1 Introduction

The National Diabetes Register (NDR) is a register of people living in Australia with insulin-treated diabetes. It holds information on people with all forms of insulin-treated diabetes, including Type 1, Type 2, gestational, and other types of diabetes.

The NDR was established in 1999 as a result of a recommendation of the National Diabetes Strategy and Implementation Plan to establish a national diabetes register for people with insulin-treated diabetes (Colagiuri et al. 1998). The NDR is managed by staff of the National Centre for Monitoring Diabetes at the Australian Institute of Health and Welfare (AIHW) and largely funded by the Australian Government Department of Health and Ageing (DoHA).

People are eligible to be on the NDR only if they use insulin to treat their diabetes and their insulin use started on or after 1 January 1999. The decision to establish a register based on insulin-treatment rather than type of diabetes was made because a person's type of diabetes is not as easily defined as a person's insulin-using status (AIHW 2001).

The NDR has two main data sources:

- the National Diabetes Services Scheme database (NDSS), which is the primary source of ascertainment and is administered by Diabetes Australia
- the Australasian Paediatric Endocrine Group's (APEG) state and territory databases, which are a secondary source of ascertainment for 0–14 year olds.

The NDSS subsidises the supply of insulin syringes, insulin infusion pump consumables and diagnostic reagents (blood and urine testing strips) to registered persons with diabetes (DoHA 2005). The NDSS began in 1987 and is funded by the Australian Government. It is administered by Diabetes Australia Ltd on behalf of the Australian Government, and coordinates the supply of subsidised products in all states and territories.

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

Improvement in NDSS ascertainment for the NDR means that notification of new cases of insulin-treated diabetes from the NDSS will increase from August 2003. It is therefore important to consider the impact of the improved NDSS ascertainment when interpreting trends over time in the incidence of insulin-treated diabetes based on data from the NDR. That is, it is important to be able to distinguish the effect of the NDSS form change on any increase in incidence from the underlying trend.

2 Purpose

The purpose of this information paper is to describe the impact of the phasing in of the new NDSS registration form since August 2003 on NDSS ascertainment for the NDR so that the data can be appropriately used and interpreted, particularly with respect to comparisons over time.

The specific aims are to examine:

1. the change in NDSS ascertainment rates for the NDR over time to help in the interpretation of trends in the incidence of insulin-treated diabetes based on data from the NDR
2. whether there are any differences between NDR-eligible NDSS registrants who are on the NDR (that is, consenters) and those who are not on the NDR (that is, non-consenters) that might bias interpretation of patterns and trends based on NDR data.

The following sections describe the NDSS, the methodology used to compare NDSS ascertainment rates for the NDR before and after the 2003 NDSS form change, and the results of this analysis.

It is important to note that as NDR data sourced from APEG are not affected by the changed NDSS consent arrangements for the NDR, this information paper examines only ascertainment for the NDR from the NDSS.

3 Methods

3.1 Data source

The data set used for the analysis reported in this information paper was a de-identified file provided by Diabetes Australia that contained information on all NDSS registrants who had registered with the NDSS between 1987 and 1 July 2005. The file included all the variables held on the NDR except for names and addresses.

Of the 843,356 NDSS registrants on the de-identified file, 120,739 were identified as being eligible to be on the NDR based on the fact that they had begun using insulin to manage their diabetes on or after 1 January 1999 (see Appendix B for a description of the algorithm used to identify whether an NDSS registrant was eligible to be on the NDR). After removing duplicate records, the file contained de-identified information for 120,561 NDSS registrants who were eligible to be on the NDR.

3.2 Old and new NDSS registration forms

The de-identified file contained a variable to identify different versions of the NDSS registration form. People registered on the new version of the NDSS form introduced from July 2003 were allocated a form identifier of 'DA105-2170', whereas those registered on an older version of the NDSS registration form were given a form identifier of either 'F70-0047' (if the registration form was entered onto the NDSS database after 21 July 2003) or blank (if the registration form was entered onto the NDSS database on or before 21 July 2003). As all registrants with a blank or 'F70-0047' form identifier had registered on an NDSS form that required separate consent to be given before they could be included on the NDR, these two groups were combined in the analysis undertaken for this paper. That is, for the purposes of this information paper:

- NDSS registrants with a form identifier of 'DA105-2170' were classified as having registered on a 'new' NDSS form (that is, separate NDR consent section removed)
- NDSS registrants with a blank or 'F70-0047' form identifier were classified as having registered on an 'old' NDSS form (that is, separate NDR consent section included).

The majority (69.5%) of NDSS registrants do not use insulin to manage their diabetes (Diabetes Australia 2005). However, some registrants who do not use insulin when they first register on the NDSS may subsequently start to use insulin to manage their diabetes at a later time and thus become eligible to be on the NDR. That is, if a registrant starts to use insulin at any time on or after 1 January 1999, regardless of when he or she first registered with the NDSS, then that person is eligible to be included on the NDR. When existing NDSS registrants inform Diabetes Australia that they now need to use insulin, the Diabetes Australia state office sends out a 'Change to insulin request' form. If an existing NDSS registrant does not inform Diabetes Australia of the change to insulin, a flag is triggered on the NDSS system if that registrant tries to purchase syringes. Diabetes Australia will then send out the 'Change to insulin request' form.

The 'Change to insulin request' form allows for the change in insulin status to be verified in any one of three ways:

1. a signed NDSS registration form with the relevant sections completed and signed by a doctor or credentialled diabetes educator (CDE)
2. a letter from a health professional, including CDEs, on official letterhead, confirming the need for insulin
3. a copy of the prescription for insulin or a repeat.

If option 1 (that is, a signed registration form with the relevant sections completed and signed by the registrant's doctor or CDE) were used to verify a change of insulin status, the version of the registration form used would depend on the version in use at the time the registrant started using insulin. For example, people who registered with the NDSS before July 2003 but did not start to use insulin until after July 2003 would probably have completed a 'new' NDSS form (that is, the form introduced in late July 2003) as verification of their change of insulin status; whereas people who registered with the NDSS in 1985 but did not start to use insulin until 2001 would have completed an 'old' version of NDSS form as verification of their change of insulin status. As the 'old' versions of the form cease to be used for NDSS registration, only 'new' forms should be used to notify a change of insulin status to further improve NDSS ascertainment for the NDR.

3.3 NDSS ascertainment for the NDR

NDSS ascertainment for the NDR is based on the number of NDR-eligible NDSS registrants who are on the NDR compared with the total number of NDR-eligible NDSS registrants. In other words, NDR-eligible NDSS registrants are defined as being on the NDR if:

- they registered with the NDSS on an 'old' NDSS form and consented to be on the NDR
- they registered with the NDSS on a 'new' NDSS form and did not opt to be removed from the NDR.

Note that to date no NDR-eligible NDSS registrants who registered on a 'new' NDSS form have opted to be removed from the NDR.

3.4 Content of this report

This information paper includes the following sections:

1. For all NDR-eligible NDSS registrants:
    - an examination of the total number of NDSS registrants eligible to be on the NDR (that is, NDR-eligible NDSS registrants) by year of registration and version of the NDSS registration form used (that is, 'old' or 'new')
    - a description of their sociodemographic profile
    - an investigation of ascertainment rates for NDR-eligible NDSS registrants by year of NDSS registration, year of first insulin use, type of diabetes and selected sociodemographic characteristics.

2. A description of the sociodemographic profile and an investigation of ascertainment rates by year of first insulin use and selected sociodemographic characteristics for the following groups:
    - NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes
    - NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes
    - NDR-eligible NDSS registrants with Type 2 diabetes
    - NDR-eligible NDSS registrants with gestational diabetes
    - NDR-eligible NDSS registrants with other types of diabetes.

Note that the data presented for NDR-eligible NDSS registrants with Type 1 diabetes is limited to those who began using insulin before the age of 40 years, as classification of Type 1 diabetes in this group is generally considered to be accurate (AIHW 2001:9).

4 All NDR-eligible NDSS registrants

4.1 Type of registration form by registration year

Table 4.1: Number of NDR-eligible NDSS registrants by year of registration and type of registration form as at 1 July 2005

	Type of NDSS registration form					
Year of registration	Old	New	Total	Old	New	Total
	Number			Per cent		
1987	1,499	20	1,519	98.7	1.3	100.0
1988	1,159	25	1,184	97.9	2.1	100.0
1989	1,431	32	1,463	97.8	2.2	100.0
1990	1,796	48	1,844	97.4	2.6	100.0
1991	2,667	76	2,743	97.2	2.8	100.0
1992	3,351	77	3,428	97.8	2.2	100.0
1993	3,897	111	4,008	97.2	2.8	100.0
1994	4,308	117	4,425	97.4	2.6	100.0
1995	4,934	136	5,070	97.3	2.7	100.0
1996	5,223	178	5,401	96.7	3.3	100.0
1997	5,591	160	5,751	97.2	2.8	100.0
1998	6,881	169	7,050	97.6	2.4	100.0
1999	12,972	208	13,180	98.4	1.6	100.0
2000	12,464	214	12,678	98.3	1.7	100.0
2001	12,228	208	12,436	98.3	1.7	100.0
2002	11,571	224	11,795	98.1	1.9	100.0
2003: 1 January–31 July	6,398	100	6,498	98.5	1.5	100.0
2003: 1 August–31 December	2,672	1,828	4,500	59.4	40.6	100.0
2004	2,224	8,524	10,748	20.7	79.3	100.0
2005: 1 January–1 July	729	4,111	4,840	15.1	84.9	100.0
Total	**103,995**	**16,566**	**120,561**	**86.3**	**13.7**	**100.0**

Source: AIHW analysis of National Diabetes Services Scheme data.

