



## **2 How many people have diabetes?**

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## Introduction

Recent increases in the number of people with diabetes have led to a number of claims that we are in an 'epidemic' of diabetes (Colagiuri et al. 2005). There is much concern about the likely effect of this epidemic on individual and population health, and its wider social and economic impacts. Therefore our estimates on the magnitude of the problem are essential for monitoring the impact of the disease and prevention strategies, and for planning and providing services to people with diabetes.

Two measures of disease occurrence are included here: prevalence and incidence. Both of these measures described below are important in describing the occurrence of diabetes.

*Prevalence* is the number of people with diabetes at a point in time. In this report, the time point is a single day in the case of continuous data collections such as the National Diabetes Services Scheme, or the day the respondent was questioned in the case of the various surveys. Information is presented here both in terms of the absolute number of cases, and as a percentage of the population.

*Incidence* is the number of new cases of diabetes during a period of time. The period of time used in this report is calendar years. As well as the absolute number of new cases, this is also expressed as a rate: the number of new cases during the year divided by the population at risk (multiplied by 100,000).

This chapter has five sections. The first provides information on the prevalence of all diabetes—how many people have any type of diabetes. The second section contains available information on the incidence of all diabetes regardless of type. Then three sections that follow describe the prevalence and incidence of the main types of diabetes—Type 1, Type 2 and gestational diabetes.

## Prevalence of diabetes

There are two main data sources of national diabetes prevalence in Australia. The first is the 1999–2000 Australian Diabetes, Obesity and Lifestyle Study (AusDiab study), in which diabetes prevalence was estimated on the basis

of measured blood sugar levels. The second is the Australian Bureau of Statistics (ABS) series of National Health Surveys, in which prevalence estimates are based on self-reported information. Note that gestational diabetes is excluded from the NHS estimates in this chapter.

Measured data, such as those collected in the AusDiab study, provide more accurate estimates of the prevalence of diabetes than self-reported survey data. Diabetes prevalence derived from measured data can be estimated for both diagnosed and previously undiagnosed cases. The accuracy of self-reported data, such as those collected in the NHS, relies on respondents being aware of and accurately reporting their health status, and therefore will not include previously undiagnosed cases of diabetes. However, because the NHS is conducted regularly, it is able to provide recent information and produce trends on the prevalence of diagnosed diabetes over time.

### Measurement data

The latest available national information on the prevalence of diabetes using data collected as part of a survey that included blood samples is the 1999–2000 AusDiab study. Based on data from that study, it has been estimated that nearly 880,000 Australian adults aged 25 or over had diabetes in 1999–2000, constituting 7.4% of the population (more than 1 in 14 people). The vast majority (96%) of diabetes cases in adults aged 25 years and over were Type 2.

The proportion of people with diabetes increased with age (Figure 2.1). Fewer than 3% of adults aged 35–44 years had diabetes. The rate then steadily increased to 23% for people aged 75 years and over.

The rates were higher for males than females in most age groups, particularly for the middle groups between 55 and 74 years of age.

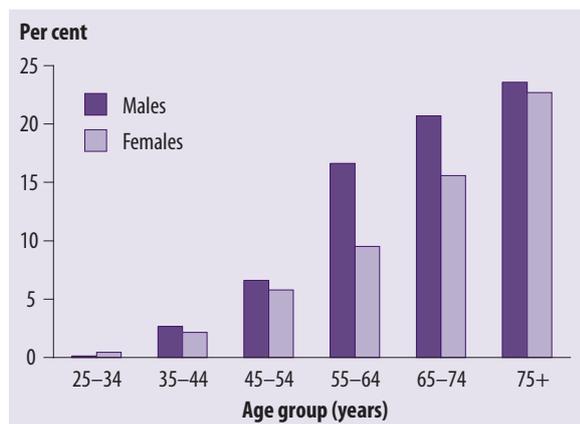
The AusDiab study found that a large proportion of total diabetes cases were undiagnosed—half of the cases detected in the survey had not previously been diagnosed. There was little variation in this pattern across age groups (Figure 2.2).

Another estimate of the proportion of undiagnosed diabetes cases was obtained in the Northwest Adelaide Health Study (NWAHS) conducted during

2000–2003. This study found fewer undiagnosed cases than the AusDiab study (see Box 2.1).

