according to the international statistical classification of diseases and related health problems ICD-10 (WHO 1992).

Features of cause of death data for NDR registrants (persons with insulin-treated diabetes only) were as follows (Table 5.3):

- 46.9% of females had diabetes included as a cause of death on the death certificate compared with 38.2% of males.
- Neoplasms were the most common underlying cause of death.
- Ischaemic heart disease and cancer of the pancreas (15.5% of deaths and 11.0% of deaths respectively) were the most commonly recorded single causes of death.
- 9.9% of males died due to cancer of the bronchus and lung compared with 3.3% of females

- 8.1% of females died from diseases of the respiratory system compared with 4.8% of males.

Table 5.3: NDR registrants: underlying causes of death for deceased registrants, 1999–2000

Underlying cause of death	Males			Females		
	No.	%	% with diabetes on death certificate	No.	%	% with diabetes on death certificate
Neoplasms	140	47.8	23.6	86	41.1	24.4
Cancer of the pancreas	32	10.9	12.5	23	11.0	13.0
Cancer of the bronchus and lung	29	9.9	37.9	7	3.3	42.9
Diseases of the circulatory system	73	24.9	45.2	55	26.3	58.2
Ischaemic heart disease	46	15.7	60.9	32	15.3	59.4
Cerebrovascular diseases	12	4.1	33.3	12	5.7	50.0
Diabetes mellitus	29	9.9	100.0	25	12.0	100.0
Diseases of the respiratory system	14	4.8	35.7	17	8.1	41.2
All other diseases	37	12.6	35.1	26	12.4	50.0
Total	293	100.0	38.2	209	100.0	46.9

Note: Results refer only to those registrants for whom an underlying code of death was available.

Source: AIHW National Death Index.

The coding of multiple causes of death on a death certificate allows for a more comprehensive picture of what other conditions present may have contributed to the death (see Glossary). For both males and females, diabetes was recorded as an associated condition in over half of deaths due to ischaemic heart disease. In contrast, only 13% of deaths due to cancer of the pancreas had diabetes recorded as an associated cause.

It should be noted that the preceding statistics are in respect of persons with insulin-treated diabetes and that differences in the mortality patterns for those with Type 1 diabetes compared with those with other types of diabetes have not been examined. This is because of clinical problems in distinguishing between persons with Type 1 and Type 2 diabetes aged 40 years and over. As the Register matures in future years, it may be possible to examine the mortality patterns of persons with Type 1 diabetes separately.

6. Statistical notes

6.1 Calculation of age at diagnosis

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

NDSS records

Age at diagnosis = date of diagnosis – date of birth

APEG records

Age at diagnosis = first injection date – date of birth

Diagnosis date is not available for most APEG records, but first injection date for children diagnosed with Type 1 diabetes is considered to be the same as diagnosis date.

6.2 Derivation of diabetes type

The following algorithm agreed by the NDR Management Committee and published in the first statistical report on the Register is used to assist in obtaining a more accurate measure of the type of diabetes. The purpose of this formula is to re-classify registrants believed to be incorrectly recorded as having Type 1 diabetes rather than Type 2. Records of registrants reporting Type 2 diabetes, gestational diabetes or other types of diabetes were excluded from this derivation. For further background information on this algorithm, please see the *National Diabetes Register, Statistical Profile, December 2000* (AIHW 2001:13).

For persons reporting Type 1 only:

If age at diagnosis is missing or age at diagnosis is less than or equal to 35 years, then diabetes type = 1.

If age at diagnosis is over 35 years and the difference between the year of diagnosis with diabetes and the year of first insulin use is greater than 2 years, then diabetes type = 2.

If the age at diagnosis is over 35 years and the difference between the year of first insulin use and the year of diagnosis with diabetes is less than or equal to 2 years, then diabetes type = 1.

Note: If the year of first insulin use is missing, the year of first syringe purchase is used as a proxy for year of first insulin use.

6.3 Age-standardised rates

Age-standardisation is a technique used to eliminate the effect of differences in population age structures when comparing rates for different periods of time, and/or different geographic areas and/or different population sub-groups. Definitions are included in the National Health Data Dictionary (AIHW 2002b).

There are two methods of age-standardisation, direct and indirect. Tables in this report have been footnoted to identify which method was used.

Direct age-standardisation

To control for any effects of varying age structures of population, direct age-standardisation is used to calculate rates. The 1991 Australian population was used as the standard population in calculating age-standardised rates, using the following formula (Armitage et al. 2002):

$$SR = \frac{\sum (R_i P_i)}{\sum P_i}$$

where SR = standardised rate, R_i = the age-specific rate for age group i for the population being studied, and P_i = the Australian standard population (persons) as at 30 June 1991 for age group i .