As at 1 July 2005, 86% of all NDSS registrants eligible to be on the NDR had registered with the NDSS on an old NDSS form and 14% had registered on a new NDSS form (Table 4.1). As would be expected, the major change in the version of the NDSS form used for NDSS registration occurred in August 2003, which is consistent with the introduction of the new NDSS registration form and NDR consent arrangements from July 2003. Almost 98% of the 100,473 NDSS registrants eligible to be on the NDR who initially registered before August 2003 were registered on an 'old' NDSS form. The remaining 2% were registered on a 'new' form, which implies that for some reason their NDSS registration details had been updated

since August 2003. In contrast, of those registered on the NDSS from August 2003 (20,088 NDR-eligible NDSS registrants), 28% (5,625 registrants) were registered on an old form and 72% (14,463 registrants) were registered on a new NDSS form. Despite the reduction in the proportion of old form registrations since August 2003, there is still scope to improve NDSS ascertainment for the NDR as 15% of registrations in the first half of 2005 were on an old form.

4.2 Sociodemographic profile

As at 1 July 2005, half of all NDR-eligible NDSS registrants were male and half were female (Table 4.2); however, proportionately more females (52.7%) than males (47.3%) were registered on a new NDSS form.

Almost one quarter (24%) of all NDR-eligible NDSS registrants were aged 0–39 years at first insulin use, and slightly less than 75% were aged 40 years and over. However, of those registered on a new form, 38.5% were aged 0–39 years at first insulin use and 61% were aged 40 years and over.

On average, the time between age at diagnosis and age at first insulin use for NDR-eligible NDSS registrants was 5.0 years. Just over one-quarter (26.5%) of all NDR-eligible NDSS registrants were aged 0–39 years at diagnosis, and 46% were aged 40 years and over. However, age at diagnosis could not be calculated for 27.5% of all NDR-eligible NDSS registrants because date of diagnosis was not recorded on the NDSS registration form. Over 80% of NDR-eligible NDSS registrants for whom date of diagnosis was not recorded were aged 50 years and over at first insulin use. As for age at first insulin use, the distribution of NDR-eligible NDSS registrants by age at diagnosis was somewhat different for those registered on a new NDSS form, with 38.5% aged 0–39 years at diagnosis, 38.3% aged 40 years and over, and 23.2% missing age at diagnosis.

Almost 40% of NDR-eligible NDSS registrants live in New South Wales, whereas the Northern Territory and the Australian Capital Territory are home to only 1% each. The small proportion of NDR-eligible registrants living in the Northern Territory may be due to the fact that in remote areas of the Northern Territory diabetes products may be obtained from remote area pharmacy services that are not part of the NDSS. For example, registration on the NDSS is known to be very low among Aboriginal and Torres Strait Islander peoples living in rural and remote areas because Section 100 of the *National Health Act 1953* covers diabetes products for these people.

One-third (33.1%) of all NDR-eligible NDSS registrants were born in Australia and 29.8% were born overseas. Country of birth was not recorded on the NDSS registration form for 37.1% of all NDR-eligible NDSS registrants. In contrast to all NDR-eligible NDSS registrants, proportionately more of those registered on a new NDSS form were born overseas (40.3%) and proportionately fewer were born in Australia (23.0%).

Table 4.2: Sociodemographic profile of NDSS registrants eligible to be on the NDR as at 1 July 2005

	Old form		New form		All forms	
Sociodemographic characteristic	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Total	**103,995**	**100.0**	**16,566**	**100.0**	**120,561**	**100.0**
Sex						
Male	52,538	50.5	7,841	47.3	60,379	50.1
Female	51,452	49.5	8,725	52.7	60,177	49.9
Unknown	5	0.0	0	0.0	5	0.0
Age at first insulin use (years)						
0–14	4,837	4.7	1,376	8.3	6,213	5.2
15–24	3,297	3.2	935	5.6	4,232	3.5
25–39	14,292	13.7	4,073	24.6	18,365	15.2
40–49	11,894	11.4	1,757	10.6	13,651	11.3
50–59	20,996	20.2	2,606	15.7	23,602	19.6
60–69	22,991	22.1	2,568	15.5	25,559	21.2
70–79	17,824	17.1	2,163	13.1	19,987	16.6
80+	6,274	6.0	990	6.0	7,264	6.0
Not stated	1,590	1.5	98	0.6	1,688	1.4
Age at diagnosis (years)						
0–14	4,935	4.7	1,369	8.3	6,304	5.2
15–24	3,855	3.7	949	5.7	4,804	4.0
25–39	16,741	16.1	4,058	24.5	20,799	17.3
40–49	14,204	13.7	1,856	11.2	16,060	13.3
50–59	15,649	15.0	1,904	11.5	17,553	14.6
60–69	11,528	11.1	1,454	8.8	12,982	10.8
70–79	5,943	5.7	840	5.1	6,783	5.6
80+	1,804	1.7	292	1.8	2,096	1.7
Not stated	29,336	28.2	3,844	23.2	33,180	27.5
State/territory of usual residence						
NSW	39,188	37.7	6,890	41.6	46,078	38.2
Vic	25,585	24.6	3,801	22.9	29,386	24.4
Qld	17,926	17.2	3,105	18.7	21,031	17.4
WA	8,007	7.7	974	5.9	8,981	7.4
SA	8,204	7.9	1,294	7.8	9,498	7.9
Tas	3,059	2.9	120	0.7	3,179	2.6
ACT	1,141	1.1	208	1.3	1,349	1.1
NT	878	0.8	173	1.0	1,051	0.9
Unknown	7	0.0	1	0.0	8	0.0
Region of birth						
Australian-born	36,097	34.7	3,808	23.0	39,905	33.1
Overseas-born	29,308	28.2	6,676	40.3	35,984	29.8
Not stated	38,590	37.1	6,082	36.7	44,672	37.1

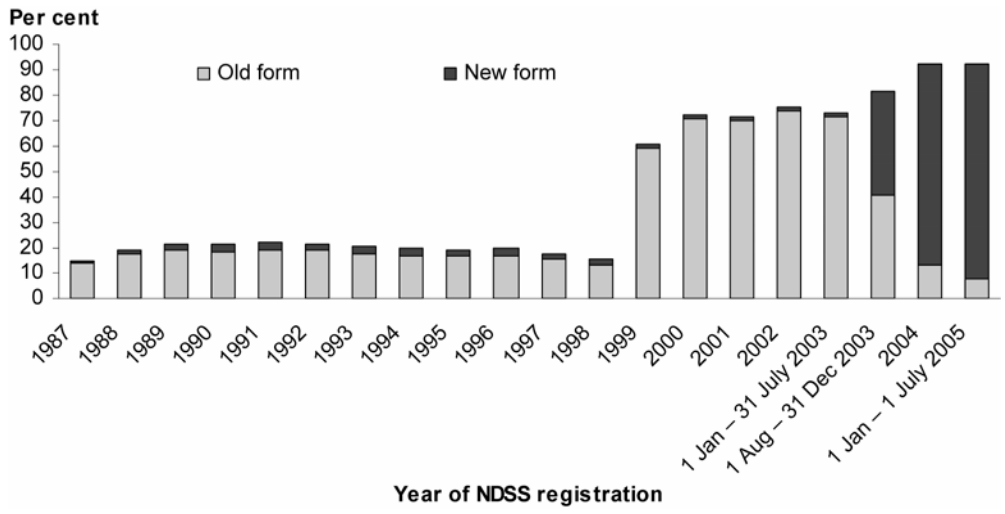
Source: AIHW analysis of National Diabetes Services Scheme data.

4.3 Ascertainment rates

Year of NDSS registration

As stated earlier, the NDSS began in 1987 and the NDR in 1999. However, people registered on the NDSS before 1999 can still be eligible for the NDR if they started using insulin on or after 1 January 1999. Of people who registered with the NDSS before 1999 but subsequently became eligible to be on the NDR, an average of only 19% were actually on the NDR as at 1 July 2005 (Figure 4.1, Tables A1–A4). In contrast, the ascertainment rate for NDR-eligible NDSS registrants registering with the NDSS from 1999 increased from 61% for those registering in 1999 to 93% for those registering over the period from 1 January to 1 July 2005. In particular, ascertainment rates increased substantially from August 2003, from 81% for those registering in August to December 2003 (up from 73% for those registering in January to July 2003) to 92% for those registering in 2004.

These results indicate that the introduction of the new NDSS form and consent arrangements for the NDR from August 2003 have significantly improved NDSS ascertainment rates for the NDR. Further, as old versions of the NDSS registration form cease to be used and the majority of all NDR-eligible NDSS registrants are registered on a new NDSS registration form, ascertainment should approach 100%. However, there remains significant scope for improving the ascertainment among people who initially registered for the NDSS on an old form.



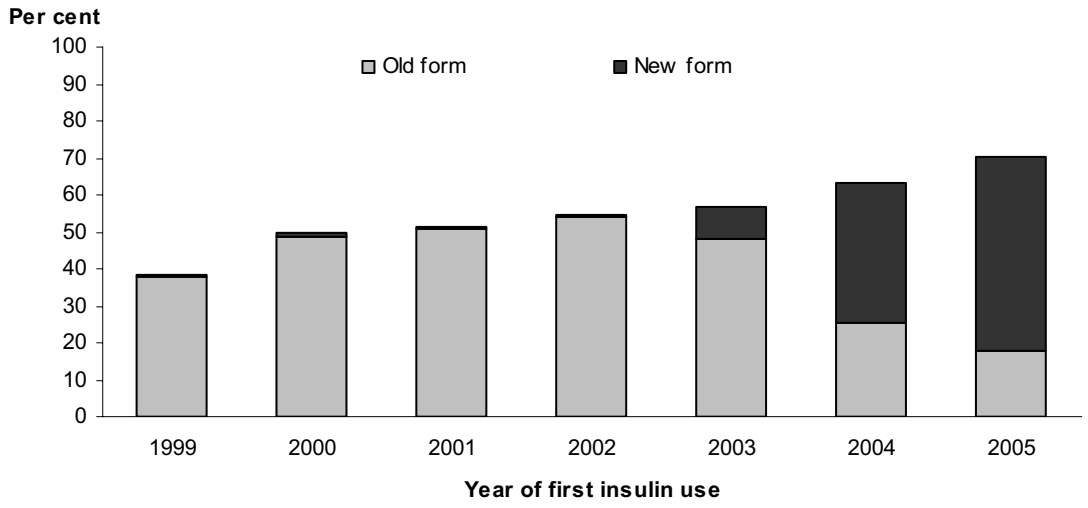
Source: AIHW analysis of National Diabetes Services Scheme data.