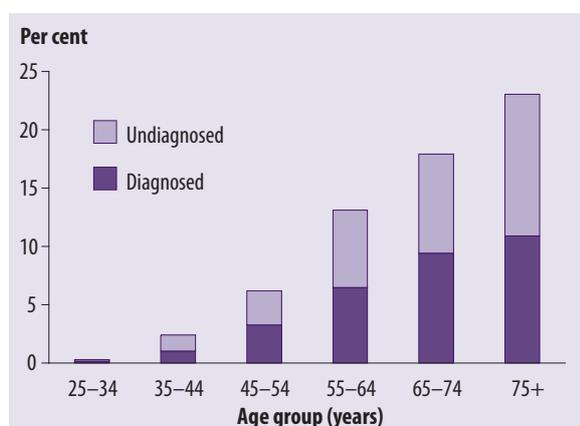
In 2000–2003, the NWAHS found that 6.6% of the population aged 18 years and over had diabetes. Blood measurements were taken; however, there are a number of reasons why this estimate cannot be directly compared with the AusDiab estimate. These include the use of different blood tests (outlined in Box 2.1) and different scopes (age range and geographical populations covered).

The NWAHS found similar age and sex patterns to the AusDiab study. The percentage of people in the population with diabetes was higher in males compared with females, and the percentage increased with age.



Source: AIHW analysis of the 1999–2000 AusDiab study.

**Figure 2.1: Age-specific prevalence of diabetes, by sex, 1999–2000**



Source: AIHW analysis of the 1999–2000 AusDiab study.

**Figure 2.2: Age-specific prevalence of diagnosed and undiagnosed diabetes, 1999–2000**

Little information is available on trends in diabetes based on measurement data.

Comparisons can be made between the National Heart Foundation (NHF) Risk Factor Prevalence Survey conducted in 1983 and the 1999–2000 AusDiab survey. The valid comparison is for the overlapping population of 25–64 year olds living in capital cities. Diabetes cases are included if the fasting plasma sugar was 7.0 mmol/l or more. Using this comparison and adjusting for age, 1.2% of this population had diabetes in 1983. By 1999–2000, this had increased to 3.2%.

### Box 2.1: Diagnosed versus undiagnosed diabetes?

The following two Australian studies have examined the ratio of diagnosed versus undiagnosed diabetes.

**1999–2000 Australian Diabetes and Lifestyle Study (AusDiab)** In the 1999–2000 AusDiab study, people with known (diagnosed) diabetes were defined as those receiving treatment in the form of tablets or insulin at the time of the study or who had been told by a doctor or nurse that they had diabetes and had a fasting blood sugar level of at least 7.0 mmol/L or a 2-hr post load sugar level of at least 11.1 mmol/L. People with undiagnosed diabetes were defined as those who had never been diagnosed with diabetes and were not receiving treatment and who had a fasting blood sugar level of at least 7.0 mmol/L or a 2-hr post load sugar level of at least 11.1 mmol/L. The study found a ratio of 1:1 for diagnosed versus undiagnosed diabetes; in other words, for every known case of diabetes there was one newly diagnosed case (Dunstan et al. 2002).

**North West Adelaide Health Study (NWAHS)** In the NWAHS, people with diagnosed diabetes were defined as those reporting that they had been told by a doctor that they had diabetes. People with previously undiagnosed diabetes were defined as having a fasting plasma sugar level of at least 7.0 mmol/L but did not report having been told by a doctor that they had diabetes. The study found a ratio of 1:5–6 for diagnosed versus undiagnosed diabetes; in other words, for approximately every five or six people with diagnosed diabetes, one person had undiagnosed diabetes (Grant 2005).

How many people have diabetes?

## Self-reported data

Self-reported data are easier to collect than measurement data but have certain limitations: the data cannot identify undiagnosed cases, and they rely on the respondent accurately reporting that they have been diagnosed with diabetes.

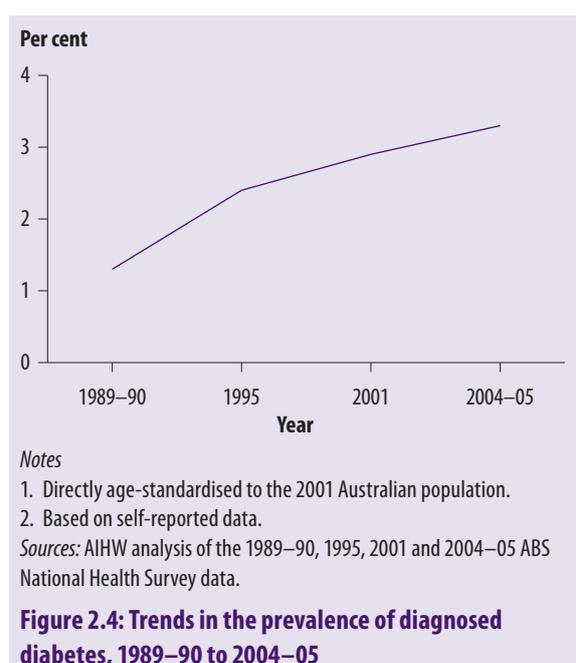
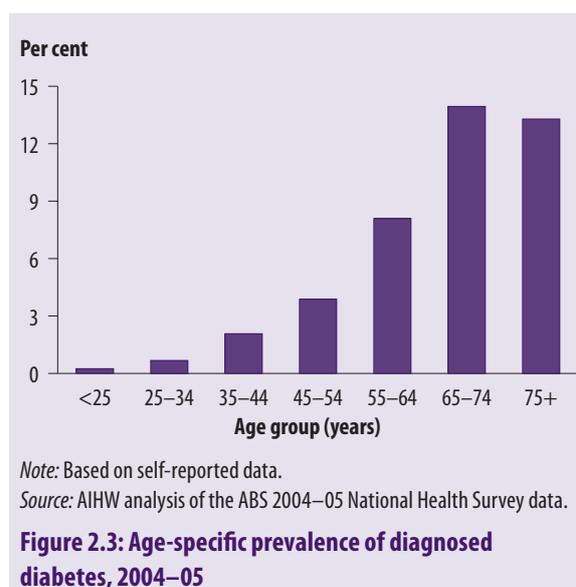
From self-reported data in the 2004–05 NHS, about 700,000 Australians (3.6% of the population) had been diagnosed with diabetes (ABS 2006b). The proportion of people with diabetes increased with age, and the highest prevalence rates were for those aged 65–74 years (Figure 2.3). Males had a higher prevalence than females (4.0% and 3.2%, respectively).