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 (Armitage et al. 2002). The formula is as follows:

$$SR = \frac{C}{\sum (R_i P_i)} \times R$$

where SR = standardised rate, C is the actual number of cases in the population being studied, R_i = the age-specific rate of the standard population for age group i , P_i = the population age group i for the population being studied, R = crude rate of the standard population.

6.4 Mortality rates

Mortality rates for both the Register population and total Australia were calculated using the indirect standardisation formula (see Section 6.3 above). However, an adjustment was made to the Register's annual standardised mortality rates to account for the average period that the population was on the Register and therefore exposed to the risk of death.

For example, for registrants who joined the Register in 1999, the average period was only 0.37 of a year, reflecting a relatively lower rate of registrations in the first half of 1999. If registrants had joined the Register evenly throughout 1999 (as they did in 2000 and 2001), the average time spent on the Register in that year would have been 0.5 of a year.

The adjusted standardised mortality rates for the Register population were obtained by multiplying the standardised mortality rate by the inverse of the average period of time that the Register population was exposed to the risk of death as a registrant. In the case of the 1999 death rate, the adjustment factor was 2.70, that is 1/0.37.

6.5 Confidence intervals

The 95% confidence intervals in this report indicate the variation that might be expected in incidence numbers purely by chance. The confidence intervals are calculated using the following formula, which has been adapted from that presented in AIHW & AACR (2002):

$$95\% \text{ CI} = R \pm 1.96 \times \frac{R}{\sqrt{\text{Number of cases}}}$$

where R = average yearly cases (per 100,000 population).

7. Diabetes research

The Register is available for diabetes research. A package 'Access to the National Diabetes Register' is available on the AIHW web site at <<http://www.aihw.gov.au>> or alternatively, by contacting:

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

Applications to access the Register 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. Application forms for approval are a component of the above-mentioned research package.

Appendix 1: Data collected by the Register

Data for the Register are provided by Diabetes Australia (DA) which operates and maintains the National Diabetes Services Scheme (NDSS), the Australasian Paediatric Endocrine Group (APEG) state-based registers, and the Menzies Centre for Population Health in Tasmania which operates the Tasmanian Insulin Treated Diabetes Register (TITDR).

The NDSS database contains information about people with diabetes in all age groups and with different types of diabetes. The NDSS registration form contains a NDR consent section which was introduced to coincide with the introduction of the Register on 1 January 1999.

Signed consent by the NDSS registrant means agreement to Diabetes Australia providing his/her NDSS information to the NDR.

The APEG registers focus on children with insulin-treated diabetes who are aged under 15 years at time of diagnosis. Each APEG state office established its register independently at varying times since 1983; all collect the same minimum data set. The APEG registration form also contains a consent section for registration with both APEG and the Register.

Table A1 lists the data items held on the Register, the source of the data item, and a description of output categories available for each item. Identifiable information (e.g. name and address details) about the registrant, their medical practitioner and their carers (if applicable) are only used for AIHW's management of the Register and are not available as output from the Register. These are marked accordingly.

Table A1: Data collected by the Register: field by source and output categories

Field	Collected by DA	Collected by APEG	Derived Item	Output categories	Comments
Registrant information					
Source			X	N—NDSS A—APEG B—Both O—Other	
Registration number	X	X		Not available	Unique registration for NDSS or APEG
state/territory of registration	X	X	X	1—NSW 2—VIC 3—QLD 4—SA 5—WA 6—TAS 7—NT 8—ACT	
Register consent	X	X			Must consent to be included on Register
Research consent		X		Yes No	

(continued)

Table A1 (continued): Data collected by the Register: field, by source and output categories

Field	Collected by DA	Collected by APEG	Derived Item	Output categories	Comments
Registrant type			X	New Existing	Only for NDSS registrants
Title (Mr, Mrs, Dr etc)	X			Not available	
Surname	X	X		Not available	
First name	X	X		Not available	
Second name	X	X		Not available	
Other name(s)	X			Not available	
Sex	X	X		Male Female	
Address 1	X	X		Not available	
Address 2	X	X		Not available	
Address 3	X	X		Not available	
state/territory of usual residence			X	1—NSW 2—VIC 3—QLD 4—SA 5—WA 6—TAS 7—NT 8—ACT	Derived from postcode of usual residence
Postcode of usual residence	X	X			
Phone	X			Not available	
Date of birth	X	X		Not available	
Age			X	5-year age groups	Expressed as age at a particular point in time
Indigenous status	X	X		Indigenous Non-Indigenous Not stated	
Country of birth	X	X		Australian Standard Classification of Countries for Social Statistics, ABS Cat. No. 1269.0	
Postcode at diagnosis	X	X			
Diabetes type—reported	X	X		1 – Type 1 2 – Type 2 3 – Gestational 4 – Other types of diabetes	
Diabetes type—derived			X	1 – Type 1 2 – Type 2 3 – Gestational 4 – Other types of diabetes 9 – Not derived	