Figure 4.1: Proportion of NDR-eligible NDSS registrants who are on the NDR by year of NDSS registration and type of NDSS registration form

Year of first insulin use

The NDSS ascertainment rate for the NDR increased dramatically from 38.5% for people who began using insulin in 1999 to 70.2% for those who began using insulin in 2005 (Figure 4.2, Tables A1–A3 and A5). The biggest absolute increase in the ascertainment rate occurred for those people who began using insulin between 1999 and 2000 (an 11% increase). The ascertainment rate for people who began using insulin between 2000 (49.6%) and 2003 (56.5%) increased only modestly but then increased by around 7% per year for those who began using insulin in 2004 (63.4%) and 2005 (70.2%). This trend reflects the changed NDSS consent arrangements for the NDR from August 2003. However, it is interesting to note that NDSS ascertainment for the NDR was improving, although at a slower rate, even before the introduction of the new NDSS registration form.

As expected, the contribution of the old NDSS form to ascertainment rates for the NDR by year of first insulin use has been falling since 2003 (Figure 4.2). For example, for people who registered with the NDSS in 2003 and also began using insulin in that year, old form registrations contributed 59.6% (in absolute terms) to the overall 76.2% ascertainment rate (Tables A1–A3). In contrast, for people who registered with the NDSS in 2004 and began using insulin in that year, old form registrations only contributed 13.0% to the overall ascertainment rate of 92.4%. However, the impact of the old form is still significant, even for people who began using insulin in 2005.



Source: AIHW analysis of National Diabetes Services Scheme data.

Figure 4.2: Proportion of NDR-eligible NDSS registrants who were on the NDR as at 1 July 2005 by year of first insulin use

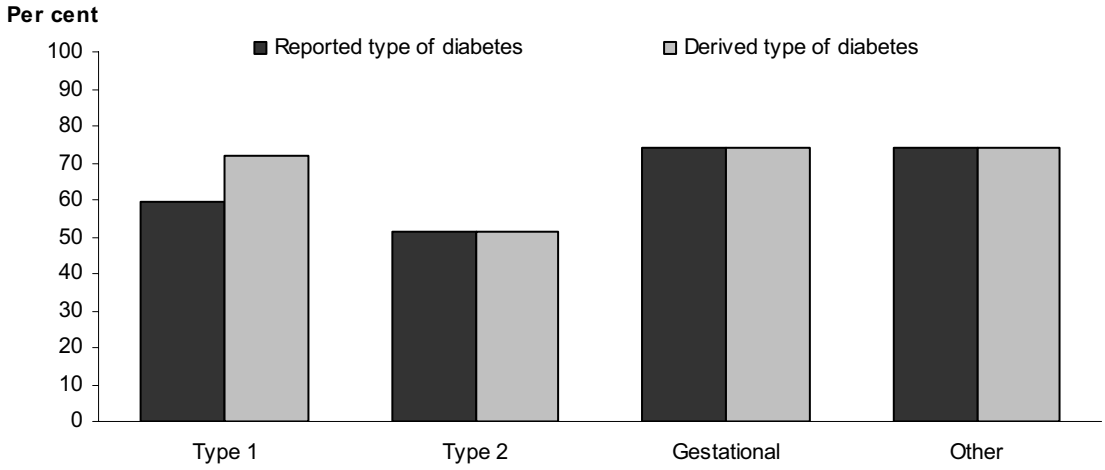
Type of diabetes

Type of diabetes is reported on the NDSS registration form by either a medical practitioner or a credentialled diabetes educator. As at 1 July 2005, 69% of NDR-eligible NDSS registrants were reported as having Type 2 diabetes, 22% as having Type 1 diabetes, 8% as having gestational diabetes and 1% as having other types of diabetes.

For all NDR-eligible NDSS registrants, the NDSS ascertainment rate for the NDR as at 1 July 2005 was highest for women reported as having gestational diabetes mellitus (74.1%) and people reported as having 'Other' types of diabetes (73.9%) (Figure 4.3, Table A6). In contrast, NDSS ascertainment for the NDR was lowest for people reported as having Type 2 diabetes (51.1%).

However, previous research has 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). Therefore, an algorithm has been developed that reclassifies type of diabetes for some NDR-eligible registrants reported as having Type 1 diabetes that was diagnosed after the age of 40 years. The algorithm is based on age at diagnosis and the period of time between diagnosis and first insulin use (see Appendix B for more detail). As at 1 July 2005, 26,763 NDR-eligible NDSS registrants were reported as having Type 1 diabetes. Based on the algorithm, 3,176 of these registrants had their type of diabetes reclassified from Type 1 to Type 2 diabetes. Type of diabetes could not be derived for another 5,225 registrants with reported Type 1 diabetes because of missing information on the NDSS registration form. The reclassification of diabetes type for these 8,401 registrants (that is, 3,176 + 5,225) meant that the number of people considered to actually have Type 1 diabetes reduced from to 26,763 to 18,362 registrants, and this improved the ascertainment rate for Type 1 diabetes from 59.3% for reported Type 1 diabetes to 72.0% for derived Type 1 diabetes (Figure 4.3, Table A7).

An algorithm was also used to reclassify women reported as having gestational diabetes who were aged 50 years and over at diagnosis to Type 2 diabetes (see Appendix B for more detail). In total, 23 women aged 50 years and over at diagnosis who were reported as having gestational diabetes mellitus had their type of diabetes reclassified to Type 2 diabetes. However, this did not change the ascertainment rate for women with gestational diabetes.



Source: AIHW analysis of National Diabetes Services Scheme data.

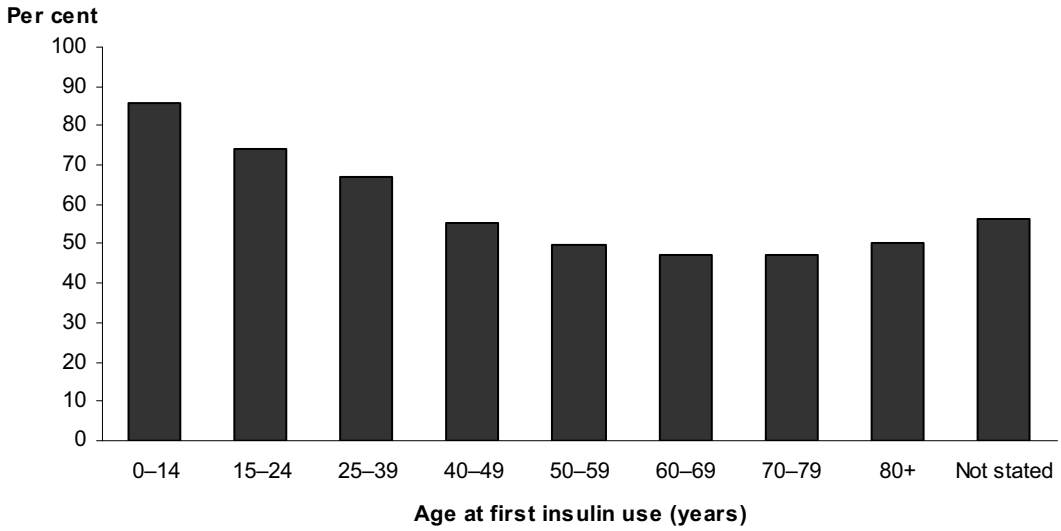
Figure 4.3: Proportion of NDR-eligible NDSS registrants who were on the NDR as at 1 July 2005 by type of diabetes

Sociodemographic characteristics

The overall NDSS ascertainment rate for the NDR for all NDR-eligible NDSS registrants was 54.9% as at 1 July 2005 (Table 4.3). Females were slightly more likely to be on the NDR (55.6%) than males (54.3%).

NDR-eligible NDSS registrants who began using insulin early in life were more likely than older registrants to be on the NDR (Figure 4.4). Ascertainment rates by age at first insulin use were highest for those aged 0–14 years (85.7%), then fell with increasing age of first insulin use to 49.0% for 70–79 year olds but increased slightly again for people aged 80 years and over (50.4%).

The pattern by age at diagnosis generally mirrored that for age at first insulin use but ascertainment rates by age at diagnosis were more than 10% higher than those by age at first insulin use for people aged 40 years and over. It should be remembered, however, that age at diagnosis could not be calculated for 27.5% of NDR-eligible NDSS registrants because date of diagnosis was not recorded on the NDSS form. Of NDR-eligible registrants with missing age at diagnosis, only 23.3% were on the NDR. In contrast, age at first insulin use could not be derived for 1.4% of NDR-eligible NDSS registrants and 56.5% of these people were on the NDR.



Source: AIHW analysis of National Diabetes Services Scheme data.

Figure 4.4: Proportion of NDR-eligible NDSS registrants who were on the NDR as at 1 July 2005 by age at first insulin use

Three-quarters of all NDR-eligible NDSS registrants living in Western Australia were on the NDR. In contrast, only 40% of eligible registrants living in South Australia and the Northern Territory were on the NDR.

NDR-eligible NDSS registrants born in Australia had a higher ascertainment rate for the NDR (72%) than those born overseas (65%). Country of birth was not stated on the NDSS registration form for 37% of NDR-eligible NDSS registrants and, of these registrants, the ascertainment rate for the NDR was only 31%.

For each sociodemographic characteristic examined, a similar pattern of ascertainment was observed for NDR-eligible NDSS registrants registered on an old NDSS form as that observed for all NDR-eligible NDSS registrants (Tables A8–A12). For example, NDR-eligible females registered on an old NDSS form were slightly more likely to be on the NDR (48%) than NDR-eligible males who had registered on an old NDSS form (47%). This is probably not surprising given that as at 1 July 2005, 86% of NDR-eligible registrants had registered with the NDSS on an old NDSS form.