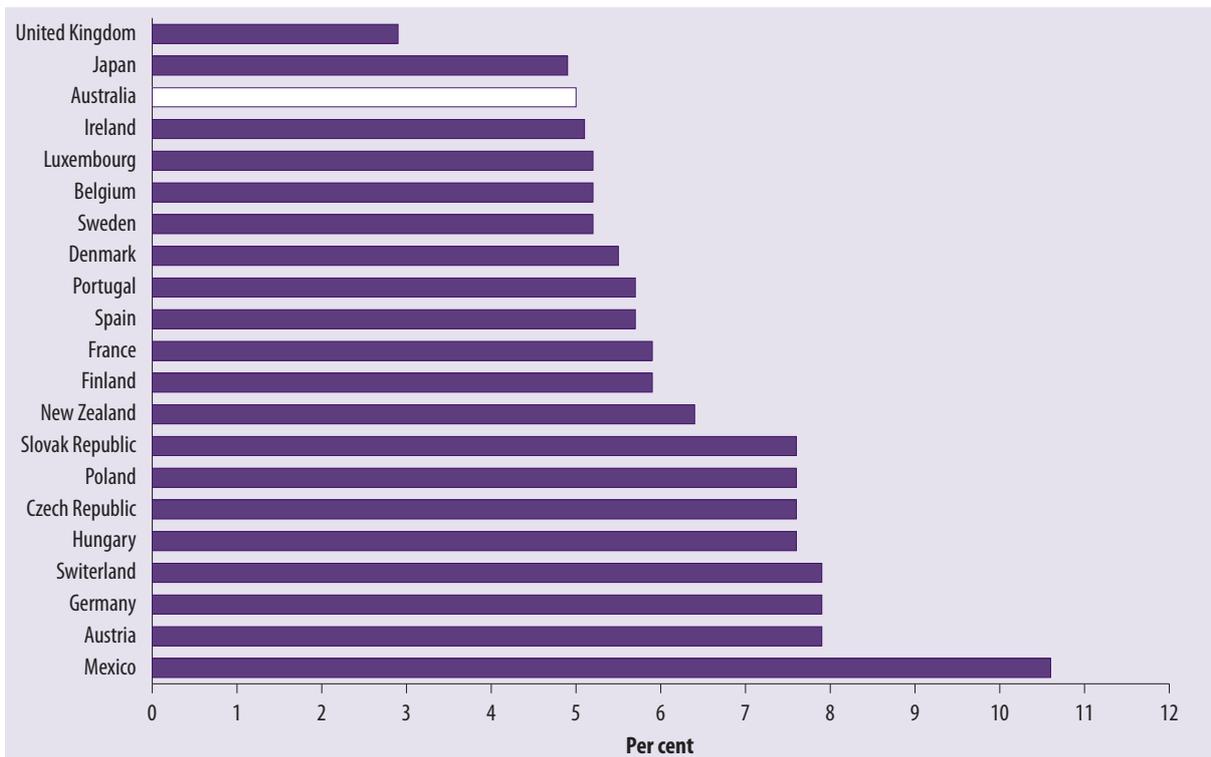
The NHS found that, among people with diabetes, 13% had Type 1 diabetes, while 83% had Type 2 and a further 4% did not know which type they had.

The number of people with diabetes has increased substantially in recent years. Results from the four National Health Surveys indicate that the number of people with diagnosed diabetes more than doubled between 1989–90 and 2004–05 from around 250,000 to 640,000 (age-standardised). The corresponding percentage of the population with diabetes increased from 1.3% to 3.3% (Figure 2.4). This is a substantial increase, believed to be related to more people developing diabetes, people living longer with the disease, and potentially better detection of the disease (Colaguiri et al. 2005).