(continued)

Table A1 (continued): Data collected by the Register: field, by source and output categories

Field	Collected by DA	Collected by APEG	Derived Item	Output categories	Comments
Diagnosis date	X			Year of diagnosis	For APEG diagnosis date is assumed to be the same date as date of first insulin use
Age at diagnosis			X	5-year age groups	Derived from date of birth and date of diagnosis
Age at first insulin use			X	5-year age groups	Derived from date of birth and date of first insulin injection
Date of first insulin injection	X	X		Year of first insulin use	
Vital status			X	1—Alive 2—Deceased	
Year of death			X	Year of death	
Cause of death			X	ICD-10 coding	
Medicare number				Not available	
Registration date	X	X		Year of registration	Year of registration with NDSS or APEG
Doctor's details					
Certifying doctor's name	X	X		Not available	
Doctor's address 1	X	X		Not available	
Doctor's address 2	X	X		Not available	
Doctor's address 3	X	X		Not available	
Doctor type	X	X		G—General practitioner E—Endocrinologist S—Specialist O—Other medical practitioner D—Diabetes educator	
Doctor's provider number	X	X		Not available	
Doctor's research involvement		X		Not available	
Carer details					
Carer title	X			Not available	
Carer surname	X	X		Not available	
Carer first name	X	X		Not available	
Carer second name	X			Not available	
Carer address 1	X			Not available	
Carer address 2	X			Not available	
Carer address 3	X			Not available	
Carer state/territory of usual residence	X			Not available	
Carer phone number	X	X		Not available	
Carer postcode	X			Not available	
Carer relationship	X			Not available	

Appendix 2: Data concordance

Many records for those who were aged less than 15 years at diagnosis are common to both NDSS and APEG. The level of concordance between the two data providers for children's records varies among states and territories. This is largely due to levels of consent from both data sources, with consent levels from APEG much lower than for the NDSS (this is being addressed by APEG). However, the period between registration with a data source and arrival of the record at the AIHW can also vary. For NDSS records, the majority of records for the Register arrive within the first 3 months after registration with Diabetes Australia. For some APEG state offices, the process of certification of diabetes type by a medical specialist takes additional time, particularly when travel by endocrinologists to rural areas is required. The level of concordance between the two data sources is shown in Table A2.

Table A2: Concordance between NDSS and APEG records: registrants first diagnosed in 1999–2001 and aged under 15 years at time of diagnosis

state	Both APEG and NDSS	NDSS only	APEG only	Total
		Number		
NSW	399	276	97	772
Vic	263	229	76	568
Qld	209	201	39	449
SA	118	38	35	191
WA	213	9	27	249
Tas	43	17	1	61
NT ^(a)	7	7	1	15
ACT ^(b)	22	11	7	40
Australia	1,274	788	283	2,345
		Per cent		
NSW	51.7	35.8	12.6	100.0
Vic	46.3	40.3	13.4	100.0
Qld	46.5	44.8	8.7	100.0
SA	61.8	19.9	18.3	100.0
WA	85.5	3.6	10.8	100.0
Tas	70.5	27.9	1.6	100.0
NT ^(a)	46.7	46.7	6.7	100.0
ACT ^(b)	55.0	27.5	17.5	100.0
Australia	54.3	33.6	12.1	100.0

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

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

Data provided by the Menzies Centre in Tasmania showed 100 per cent concordance to existing data on the Register.

Appendix 3: Register holdings

Ascertainment for the Register is based on the number of NDSS registrants who consent to join the Register compared with the number of NDSS registrants who are eligible to join. In the Register's initial stages, the proportion of eligible NDSS registrants consenting to join the Register was very low, mainly due to the continuing use of superseded forms, which did not contain a NDR consent section. As these old forms were removed from use, consent rates increased, then stabilised after September 1999; however, there were still fluctuations in the consent rates in 2000 and 2001. This will be examined in detail when the full data of the NDSS become available to the AIHW with the introduction of the new NDSS system (expected late 2003)—including improved privacy arrangements. The new system will allow all NDSS insulin-treated registrants to be included in the Register. Thus, ascertainment rates will then not be relevant and need not be calculated.

Table A3: Proportion of new NDSS registrations on the NDR, by quarter, 1999–2001

Quarter	Australia
Jan 99–Mar 99	31.9
Apr 99–Jun 99	60.2
Jul 99–Sep 99	70.6
Oct 99–Dec 99	72.8
Jan 00–Mar 00	73.0
Apr 00–Jun 00	72.8
Jul 00–Sep 00	72.0
Oct 00–Dec 00	71.0
Jan 00–Mar 01	64.0
Apr 01–Jun 01	67.1
Jul 01–Sep 01	67.0
Oct 01–Dec 01	68.5

- Ascertainment from APEG has been estimated at 100% from most state registers. At time of writing, the Institute had received data for the first half of 2002.