Table 4.3: Ascertainment rates for the NDR as at 1 July 2005 for all NDR-eligible NDSS registrants by selected sociodemographic characteristics

Sociodemographic characteristic	On NDR	Not on NDR	Total	On NDR	Not on NDR	Total
	Number			Per cent		
Total	**66,226**	**54,335**	**120,561**	**54.9**	**45.1**	**100.0**
Sex[(a)]						
Male	32,767	27,612	60,379	54.3	45.7	100.0
Female	33,459	26,718	60,177	55.6	44.4	100.0
Age at first insulin use (years)						
0–14	5,327	886	6,213	85.7	14.3	100.0
15–24	3,141	1,091	4,232	74.2	25.8	100.0
25–39	12,339	6,026	18,365	67.2	32.8	100.0
40–49	7,534	6,117	13,651	55.2	44.8	100.0
50–59	11,786	11,816	23,602	49.9	50.1	100.0
60–69	12,080	13,479	25,559	47.3	52.7	100.0
70–79	9,403	10,584	19,987	47.0	53.0	100.0
80+	3,663	3,601	7,264	50.4	49.6	100.0
Not stated	953	735	1,688	56.5	43.5	100.0
Age at diagnosis (years)						
0–14	5,380	924	6,304	85.3	14.7	100.0
15–24	3,574	1,230	4,804	74.4	25.6	100.0
25–39	14,462	6,337	20,799	69.5	30.5	100.0
40–49	10,466	5,594	16,060	65.2	34.8	100.0
50–59	11,036	6,517	17,553	62.9	37.1	100.0
60–69	7,995	4,987	12,982	61.6	38.4	100.0
70–79	4,234	2,549	6,783	62.4	37.6	100.0
80+	1,333	763	2,096	63.6	36.4	100.0
Not stated	7,746	25,434	33,180	23.3	76.7	100.0
State/territory of usual residence[(b)]						
NSW	23,319	22,759	46,078	50.6	49.4	100.0
Vic	16,398	12,988	29,386	55.8	44.2	100.0
Qld	13,098	7,933	21,031	62.3	37.7	100.0
WA	6,743	2,238	8,981	75.1	24.9	100.0
SA	3,830	5,668	9,498	40.3	59.7	100.0
Tas	1,606	1,573	3,179	50.5	49.5	100.0
ACT	807	542	1,349	59.8	40.2	100.0
NT	421	630	1,051	40.1	59.9	100.0
Region of birth						
Australian-born	28,725	11,180	39,905	72.0	28.0	100.0
Overseas-born	23,459	12,525	35,984	65.2	34.8	100.0
Not stated	14,042	30,630	44,672	31.4	68.6	100.0

(a) Sex was unknown for 5 NDR-eligible NDSS registrants.

(b) State/territory of usual residence was unknown for 8 NDR-eligible NDSS registrants.

Source: AIHW analysis of National Diabetes Services Scheme data.

5 Type 1 diabetes: 0–14 year olds

In this and the following sections, information similar to that presented in Section 3 is provided for NDR-eligible NDSS registrants by specific types of insulin-treated diabetes and age groups at first insulin use. This section profiles 0–14 year olds.

5.1 Sociodemographic profile

Table 5.1: Sociodemographic profile of NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes as at 1 July 2005

	Old form		New form		All forms	
Sociodemographic characteristic	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Total	**4,657**	**100.0**	**1,326**	**100.0**	**5,983**	**100.0**
Sex						
Male	2,381	51.1	681	51.4	3,062	51.2
Female	2,276	48.9	645	48.6	2,921	48.8
Age at first insulin use (years)						
0–4	958	20.6	276	20.8	1,234	20.6
5–9	1,600	34.4	491	37.0	2,091	34.9
10–14	2,099	45.1	559	42.2	2,658	44.4
Age at diagnosis (years)						
0–4	970	20.8	271	20.4	1,241	20.7
5–9	1,577	33.9	470	35.4	2,047	34.2
10–14	2,007	43.1	536	40.4	2,543	42.5
Not stated	103	2.2	49	3.7	152	2.5
State/territory of usual residence						
NSW	1,384	29.7	503	37.9	1,887	31.5
Vic	1,202	25.8	344	25.9	1,546	25.8
Qld	920	19.8	245	18.5	1,165	19.5
WA	514	11.0	65	4.9	579	9.7
SA	374	8.0	115	8.7	489	8.2
Tas	163	3.5	13	1.0	176	2.9
ACT	67	1.4	30	2.3	97	1.6
NT	32	0.7	11	0.8	43	0.7
Unknown	1	0.0	0	0.0	1	0.0
Region of birth						
Australian-born	3,194	68.6	434	32.7	3,628	60.6
Overseas-born	385	8.3	214	16.1	599	10.0
Not stated	1,078	23.1	678	51.1	1,756	29.3

Source: AIHW analysis of National Diabetes Services Scheme data.

NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes accounted for 5% of all NDR-eligible NDSS registrants as at 1 July 2005. Over three-quarters (78%) of these registrants had registered with the NDSS on an old form and 22% had registered on a new form.

Proportionately more males (51%) than females (49%) aged 0–14 years at first insulin use were registered on the NDSS and eligible to be on the NDR as at 1 July 2005 (Table 5.1).

One-fifth of NDR-eligible NDSS registrants in this category were aged less than 5 years at first insulin use; 35% were aged 5–9 years and 44% were aged 10–14 years.

The distribution of NDR-eligible NDSS registrants aged 0–14 years with Type 1 diabetes by age at diagnosis was very similar to that by age at first insulin use. This is to be expected given that most children aged 0–14 years with Type 1 diabetes would begin using insulin very soon after diagnosis. Slightly over half (52%) of the 152 registrants for whom age at diagnosis could not be calculated because date of diagnosis was not recorded on the NDSS form were aged 10–14 years at first insulin use.

The majority of these NDR-eligible NDSS registrants (77%) live in New South Wales, Victoria and Queensland, and less than 1% live in the Northern Territory.

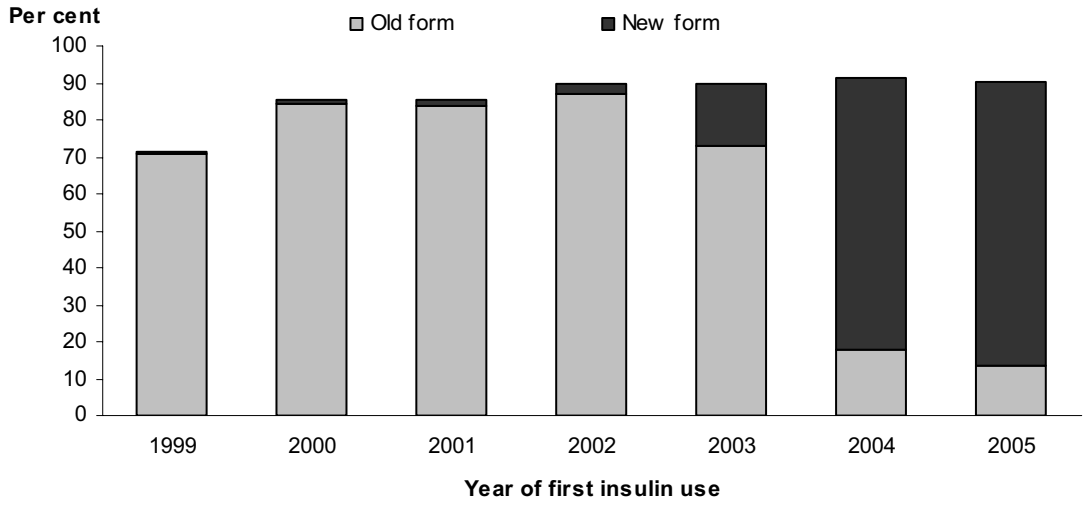
Just over 60% of NDR-eligible NDSS registrants aged 0–14 years with Type 1 diabetes were born in Australia and 10% were born overseas. However, country of birth was not recorded for 29%.

5.2 Ascertainment rates

Year of first insulin use

NDSS ascertainment rates for the NDR by year of first insulin use were much higher for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes than for all NDR-eligible NDSS registrants, with rates ranging from 71.4% in 1999 to 91.2% in 2004 (Figure 5.1, Table A13). The ascertainment rate for 2005 (90.5%) was slightly lower than that for 2004 but is based on only half a year's NDSS registrations. The biggest absolute increase in the ascertainment rate occurred for children who began using insulin between 1999 and 2000 (a 14% increase). Ascertainment rates for children who began using insulin since 2002 (90%) have been fairly stable.

As expected, the contribution of the old NDSS form to ascertainment rates for the NDR by year of first insulin use has been falling since 2003. For example, for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes who began using insulin in 2003, old form registrations contributed 73% (in absolute terms) to the overall 90% ascertainment rate. In contrast, for those who began using insulin in 2005, old form registrations contributed only 13% to the overall ascertainment rate of 91%. However, there are still 10% of people who started using insulin in 2005 who were registered on an old form and are not on the NDR, which remains an area for improvement of ascertainment.



Source: AIHW analysis of National Diabetes Services Scheme data.

Figure 5.1: Proportion of NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes who were on the NDR as at 1 July 2005 by year of first insulin use

Sociodemographic characteristics

The overall ascertainment rate for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes was 86% (Table 5.2). Males and females aged 0–14 years at first insulin use with Type 1 diabetes were equally likely to be on the NDR (86.4% and 85.9% respectively).

Ascertainment rates decreased with increasing age at first insulin use, from 88% for 0–4 year olds to 84% for 10–14 year olds.

Registrants living in Western Australia had the highest ascertainment rate (93%). In contrast, only 72% of registrants living in the Northern Territory were on the NDR.

Those born overseas had a higher ascertainment rate (89%) than those born in Australia (86%), although the number of registrants born overseas was very small compared with the number born in Australia. Country of birth was not stated for 29% of registrants but, of these, the ascertainment rate was 86%.

For each sociodemographic characteristic examined, a similar pattern of ascertainment was generally observed for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes registered on an old NDSS form as that observed for those registered on all forms (Tables A13–A18). For example, children aged 0–4 years at first insulin use who registered on an old NDSS form were more likely to be on the NDR (85%) than children aged 10–14 years at first insulin use who had registered on an old NDSS form (80%).