## International comparisons

Comparisons of the percentage of people with diabetes in 20 other OECD countries show that Australia, with a prevalence rate of 5%, is towards the bottom of this group of countries (Figure 2.5). These estimates of the prevalence for people aged 20 to 79 years of age have been adjusted for differences in the age structure of the populations. The highest rate (>10%) was found in Mexico, while the lowest rate (around 3%) was in the United Kingdom.





Source: International Diabetes Federation 2006.

**Figure 2.5: Estimated diabetes prevalence, 20–79 year olds, 2007**

## Incidence of diabetes

There is limited national information on the incidence of diabetes in Australia. The exception is Type 1 diabetes for which there are good incidence data from 1999 onwards from the NDR. In addition state-level incidence data has been published from Western Australia since the 1980s and New South Wales since 1990 (Haynes et al. 2004; Taplin 2005; Craig 2007).

This section presents available information on the incidence of all diabetes, while subsequent sections present more detail on different types of diabetes where available.

### Disease register and administrative data

Recent evidence from disease registers and administrative data shows that there are at least 45,000 new cases—about 1 new case for every 450 people—of diagnosed diabetes (excluding gestational diabetes) each year (Table 2.1). This includes around 5,000 new cases of diabetes

that are insulin-treated (new cases of Type 1 diabetes and new cases of Type 2 and ‘other diabetes’ starting insulin treatment within approximately a year of diagnosis). Registration data for the NDSS show that, by 30 September 2006, there were at least another 40,000 people newly diagnosed in 2003 who do not use insulin. There is also a sizeable proportion of NDSS registrations where diagnosis year is missing: 19% of people registered since 2003 do not have a diagnosis year recorded. At least some of these cases are likely to have been diagnosed in 2003. Distributing the registrations without diagnosis year according to the distribution of the cases that did have a diagnosis year leads to another 12,000 registrations that may have been diagnosed in 2003.

Using the latest available national hospital data, each year there are around 11,000 cases of diagnosed gestational diabetes. This estimate comes from counting the number of deliveries in hospital where gestational diabetes was recorded in the hospital record (see Gestational diabetes section for more information).

**Table 2.1: New cases of diagnosed diabetes recorded in disease register and administrative data by year of diagnosis, 2003–2005**

Type of diabetes <sup>(b)</sup>	New insulin-treated diabetes per year	National Diabetes Services Scheme registrants <sup>(a)</sup>	Deliveries in hospital with gestational diabetes per year	Estimate of total new cases <sup>(c)</sup>
	National Diabetes Register, 2003–2005	NDSS database, diagnosed 2003	AIHW National Hospital Morbidity Database, 2003–04 to 2004–05 <sup>(c)</sup>	
Type 1	2,000	(refer to NDR data)	–	2,000
Type 2	3,100	43,100	–	43,100
Gestational	1,700	6,700	10,800	10,800
Other	100	300	–	300
<i>Total excl gestational</i>	<i>5,200</i>	<i>45,400</i>	–	<i>45,400</i>
<i>Total</i>	<i>6,900</i>	<i>52,100</i>	<i>10,800</i>	<i>56,200</i>

(a) As at 30 September 2006. Excluding NDSS registrations with missing diagnosis year information (19% of registrations occurring since 1 January 2003). Only cases diagnosed in 2003 have been used in this estimate due to the known time delay between diagnosis and registration for a proportion of people with Type 2 diabetes.

(b) Data from the National Diabetes Register and the National Diabetes Services Scheme data are grouped using 'derived type of diabetes' (AIHW: Catanzariti et al. 2007). Gestational diabetes cases in the hospital data are identified using ICD-10-AM code O24.4, and have only been counted when present at the time of delivery.

(c) Estimate of the number of new cases as recorded in these databases.

Note: Numbers rounded to nearest 100.

Sources: National Diabetes Register, AIHW analysis of National Diabetes Services Scheme database, AIHW analysis of AIHW National Hospital Morbidity Database.

## Cohort study

The AusDiab 5-year follow-up study determined that 0.8% of Australian adults aged 25 years and over developed diabetes (excluding gestational diabetes) each year between 2000 and 2005. This corresponds to an estimated 275 people developing the disease each day, or around 100,000 per year. Overall, there were more new cases of diabetes per year for males than for females; for males the incidence of diabetes peaked between the ages of 55 and 74 years while for females the incidence was highest for those aged 65 years and over (Barr et al. 2006). Note that only around 75% of these cases identified using only one blood sample (the standard practice in these types of surveys) would be expected to be true clinical cases (WHO 2006). Therefore this number should be seen as an upper limit of the number of cases developing.