Table A4: APEG data held on the NDR

APEG state office	Months available on Register at September 2002
NSW ^(a)	January 1999–July 2002
Vic	January 1999–August 2002
Qld ^(b)	January 1999–August 2002
SA ^(c)	January 1999–July 2002
WA	January 1999–September 2002
Tas	January 1999–June 2002

- (a) The New South Wales state APEG register is responsible for collection of information in the Australian Capital Territory, and may collect some data for the south-east corner of the Northern Territory.
- (b) The Queensland state APEG Register is responsible for collection of information collected by paediatric endocrinologists from Darwin.
- (c) The South Australian APEG Register is responsible for collection of information by paediatric endocrinologists from Alice Springs.

Glossary

Derived diabetes type: In some instances the diabetes type entered on the registration form is considered to be incorrect. This largely reflects the misconception among some people and health professionals that only people with Type 1 diabetes use insulin injections regularly to manage their condition. In an effort to describe the distribution of registrants by type of diabetes more accurately, the NDR Management Committee recommended use of another data item based on age of diagnosis, and the period of time between the date of diagnosis and commencement of insulin use. The formula used for this derivation is shown in Chapter 6, Statistical Notes.

Diabetes (diabetes mellitus): The term 'diabetes mellitus' describes a metabolic disorder of multiple aetiology characterised by chronic hyperglycaemia with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both (WHO 1999).

Although diabetes is often mistaken as a single disease, there are several different forms of this condition with the common feature of abnormal blood glucose levels. The most common forms of diabetes are Type 1, Type 2 and gestational (GDM).

Gestational diabetes mellitus (GDM): Gestational diabetes is carbohydrate intolerance resulting in hyperglycaemia of variable severity, with onset or first recognition during pregnancy (WHO 1999).

Women who have had diabetes diagnosed prior to a pregnancy do not fall into this category. GDM increases the risk of perinatal morbidity and mortality and substantially increases the mother's risk of developing diabetes later in life (AIHW 2002a).

Impaired glucose tolerance: Impaired glucose regulation refers to a metabolic state intermediate between normal glucose homeostasis and diabetes (WHO 1999).

People with IGT have a 1 in 3 chance of developing Type 2 diabetes within 10 years (AIHW 2002a).

Insulin-treated diabetes mellitus (ITDM): A classification of diabetes which includes all those who use insulin to treat their diabetes, which includes those with Type 1, Type 2, gestational and other types of diabetes.

Multiple causes of death: These may include those conditions involved in the morbid train of events leading to death which were classified as either the underlying cause, the immediate cause, or any intervening causes and those conditions which contributed to death, but were not related to the disease or condition causing death (ABS 2002a).

National Death Index (NDI): The NDI is a data set, housed at the AIHW, which contains records of all deaths occurring in Australia since 1980, provided by the Registrars of Births, Deaths and Marriages in all states and territories.

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

- genetic defects of beta-cell function;
- genetic defects in insulin action;
- diseases of the exocrine pancreas;
- endocrinopathies;

- drug- or chemical-induced diabetes;
- uncommon but specific forms of immuni-mediated diabetes mellitus; and
- 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 in the National Diabetes Register.

Reported diabetes type: In order to receive syringes at a subsidized cost, a NDSS registrant must have his or her requirement for insulin verified by a medical practitioner, or since 2001, a registered diabetes educator. As part of that process, the type of diabetes is also noted on the form. This is the reported diabetes type.

For APEG registrants, the diabetes type is verified by the child's doctor; in most cases the doctor is an endocrinologist or paediatrician.

Type 1 diabetes: This form of diabetes, previously encompassed by the terms 'insulin-dependent diabetes' or 'juvenile-onset diabetes', results from autoimmune mediated destruction of the beta cells of the pancreas (WHO 1999).

People with Type 1 diabetes require daily insulin therapy to survive. Type 1 diabetes is most commonly diagnosed before the age of 30 years.

Type 2 diabetes: Type 2 diabetes is the most common form of diabetes. It is often associated with lifestyle—obesity, inactivity and poor diet are considered major contributing factors. Often this type of diabetes can be managed with changes to diet and exercise. However, in some cases insulin is required and only insulin-treated persons with Type 2 diabetes are included in the National Diabetes Register. Type 2 diabetes is most commonly diagnosed after the age of 40 years; however, recent trends have indicated an increase in diagnosis in younger years.

Underlying cause of death: The disease or injury which initiated the train of morbid events leading directly to death.

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