Table 5.2: Ascertainment rates for the NDR as at 1 July 2005 for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by selected sociodemographic characteristics

Sociodemographic characteristic	On NDR	Not on NDR	Total	On NDR	Not on NDR	Total
	Number			Per cent		
Total	**5,157**	**826**	**5,983**	**86.2**	**13.8**	**100.0**
Sex						
Male	2,647	415	3,062	86.4	13.6	100.0
Female	2,510	411	2,921	85.9	14.1	100.0
Age at first insulin use (years)						
0–4	1,087	147	1,234	88.1	11.9	100.0
5–9	1,836	255	2,091	87.8	12.2	100.0
10–14	2,234	424	2,658	84.0	16.0	100.0
State/territory of usual residence[(a)]						
NSW	1,621	266	1,887	85.9	14.1	100.0
Vic	1,287	259	1,546	83.2	16.8	100.0
Qld	1,037	128	1,165	89.0	11.0	100.0
WA	536	43	579	92.6	7.4	100.0
SA	410	79	489	83.8	16.2	100.0
Tas	150	26	176	85.2	14.8	100.0
ACT	84	13	97	86.6	13.4	100.0
NT	31	12	43	72.1	27.9	100.0
Region of birth						
Australian-born	3,119	509	3,628	86.0	14.0	100.0
Overseas-born	532	67	599	88.8	11.2	100.0
Not stated	1,506	250	1,756	85.8	14.2	100.0

(a) State/territory of usual residence was unknown for 1 NDR-eligible NDSS registrant.

Source: AIHW analysis of National Diabetes Services Scheme data.

6 Type 1 diabetes: 15–39 year olds

6.1 Sociodemographic profile

NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes accounted for 6% of all NDR-eligible NDSS registrants as at 1 July 2005. Of these registrants 83% had registered with the NDSS on an old NDSS registration form and 17% on a new form.

Proportionately more males (58%) than females (42%) aged 15–39 years at first insulin use with Type 1 diabetes were registered on the NDSS and eligible to be on the NDR as at 1 July 2005 (Table 6.1).

The distribution of NDR-eligible NDSS registrants by age at first insulin use was fairly evenly distributed with approximately 20% of registrants falling into each 5-year age grouping.

The distribution of NDR-eligible NDSS registrants by age at diagnosis was fairly similar to that by age at first insulin use for those aged less than 25 years at diagnosis, but there were proportionately fewer registrants in each age group at diagnosis for those aged 25–39 years. Over three-quarters (78%) of those for whom age at diagnosis could not be determined because date of diagnosis was not recorded on the NDSS form were aged 25–39 years at first insulin use.

The majority of NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes (76%) live in New South Wales, Victoria and Queensland, and only 1% live in the Northern Territory.

One-fifth of registrants in this category were born overseas compared with 47% born in Australia. Country of birth was not recorded for 34% of NDR-eligible NDSS registrants.

6.2 Ascertainment rates

Year of first insulin use

Ascertainment rates by year of first insulin use for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes ranged from 48% in 1999 to 79% in 2005 (Figure 6.1, Table A19). Although these rates were lower than the corresponding rates for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes, they were higher than the rates for all NDR-eligible NDSS registrants. The biggest absolute increase in the ascertainment rate occurred for those people who began using insulin between 1999 and 2000 (a 19% increase), followed by a 5% increase between 2003 and 2004.

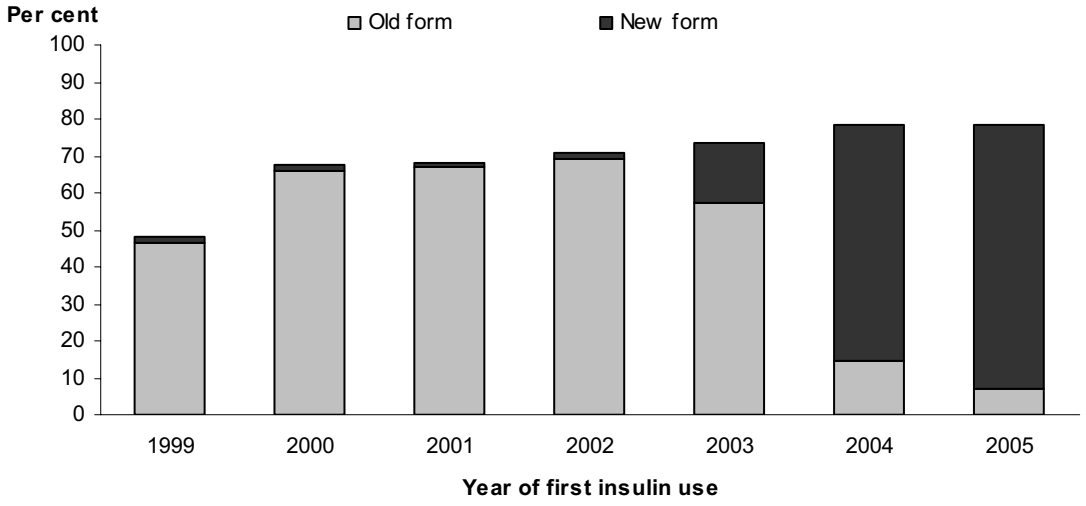
As expected, the contribution of the old NDSS form to ascertainment rates by year of first insulin use has been falling since 2003. For example, for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes who began using insulin in 2003, old form registrations contributed 57% (in absolute terms) to the overall 74% ascertainment rate. In contrast, for those who began using insulin in 2005, old form registrations contributed

only 7% to the overall ascertainment rate of 79%. However, there are still 21% of people who started using insulin in 2005 who were registered on an old form and are not on the NDR, which remains an area for improvement of ascertainment.

Table 6.1: Sociodemographic profile of NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes as at 1 July 2005

	Old form		New form		All forms	
Sociodemographic characteristic	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Total	**6,122**	**100.0**	**1,291**	**100.0**	**7,413**	**100.0**
Sex						
Male	3,474	56.7	832	64.4	4,306	58.1
Female	2,648	43.3	459	35.6	3,107	41.9
Age at first insulin use (years)						
15–19	1,267	20.7	312	24.2	1,579	21.3
20–24	1,087	17.8	283	21.9	1,370	18.5
25–29	1,303	21.3	254	19.7	1,557	21.0
30–34	1,267	20.7	248	19.2	1,515	20.4
35–39	1,198	19.6	194	15.0	1,392	18.8
Age at diagnosis (years)						
0–4	20	0.3	5	0.4	25	0.3
5–9	24	0.4	8	0.6	32	0.4
10–14	48	0.8	9	0.7	57	0.8
15–19	1,235	20.2	303	23.5	1,538	20.7
20–24	1,050	17.2	273	21.1	1,323	17.8
25–29	1,127	18.4	236	18.3	1,363	18.4
30–34	1,022	16.7	202	15.6	1,224	16.5
35–39	719	11.7	159	12.3	878	11.8
Not stated	877	14.3	96	7.4	973	13.1
State/territory of usual residence						
NSW	1,817	29.7	447	34.6	2,264	30.5
Vic	1,516	24.8	306	23.7	1,822	24.6
Qld	1,245	20.3	273	21.1	1,518	20.5
WA	654	10.7	115	8.9	769	10.4
SA	521	8.5	102	7.9	623	8.4
Tas	209	3.4	11	0.9	220	3.0
ACT	102	1.7	22	1.7	124	1.7
NT	58	0.9	15	1.2	73	1.0
Region of birth						
Australian-born	3,173	51.8	305	23.6	3,478	46.9
Overseas-born	1,089	17.8	355	27.5	1,444	19.5
Not stated	1,860	30.4	631	48.9	2,491	33.6

Source: AIHW analysis of National Diabetes Services Scheme data.



Source: AIHW analysis of National Diabetes Services Scheme data.

Figure 6.1: Proportion of NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes who were on the NDR as at 1 July 2005 by year of first insulin use

Sociodemographic characteristics

The overall ascertainment rate for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes was 67% (Table 6.2). Males were considerably more likely to be on the NDR (73%) than females (59%).

Ascertainment rates decreased with increasing age at first insulin use, from 77% for 15–19 year olds to 57% for 35–39 year olds.

Registrants living in Western Australia (79%) and the Australian Capital Territory (74%) had the highest ascertainment rates, whereas those living in Tasmania (54%), the Northern Territory (55%) and South Australia (56%) had the lowest ascertainment rates.

Australian-born NDR-eligible NDSS registrants were more likely to be on the NDR (75%) than those born overseas (72%). Just over half of NDR-eligible NDSS registrants for whom country of birth was not recorded on the NDSS form were on the NDR (53%).

For each sociodemographic characteristic examined, a similar pattern of ascertainment was generally observed for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes registered on an old NDSS form as that observed for all those registrants on all forms (Tables A19–A24). For example, males registered on an old NDSS form were more likely to be on the NDR (66%) than females who had registered on an old NDSS form (52%).

Table 6.2: Ascertainment rates for the NDR as at 1 July 2005 for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by selected sociodemographic characteristics

Sociodemographic characteristic	On NDR	Not on NDR	Total	On NDR	Not on NDR	Total
	Number			Per cent		
Total	**4,967**	**2,446**	**7,413**	**67.0**	**33.0**	**100.0**
Sex						
Male	3,131	1,175	4,306	72.7	27.3	100.0
Female	1,836	1,271	3,107	59.1	40.9	100.0
Age at first insulin use (years)						
15–19	1,219	360	1,579	77.2	22.8	100.0
20–24	996	374	1,370	72.7	27.3	100.0
25–29	1,003	554	1,557	64.4	35.6	100.0
30–34	960	555	1,515	63.4	36.6	100.0
35–39	789	603	1,392	56.7	43.3	100.0
State/territory of usual residence						
NSW	1,492	772	2,264	65.9	34.1	100.0
Vic	1,208	614	1,822	66.3	33.7	100.0
Qld	1,060	458	1,518	69.8	30.2	100.0
WA	610	159	769	79.3	20.7	100.0
SA	346	277	623	55.5	44.5	100.0
Tas	119	101	220	54.1	45.9	100.0
ACT	92	32	124	74.2	25.8	100.0
NT	40	33	73	54.8	45.2	100.0
Region of birth						
Australian-born	2,607	871	3,478	75.0	25.0	100.0
Overseas-born	1,043	401	1,444	72.2	27.8	100.0
Not stated	1,317	1,174	2,491	52.9	47.1	100.0

Source: AIHW analysis of National Diabetes Services Scheme data.