It is unlikely that 100,000 people will be diagnosed with diabetes in a year. However, for a number of reasons it is difficult to compare this estimate of newly developed cases of diabetes with the ones presented above on new cases of diagnosed diabetes. First, a proportion of the estimated new cases found in a survey would not be true cases

(as explained above). Second, a proportion would also remain undiagnosed, though for an unknown period of time. It is also not known whether the proportion of undiagnosed cases is changing over time. Third, there are complex flows of people moving from not having diabetes to having it, then from being undiagnosed to being diagnosed. People are not necessarily diagnosed in the year they develop diabetes, and the gap between developing diabetes and being diagnosed is likely to vary between individuals.

## Type 1 diabetes

Type 1 diabetes usually arises in childhood or youth (though it can occur at any age) and is characterised by the inability to produce insulin. People with Type 1 diabetes need insulin replacement for survival.

## Risk factors

No modifiable risk factors have been clearly identified for Type 1 diabetes. It is currently thought that a combination of genetic and environmental factors are involved in the

development of the disease (Daneman 2006; Devendra et al. 2004), though research continues into the exact nature of these risk factors.

Some environmental risk factors being researched include: viruses, nutrition including early consumption of cow's milk and vitamin D exposure (Yoon et al. 1999; Vaarala 2005; Greer et al. 2007; Littorin et al. 2006).

## How many Australians have Type 1 diabetes?

### Prevalence

There is limited information available that can be used to accurately determine the number of people in Australia with Type 1 diabetes. An indication of Type 1 diabetes prevalence can be obtained from four sources—the NHS, the NDSS, the NDR, and the Australian Diabetes, Obesity and Lifestyle Study (AusDiab). However each of these has limitations, as indicated below. Due to the nature of Type 1 diabetes, undiagnosed cases will not complicate the assessment of prevalence.

Based on self-reported data from the NHS, Type 1 diabetes accounted for 13% of all diabetes cases reported in 2004–05. This corresponds to an estimated 91,900 (0.4%) Australians affected by the disease in 2004–05. However, the type of diabetes is not accurately reported by participants in population surveys. Validation of the 1995 NHS using other information collected in the survey indicated that only around half of the people reporting Type 1 diabetes were estimated to have Type 1 diabetes.

Another indication of prevalence can be obtained using the NDSS data. As at 30 September 2006, there was an estimated maximum of 122,300 people registered with Type 1 diabetes on the NDSS (AIHW analysis of the NDSS data). However, it is likely that a proportion of these people have Type 2 diabetes rather than Type 1. The proportion falling into this category cannot be estimated from the database due to missing diagnosis information.

Further information on the number of people with Type 1 diabetes in particular subgroups can be obtained from the NDR (people diagnosed since 1999) and AusDiab (people aged 25 years and over).

There were 12,700 registrants on the NDR with derived Type 1 diabetes who were still alive at the end of 2005. This represents the total number of people diagnosed with Type 1 diabetes in the 7 years between 1999 and 2005 who did not die during that period.

Based on data from the 1999–2000 AusDiab study, Type 1 diabetes accounted for around 8.1% of all diagnosed diabetes in people aged 25 years and over—affecting approximately 35,500 Australians in this age group.

### Incidence

The NDR collects information on new cases of insulin-treated diabetes. NDR records for 0–14 year olds are received from the NDSS and the Australasian Paediatric Endocrine Group (APEG) state and territory databases. As a result, coverage of new cases of insulin-treated diabetes under 15 years of age is considered to be high thus producing reliable estimates of Type 1 diabetes incidence (AIHW: Catanzariti et al. 2007). For 15–39 year olds, the incidence estimates are adjusted to account for NDSS registrants not consenting to be on the NDR.

According to the NDR, there were 1,689 new cases of Type 1 diabetes diagnosed in 2005 among people aged less than 40 years (Table 2.2). The annual incidence of Type 1 diabetes for 0–14 year olds was 22.6 cases per 100,000 population and 10.9 cases per 100,000 population for people aged 15–39. There is substantial variation within these broad age ranges. For children, the highest rates were for the 10–14 year age group (28.0 per 100,000). For young adults, the highest rate occurred in the 15–19 year age group (17.5 per 100,000). Males accounted for 58% of cases, and incidence rates were higher for males than females across nearly all age groups.

### Trends

There was a significant increase in the incidence of Type 1 diabetes between 1999 and 2005; over the seven years, the age-adjusted rate of new cases among those aged 0–14 increased from 18.1 per 100,000 population in 1999, to 22.6 in 2005 (AIHW: Catanzariti et al. 2007). The incidence remained relatively stable for people aged 15–39 years (around 15 per 100,000 for males and 10 per 100,000 for females).

## International comparisons

Australia's incidence rate for Type 1 diabetes in the late 1990s to early 2000s was at the upper end of the range of estimates for OECD countries

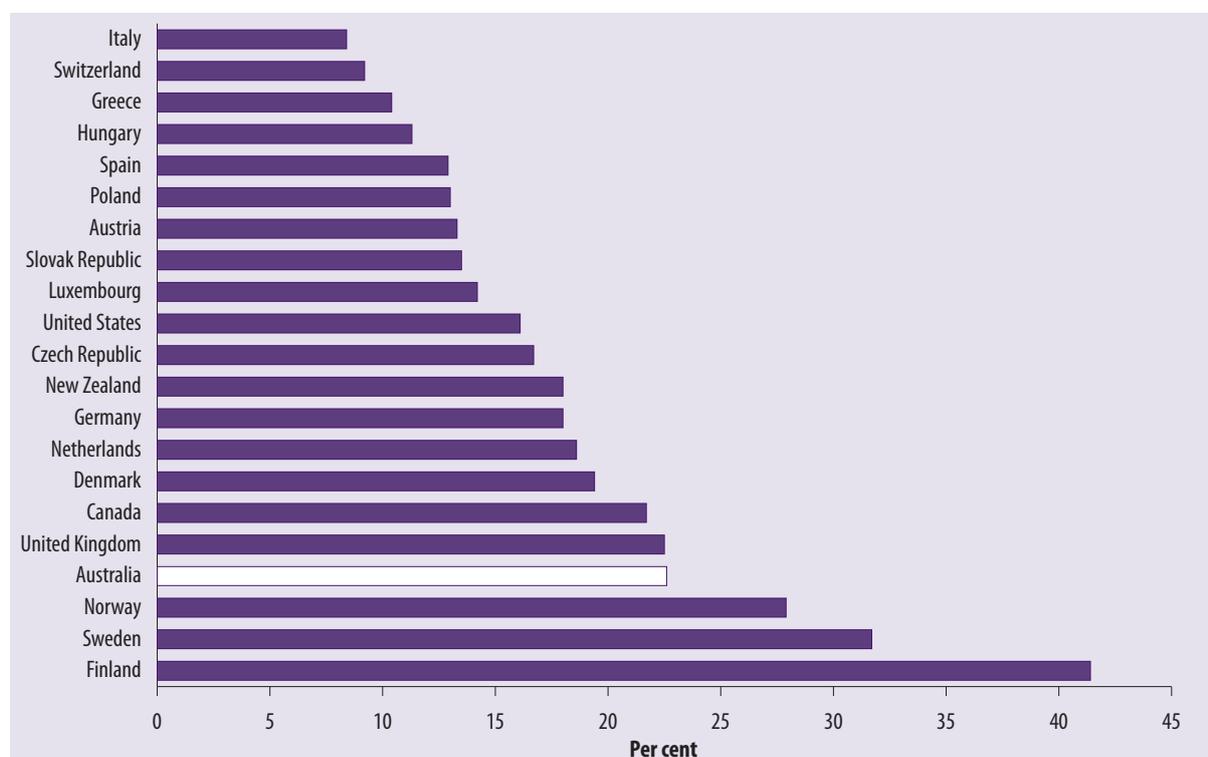
(Figure 2.6). Three of the Nordic countries had the highest rates (up to 41 per 100,000), followed by Australia, the United Kingdom and Canada with rates around 22–23 per 100,000. The lowest rate was 8.4 per 100,000 in Italy.

**Table 2.2: Incidence of Type 1 diabetes among those aged 0–39 years at their first insulin use, by age and sex, 2005**

	Males		Females		Persons	
	Number	Rate	Number	Rate	Number	Rate
0–4 years	109	16.8	92	14.9	201	15.9
5–9 years	156	23.0	154	23.9	310	23.5
10–14 years	207	29.0	183	27.0	390	28.0
<i>Total 0–14<sup>(a)</sup></i>	<i>472</i>	<i>23.0</i>	<i>429</i>	<i>22.1</i>	<i>901</i>	<i>22.6</i>
15–19 years	150	21.1	93	13.7	243	17.5
20–24 years	112	15.3	70	10.0	182	12.7
25–29 years	96	13.9	48	7.1	144	10.6
30–34 years	101	13.5	38	5.0	139	9.2
35–39 years	54	7.4	26	3.5	80	5.4
<i>Total 15–39<sup>(a)</sup></i>	<i>513</i>	<i>14.1</i>	<i>275</i>	<i>7.7</i>	<i>788</i>	<i>10.9</i>
<b>Total 0–39</b>	<b>985</b>		<b>704</b>		<b>1,689</b>	

(a) Directly age-standardised to the 2001 Australian population.

Source: AIHW: Catanzariti et al. 2007.



Sources: International Diabetes Federation 2006, National Diabetes Register.