7 Type 2 diabetes

The data for Type 2 diabetes presented in this section are based on derived type of diabetes and not reported type of diabetes. That is, the data include people reported as having Type 1 diabetes who had their type of diabetes reclassified to Type 2 diabetes based on their age at diagnosis and the period of time between their diagnosis and first insulin use (as explained on page 11; see Appendix B for more information). The data also include women reported as having gestational diabetes who were reclassified as having Type 2 diabetes because they were aged 50 years and over at diagnosis (see Appendix B for more information).

7.1 Sociodemographic profile

NDR-eligible NDSS registrants with derived Type 2 diabetes accounted for 72% of all NDR-eligible NDSS registrants as at 1 July 2005. Of these registrants, 88% had registered with the NDSS on an old NDSS registration form and 12% on a new form.

Proportionately more males (54%) than females (46%) with derived Type 2 diabetes were registered on the NDSS and eligible to be on the NDR as at 1 July 2005 (Table 7.1).

The majority (84%) of eligible registrants with derived Type 2 diabetes were aged between 40 and 79 years of age at first insulin use. Just under 8% were aged less than 40 years at first insulin use and 8% were aged 80 years and over.

On average, the time between age at diagnosis and age at first insulin use for NDR-eligible NDSS registrants with derived Type 2 diabetes was 6.8 years. Just under 12% of all NDR-eligible NDSS registrants with derived Type 2 diabetes were aged 0–39 years at diagnosis, and 57% were aged 40 years and over. However, age at diagnosis could not be calculated for 31% because date of diagnosis was not recorded on the NDSS registration form. Almost 90% of NDR-eligible NDSS registrants for whom date of diagnosis was not recorded were aged 50 years and over at first insulin use.

Almost 40% of NDR-eligible NDSS registrants with derived Type 2 diabetes live in New South Wales, with a further 25% living in Victoria and 18% in Queensland. The Northern Territory and the Australian Capital Territory are home to less than 1% of registrants each.

The proportion of NDR-eligible NDSS registrants with derived Type 2 diabetes who were born overseas was slightly higher (31%) than the proportion born in Australia (30%). However, country of birth was not stated on the NDSS form for 38.6% of NDR-eligible NDSS registrants with derived Type 2 diabetes.

Table 7.1: Sociodemographic profile of NDR-eligible NDSS registrants with derived Type 2 diabetes as at 1 July 2005

	Old form		New form		All forms	
Sociodemographic characteristic	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Total	**76,351**	**100.0**	**10,301**	**100.0**	**86,652**	**100.0**
Sex						
Male	40,944	53.6	5,857	56.9	46,801	54.0
Female	35,404	46.4	4,444	43.1	39,848	46.0
Unknown	3	0.0	0	0.0	3	0.0
Age at first insulin use (years)						
0–14	109	0.1	35	0.3	144	0.2
15–24	435	0.6	124	1.2	559	0.6
25–39	4,920	6.4	921	8.9	5,841	6.7
40–49	9,091	11.9	1,302	12.6	10,393	12.0
50–59	18,597	24.4	2,419	23.5	21,016	24.3
60–69	20,733	27.2	2,450	23.8	23,183	26.8
70–79	16,121	21.1	2,076	20.2	18,197	21.0
80+	5,574	7.3	925	9.0	6,499	7.5
Not stated	771	1.0	49	0.5	820	0.9
Age at diagnosis (years)						
0–14	173	0.2	45	0.4	218	0.3
15–24	891	1.2	150	1.5	1,041	1.2
25–39	7,724	10.1	1,126	10.9	8,850	10.2
40–49	12,443	16.3	1,470	14.3	13,913	16.1
50–59	14,511	19.0	1,765	17.1	16,276	18.8
60–69	10,496	13.7	1,373	13.3	11,869	13.7
70–79	5,181	6.8	788	7.6	5,969	6.9
80+	1,424	1.9	257	2.5	1,681	1.9
Not stated	23,508	30.8	3,327	32.3	26,835	31.0
State/territory of usual residence						
NSW	29,295	38.4	4,239	41.2	33,534	38.7
Vic	19,015	24.9	2,348	22.8	21,363	24.7
Qld	13,179	17.3	1,988	19.3	15,167	17.5
WA	5,755	7.5	671	6.5	6,426	7.4
SA	5,605	7.3	749	7.3	6,354	7.3
Tas	2,157	2.8	85	0.8	2,242	2.6
ACT	710	0.9	110	1.1	820	0.9
NT	629	0.8	110	1.1	739	0.9
Unknown	6	0.0	1	0.0	7	0.0
Region of birth						
Australian-born	23,709	31.1	2,315	22.5	26,024	30.0
Overseas-born	22,748	29.8	4,474	43.4	27,222	31.4
Not stated	29,894	39.2	3,512	34.1	33,406	38.6

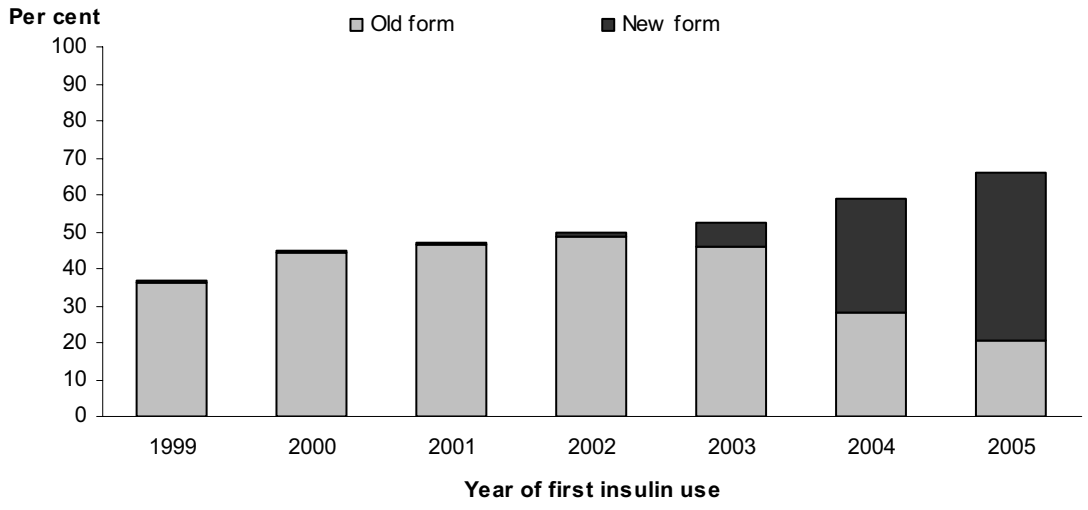
Source: AIHW analysis of National Diabetes Services Scheme data.

7.2 Ascertainment rates

Year of first insulin use

Ascertainment rates by year of first insulin use for NDR-eligible NDSS registrants with derived Type 2 diabetes ranged from 37% in 1999 to 66% in 2005 (Figure 7.1, Table A25). Between 2000 and 2003, the ascertainment rate increased relatively slowly, but increased by 6% (in absolute terms) between 2003 and 2004 and then by a further 7% between 2004 and 2005.

As expected, the contribution of the old NDSS form to ascertainment rates for the NDR by year of first insulin use has been falling since 2003, with just under half of NDR-eligible NDSS registrants with derived Type 2 diabetes registered on an old NDSS form in 2004 and approximately 30% registered on an old NDSS form in 2005. However, there is still a large number of old forms affecting the ascertainment rates for 2005. Notably, 34% of people with Type 2 diabetes who began using insulin in 2005 were registered on an old form and did not consent to be on the NDR.



Source: AIHW analysis of National Diabetes Services Scheme data.

Figure 7.1: Proportion of NDR-eligible NDSS registrants with derived Type 2 diabetes who were on the NDR as at 1 July 2005 by year of first insulin use

Sociodemographic characteristics

The overall ascertainment rate for NDR-eligible NDSS registrants with derived Type 2 diabetes was 51% (Table 7.2). Males were only slightly more likely to be on the NDR (52%) than females (51%).

Table 7.2: Ascertainment rates for the NDR as at 1 July 2005 for NDR-eligible NDSS registrants with derived Type 2 diabetes by selected sociodemographic characteristics

	On NDR	Not on NDR	Total	On NDR	Not on NDR	Total
Sociodemographic characteristic	**Number**			**Per cent**		
Total	**44,508**	**42,144**	**86,652**	**51.4**	**48.6**	**100.0**
Sex[(a)]						
Male	24,319	22,482	46,801	52.0	48.0	100.0
Female	20,189	19,659	39,848	50.7	49.3	100.0
Age at first insulin use (years)						
0–14	100	44	144	69.4	30.6	100.0
15–24	373	186	559	66.7	33.3	100.0
25–39	3,587	2,254	5,841	61.4	38.6	100.0
40–49	5,797	4,596	10,393	55.8	44.2	100.0
50–59	10,741	10,275	21,016	51.1	48.9	100.0
60–69	11,282	11,901	23,183	48.7	51.3	100.0
70–79	8,793	9,404	18,197	48.3	51.7	100.0
80+	3,326	3,173	6,499	51.2	48.8	100.0
Not stated	509	311	820	62.1	37.9	100.0
Age at diagnosis (years)						
0–14	158	60	218	72.5	27.5	100.0
15–24	691	350	1,041	66.4	33.6	100.0
25–39	5,779	3,071	8,850	65.3	34.7	100.0
40–49	8,969	4,944	13,913	64.5	35.5	100.0
50–59	10,195	6,081	16,276	62.6	37.4	100.0
60–69	7,313	4,556	11,869	61.6	38.4	100.0
70–79	3,759	2,210	5,969	63.0	37.0	100.0
80+	1,081	600	1,681	64.3	35.7	100.0
Not stated	6,563	20,272	26,835	24.5	75.5	100.0
State/territory of usual residence[(b)]						
NSW	15,552	17,982	33,534	46.4	53.6	46.4
Vic	11,071	10,292	21,363	51.8	48.2	51.8
Qld	9,066	6,101	15,167	59.8	40.2	59.8
WA	4,842	1,584	6,426	75.4	24.6	75.4
SA	2,195	4,159	6,354	34.5	65.5	34.5
Tas	1,056	1,186	2,242	47.1	52.9	47.1
ACT	448	372	820	54.6	45.4	54.6
NT	275	464	739	37.2	62.8	37.2
Region of birth						
Australian-born	18,270	7,754	26,024	70.2	29.8	70.2
Overseas-born	17,419	9,803	27,222	64.0	36.0	64.0
Not stated	8,819	24,587	33,406	26.4	73.6	26.4

(a) Sex was unknown for 3 NDR-eligible NDSS registrants.

(b) State/territory of usual residence was unknown for 7 NDR-eligible NDSS registrants.

Source: AIHW analysis of National Diabetes Services Scheme data.

Up to 79 years of age, ascertainment rates decreased with increasing age at first insulin use, from 69% for 0–14 year olds to 48% for 70–79 year olds. Just over half of eligible registrants with derived Type 2 diabetes aged 80 years and over at first insulin use were on the NDR.

The pattern by age at diagnosis generally mirrored that for age at first insulin use but ascertainment rates by age at diagnosis were 9–13% higher than those by age at first insulin use for people aged 40 years and over. It should be remembered, however, that age at diagnosis could not be calculated for 31% of NDR-eligible NDSS registrants with derived Type 2 diabetes, because date of diagnosis was not recorded on the NDSS form. Of eligible registrants with missing age at diagnosis, only 25% were on the NDR. In contrast, age at first insulin use could not be derived for 1% of NDR-eligible NDSS registrants with derived Type 2 diabetes and 62% of these people were on the NDR.

Registrants living in Western Australia (75%) had the highest ascertainment rates, and those living in South Australia (35%) and the Northern Territory (37%) had the lowest.

Australian-born NDSS registrants with derived Type 2 diabetes were more likely to be on the NDR (70%) than those born overseas (64%). Only about a quarter (26%) of registrants for whom country of birth was not stated on the NDSS form were on the NDR.

For each sociodemographic characteristic examined, a similar pattern of ascertainment was generally observed for NDR-eligible NDSS registrants with derived Type 2 diabetes registered on an old NDSS form as that observed for all NDR-eligible NDSS registrants with derived Type 2 diabetes (Tables A25–A30). For example, ascertainment rates for NDR-eligible NDSS registrants who registered on an old NDSS form decreased with increasing age at first insulin use from 60% for 0–14 year olds to 42% for 70–79 year olds.

8 Gestational diabetes

8.1 Sociodemographic profile

NDR-eligible NDSS registrants with gestational diabetes accounted for 8%of all NDR-eligible NDSS registrants as at 1 July 2005. Of the NDR-eligible NDSS registrants with gestational diabetes, 70% had registered with the NDSS on an old form and 30% on a new form.

The majority (84%) of NDR-eligible NDSS registrants with gestational diabetes were aged between 25 and 39 years of age at first insulin use (Table 8.1). Just under 7% were aged less than 25 years at first insulin use and 8% were aged 40 years or over. Age at first insulin use could not be calculated for 1% of women with gestational diabetes.

The distribution of NDR-eligible NDSS registrants with gestational diabetes by age at diagnosis was similar to that by age at first insulin use. On average, the time between age at diagnosis and age at first insulin use for NDR-eligible NDSS registrants with gestational diabetes was 6 months.

More than two-fifths of NDR-eligible NDSS registrants with gestational diabetes live in New South Wales (43%), with a further 22% living in Victoria and 18% in Queensland. Only 1% of registrants live in the Northern Territory.

Proportionately more NDR-eligible NDSS registrants with gestational diabetes were born overseas (42%) than were born in Australia (37%). Country of birth was not stated on the NDSS form for 21% of NDR-eligible NDSS registrants with gestational diabetes.

8.2 Ascertainment rates

Year of first insulin use

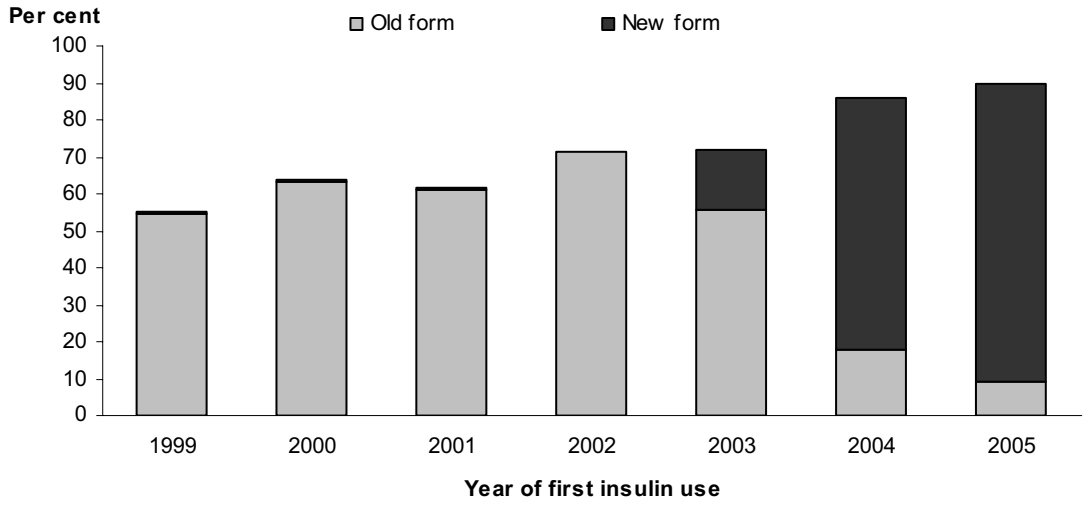
Ascertainment rates for the NDR by year of first insulin use for NDR-eligible NDSS registrants with gestational diabetes ranged from 55% in 1999 to 90% in 2005 (Figure 8.1, Table A31). Between 2000 and 2001, the ascertainment rate decreased slightly from 64% to 62%, but it then increased again to 72% in 2002. Between 2003 and 2004, the ascertainment rate increased by 14% from 72% to 86%.

The contribution of the old NDSS form to ascertainment rates for the NDR by year of first insulin use has been falling since 2003, with 20%of NDR-eligible NDSS registrants with gestational diabetes registered on an old NDSS form in 2004 and 10% registered on an old NDSS form in 2005.

Table 8.1: Sociodemographic profile of NDR-eligible NDSS registrants with gestational diabetes as at 1 July 2005

	Old form		New form		All forms	
Sociodemographic characteristic	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Total (females)	**6,528**	**100.0**	**2,852**	**100.0**	**9,380**	**100.0**
Age at first insulin use (years)						
< 20	54	0.8	24	0.8	78	0.8
20–24	378	5.8	176	6.2	554	5.9
25–29	1,479	22.7	580	20.3	2,059	22.0
30–34	2,314	35.4	1,049	36.8	3,363	35.9
35–39	1,672	25.6	810	28.4	2,482	26.5
40–44	468	7.2	190	6.7	658	7.0
45+	36	0.6	15	0.5	51	0.5
Not stated	127	1.9	8	0.3	135	1.4
Age at diagnosis (years)						
< 20	75	1.1	26	0.9	101	1.1
20–24	439	6.7	174	6.1	613	6.5
25–29	1,591	24.4	569	20.0	2,160	23.0
30–34	2,260	34.6	984	34.5	3,244	34.6
35–39	1,494	22.9	725	25.4	2,219	23.7
40–44	380	5.8	166	5.8	546	5.8
45+	28	0.4	12	0.4	40	0.4
Not stated	261	4.0	196	6.9	457	4.9
State/territory of usual residence						
NSW	2,622	40.2	1,420	49.8	4,042	43.1
Vic	1,490	22.8	588	20.6	2,078	22.2
Qld	1,287	19.7	483	16.9	1,770	18.9
WA	254	3.9	53	1.9	307	3.3
SA	425	6.5	241	8.5	666	7.1
Tas	215	3.3	5	0.2	220	2.3
ACT	163	2.5	38	1.3	201	2.1
NT	72	1.1	24	0.8	96	1.0
Region of birth						
Australian-born	2,900	44.4	592	20.8	3,492	37.2
Overseas-born	2,583	39.6	1,334	46.8	3,917	41.8
Not stated	1,045	16.0	926	32.5	1,971	21.0

Source: AIHW analysis of National Diabetes Services Scheme data.



Source: AIHW analysis of National Diabetes Services Scheme data.

Figure 8.1: Proportion of NDR-eligible NDSS registrants with gestational diabetes who were on the NDR at 1 July 2005 by year of first insulin use

Sociodemographic characteristics

The overall ascertainment rate for the NDR for NDR-eligible NDSS registrants with gestational diabetes was 74% (Table 8.2).

Excluding those whose age at first insulin use was not known, the ascertainment rate for the NDR was lowest for women who began using insulin before the age of 20 years (65%) and highest for those who began using insulin at 45 years and over (84%). Ascertainment rates for the NDR fell with increasing age at first insulin use from 77% to 72% for women who began using insulin between the ages of 20 and 44 years.

NDR-eligible NDSS registrants with gestational diabetes living in Western Australia had the highest ascertainment rates for the NDR (84%), and those living in the Northern Territory (43%) had the lowest.

Australian-born registrants were slightly more likely to be on the NDR (73%) than those born overseas (72%). Interestingly, 81% of NDR-eligible NDSS registrants for whom country of birth was not stated on the NDSS form were on the NDR.

For each sociodemographic characteristic examined, a similar pattern of ascertainment was generally observed for NDR-eligible NDSS registrants with gestational diabetes registered on an old NDSS form as that observed for all registrants with gestational diabetes (Tables A31–A35). For example, of those who registered on an old form, women who began using insulin before the age of 20 years had the lowest ascertainment rate (50%), and those aged 45 years and over had the highest rate (78%).