**Figure 2.6: Incidence of Type 1 diabetes in OECD countries, 0–14 year olds, late 1990s to early 2000s**

## Type 2 diabetes

Type 2 is the most common form of diabetes. It occurs mostly in people aged 40 years and over and is marked by reduced or less effective insulin. Although uncommon in childhood, it is becoming increasingly recognised in that group.

### Risk factors

A number of risk factors are implicated in the development of Type 2 diabetes. These may act alone, but often act together in complex interplay. Consideration of combinations of risk factors is important as it may explain why some population subgroups have higher rates of diabetes than others. Table 2.3 outlines the risk factors for Type 2 diabetes.

### How many Australians have Type 2 diabetes?

#### Prevalence

From the 1999–2000 AusDiab study, it has been estimated that nearly 840,000 Australian adults aged 25 years or above had Type 2 diabetes in 1999–2000, which constitutes 7.1% of the population. These cases represent the vast majority (96%) of cases identified in the survey.

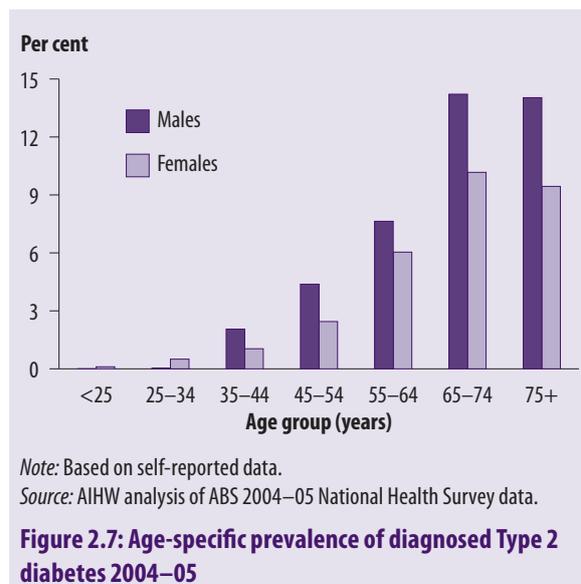
Based on self-reported data from the NHS, Type 2 diabetes accounted for 83% of all diabetes in 2004–05. This corresponds to an estimated 582,800 (3%) Australians.

Prevalence estimates based on measured data are much higher than those based on self-reports because they include people with undiagnosed diabetes. In addition, the figures from the NHS apply to the whole population, while AusDiab only covers adults aged 25 years and over.

#### Sex and age

As the vast majority of diabetes cases detected in AusDiab were Type 2, the age and sex patterns shown in the overall prevalence results earlier in this chapter also hold for Type 2 diabetes. There was a higher prevalence of Type 2 diabetes in males than females (age-standardised rate of 7.6% compared with 6.5%). Type 2 diabetes increased with age: being highest in the age group 75 years and over (22%).

Based on 2004–05 NHS data, the age-standardised prevalence of self-reported Type 2 diabetes in the general population was 1% higher for males than for females: 3% and 2%, respectively. The proportion of people reporting Type 2 diabetes increased with age, and the highest prevalence rates appeared for those aged 65 years and over (Figure 2.7).



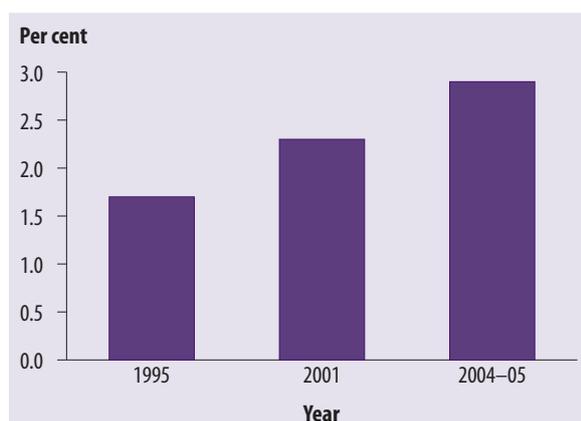
#### Trends

The prevalence of diagnosed Type 2 diabetes has increased substantially in recent years. From the National Health Surveys, it has increased from

Table 2.3: Risk factors for Type 2 diabetes

Demographic	Genetic	Lifestyle and behavioural	Biomedical/metabolic
Age	Ethnicity	Diet	Intra-uterine growth retardation
Urbanisation	Family history	Obesity (especially abdominal)	Previous gestational diabetes
	Specific genes have been identified	Physical inactivity	Impaired sugar regulation (i.e. impaired fasting sugar, impaired sugar tolerance)
		Foetal nutrition	

1.7% of the Australian population in 1995 to 2.9% in 2004–05 (Figure 2.8). This increase in the age-standardised rate reflects a likely increase in the incidence of Type 2 diabetes, better survival for people with Type 2 diabetes, and also potentially an increase in the detection of the disease (Colagiuri et al. 2005).



Note: Based on self-reported data.

Sources: AIHW analysis of ABS 1995, 2001 and 2004–05 National Health Survey data.

**Figure 2.8: Trends in the prevalence of diagnosed Type 2 diabetes, 1995 to 2004–05**

Less information is available on trends in the prevalence of Type 2 diabetes including the undiagnosed cases. As the majority of diabetes cases are Type 2, it is likely that much of the increase in overall diabetes between 1983 and 1999–2000 described in the prevalence section earlier in this chapter (from 1.1 to 2.9% for people aged 25–64 years living in capital cities) was in the Type 2 subgroup.

## Incidence

The NDR provides information on the incidence of the subset of Type 2 diabetes that is insulin-treated. In 2005, around 11,400 with Type 2 diabetes used insulin to treat their condition for the first time. Just over 2,700 of these were also newly diagnosed Type 2 cases in that year.

The 5-year follow-up AusDiab study provides an estimate of diabetes incidence (Barr et al. 2006). Results for Type 1 and Type 2 diabetes were not reported separately as the vast majority of cases were for Type 2 diabetes. Thus the results outlined in the prevalence of diabetes section earlier in this chapter are largely about Type 2 diabetes.

## Gestational diabetes

Gestational diabetes is diabetes first diagnosed during pregnancy (gestation). It may disappear after pregnancy, but signals a high risk of diabetes occurring later in life.

### Risk factors

Pregnant women who are at higher risk of developing gestational diabetes include:

- older mothers (risk increases with age)
- those with a history of sugar intolerance or gestational diabetes
- those from certain high-risk ethnic groups, such as Indigenous Australians, and people from the Indian subcontinent, the Pacific Islands, Asia or the Middle East
- women with a family history of diabetes
- women with a history of ‘large for gestational age’ babies
- women who are overweight or obese before their pregnancy.

Gestational diabetes may occur in women who have no identifiable risk factors, which is why the Australasian Diabetes in Pregnancy Society (ADIPS) recommends screening for all women.

### How many Australian women are affected by gestational diabetes?

The Australasian Diabetes in Pregnancy Society estimates that about 5% of pregnant women are affected by gestational diabetes (ADIPS 2007).

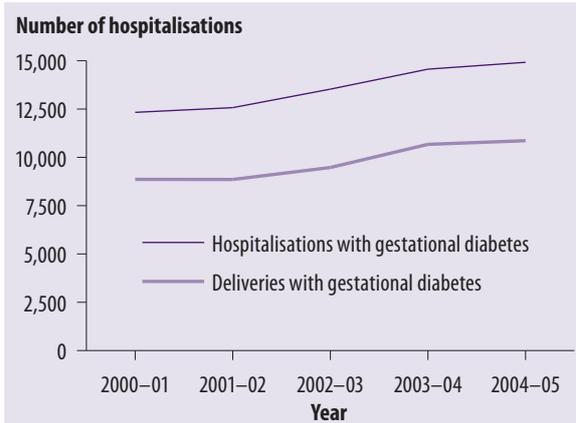
Based on self-reported data from the NHS, gestational diabetes accounted for approximately 3% of all diabetes identified in 2004–05 NHS; this corresponds to an estimated 7,930 Australian women affected by the disease at the time of the survey.

Another assessment of the number of women diagnosed with gestational diabetes can be obtained using the AIHW National Hospital Morbidity Database. During 2004–05, around 10,900 women giving birth in hospital also had diagnosed gestational diabetes, which is 4.2% of hospital births in that year. A third (32.7%) of these gestational diabetes cases were

in women over the age of 35 years, while only one-fifth (19.9%) of the deliveries occurred in this age group. As not all pregnant women are screened for gestational diabetes, it is likely that a proportion of cases remains undiagnosed, and therefore would not be included in these figures.

## Trends

Trends in hospitalisations indicate that gestational diabetes as any diagnosis has increased over the last 5 years, from 12,300 in 2000–01 to 14,900 in 2004–05 (Figure 2.9). Similarly, the number of deliveries in hospital where gestational diabetes was diagnosed has increased over the same period. In 2000–01, 8,900 women delivering babies in hospital had diagnosed gestational diabetes (3.6% of these births). By 2004–05, this had increased to almost 10,900 (4.2% of births in hospital). Some of this increase is likely to be due to the increasing average age of mothers (Laws et al. 2006).



*Note:* Gestational diabetes is classified according to ICD-10-AM code O244, for principal or additional diagnosis. Deliveries are classified according to ICD-10-AM code Z37.

*Source:* AIHW National Hospital Morbidity Database.

**Figure 2.9: Trends in hospitalisations with gestational diabetes, 2000–01 to 2004–05**



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