Table 8.2: Ascertainment rates for the NDR as at 1 July 2005 for NDR-eligible NDSS registrants with gestational diabetes by selected sociodemographic characteristics

	On NDR	Not on NDR	Total	On NDR	Not on NDR	Total
Sociodemographic characteristic	**Number**			**Per cent**		
Total (females)	**6,951**	**2,429**	**9,380**	**74.1**	**25.9**	**100.0**
Age at first insulin use (years)						
< 20	51	27	78	65.4	34.6	100.0
20–24	424	130	554	76.5	23.5	100.0
25–29	1,550	509	2,059	75.3	24.7	100.0
30–34	2,515	848	3,363	74.8	25.2	100.0
35–39	1,827	655	2,482	73.6	26.4	100.0
40–44	474	184	658	72.0	28.0	100.0
45+	43	8	51	84.3	15.7	100.0
Not stated	67	68	135	49.6	50.4	100.0
State/territory of usual residence						
NSW	2,870	1,172	4,042	71.0	29.0	100.0
Vic	1,685	393	2,078	81.1	18.9	100.0
Qld	1,344	426	1,770	75.9	24.1	100.0
WA	259	48	307	84.4	15.6	100.0
SA	467	199	666	70.1	29.9	100.0
Tas	146	74	220	66.4	33.6	100.0
ACT	139	62	201	69.2	30.8	100.0
NT	41	55	96	42.7	57.3	100.0
Region of birth						
Australian-born	2,557	935	3,492	73.2	26.8	100.0
Overseas-born	2,807	1,110	3,917	71.7	28.3	100.0
Not stated	1,587	384	1,971	80.5	19.5	100.0

Source: AIHW analysis of National Diabetes Services Scheme data.

9 Other types of diabetes

Other types of diabetes include certain conditions and syndromes such as genetic defects of beta-cell function; genetic defects of insulin action; diseases of exocrine pancreas; endocrinopathies; drug- or chemical-induced diabetes; infections; uncommon but specific forms of immune-mediated diabetes mellitus; and other genetic syndromes sometimes associated with diabetes (WHO 1999).

9.1 Sociodemographic profile

NDR-eligible NDSS registrants with other types of diabetes accounted for 1%of all NDR-eligible NDSS registrants as at 1 July 2005. Of these registrants, 86% had registered with the NDSS on an old form and 14% on a new form.

Proportionately more males (56%) than females (44%) with other types of diabetes were registered on the NDSS and eligible to be on the NDR as at 1 July 2005(Table 9.1).

The majority (64%) of NDR-eligible NDSS registrants with other types of diabetes were aged between 25 and 59 years of age at first insulin use. One fifth were aged less than 25 years at first insulin use and 13% were aged 70 years and over.

On average, the time between age at diagnosis and age at first insulin use was 1.5 years. The distribution of registrants with other types of diabetes by age at diagnosis was similar to that by age at first insulin use.

Over 80% of registrants live in New South Wales, Victoria and Queensland. Only 1% live in the Northern Territory, 1.7% live in the Australian Capital Territory and 2% live in Tasmania.

Of those registrants for whom country of birth was recorded on the NDSS registration form, just under half (48%) were born in Australia compared with one-third born overseas. However, country of birth was not stated on the NDSS form for 18% of registrants.

9.2 Ascertainment rates

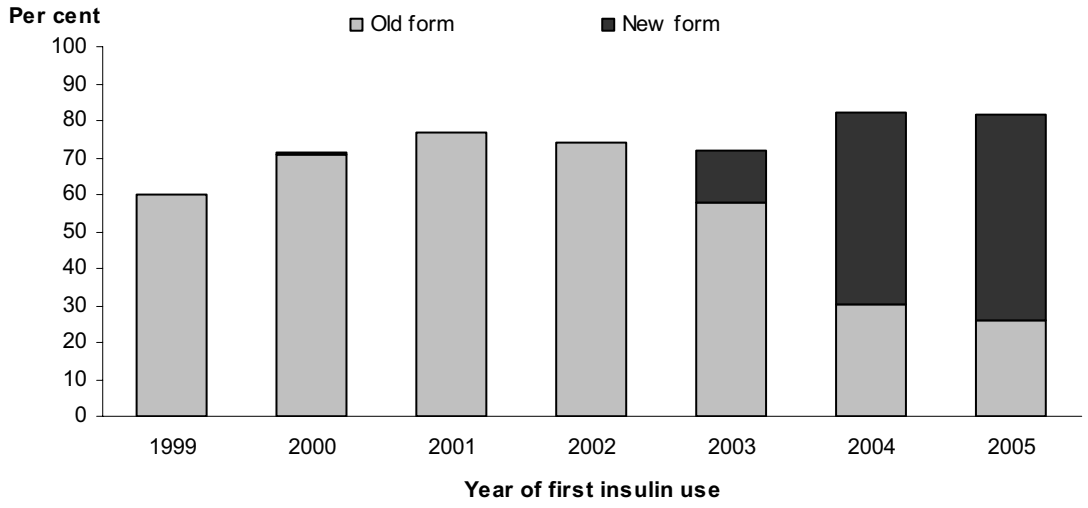
Year of first insulin use

Ascertainment rates for the NDR by year of first insulin use for NDR-eligible NDSS registrants with other types of diabetes ranged from 60% in 1999 to 82% in 2004 (Figure 9.1, Table A37). As expected, the contribution of the old NDSS form to ascertainment rates by year of first insulin use has been falling since 2003, with 30% of registrants with other types of diabetes registered on an old NDSS form in 2004 and 26% registered on an old NDSS form in 2005.

Table 9.1: Sociodemographic profile of NDR-eligible NDSS registrants with other types of diabetes as at 1 July 2005

	Old form		New form		All forms	
Sociodemographic characteristic	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
Total	**809**	**100.0**	**133**	**100.0**	**942**	**100.0**
Sex						
Male	450	55.6	78	58.6	528	56.1
Female	359	44.4	55	41.4	414	43.9
Age at first insulin use (years)						
0–14	71	8.8	14	10.5	85	9.0
15–24	76	9.4	17	12.8	93	9.9
25–39	139	17.2	17	12.8	156	16.6
40–49	107	13.2	25	18.8	132	14.0
50–59	141	17.4	18	13.5	159	16.9
60–69	130	16.1	25	18.8	155	16.5
70–79	77	9.5	10	7.5	87	9.2
80+	27	3.3	6	4.5	33	3.5
Not stated	41	5.1	1	0.8	42	4.5
Age at diagnosis (years)						
0–14	72	8.9	13	9.8	85	9.0
15–24	80	9.9	16	12.0	96	10.2
25–39	149	18.4	16	12.0	165	17.5
40–49	119	14.7	25	18.8	144	15.3
50–59	151	18.7	16	12.0	167	17.7
60–69	119	14.7	23	17.3	142	15.1
70–79	59	7.3	7	5.3	66	7.0
80+	20	2.5	6	4.5	26	2.8
Not stated	40	4.9	11	8.3	51	5.4
State/territory of usual residence						
NSW	405	50.1	33	24.8	438	46.5
Vic	160	19.8	37	27.8	197	20.9
Qld	109	13.5	21	15.8	130	13.8
WA	59	7.3	19	14.3	78	8.3
SA	42	5.2	11	8.3	53	5.6
Tas	17	2.1	2	1.5	19	2.0
ACT	10	1.2	6	4.5	16	1.7
NT	7	0.9	4	3.0	11	1.2
Region of birth						
Australian-born	430	53.2	26	19.5	456	48.4
Overseas-born	270	33.4	44	33.1	314	33.3
Not stated	109	13.5	63	47.4	172	18.3

Source: AIHW analysis of National Diabetes Services Scheme data.



Source: AIHW analysis of National Diabetes Services Scheme data.

Figure 9.1: Proportion of NDR-eligible NDSS registrants with other types of diabetes who were on the NDR as at 1 July 2005 by year of first insulin use

Sociodemographic characteristics

The overall ascertainment rate for the NDR for NDR-eligible NDSS registrants with other types of diabetes was 74% (Table 9.2). Females were slightly more likely to be on the NDR (75%) than males (73%).

Ascertainment was highest for registrants aged 0–24 years at first insulin use and lowest for those aged 80 years and over.

NDR-eligible NDSS registrants living in the Australian Capital Territory (88%) had the highest ascertainment rate, and those living in the Northern Territory had the lowest (64%), although numbers of eligible registrants were quite small in both territories compared with most of the mainland states.

Australian-born registrants were slightly more likely to be on the NDR (73%) than those born overseas (72%). Just over 80% of registrants for whom country of birth was not stated on the NDSS form were on the NDR.

For each sociodemographic characteristic examined, a similar pattern of ascertainment was generally observed for NDR-eligible NDSS registrants with other types of diabetes registered on an old NDSS form as that observed for all registrants with other types of diabetes (Tables A36–A41). For example, NDR-eligible females with other types of diabetes who had registered on an old NDSS form were slightly more likely to be on the NDR (71%) than their male counterparts (69%).

Table 9.2: Ascertainment rates for the NDR as at 1 July 2005 for NDR-eligible NDSS registrants with other types of diabetes by selected sociodemographic characteristics

	On NDR	Not on NDR	Total	On NDR	Not on NDR	Total
Sociodemographic characteristic	**Number**			**Per cent**		
Total	**696**	**246**	**942**	**73.9**	**26.1**	**100.0**
Sex[(a)]						
Male	387	141	528	73.3	26.7	100.0
Female	309	105	414	74.6	25.4	100.0
Age at first insulin use (years)						
0–14	69	16	85	81.2	18.8	100.0
15–24	79	14	93	84.9	15.1	100.0
25–39	108	48	156	69.2	30.8	100.0
40–49	97	35	132	73.5	26.5	100.0
50–59	122	37	159	76.7	23.3	100.0
60–69	117	38	155	75.5	24.5	100.0
70–79	59	28	87	67.8	32.2	100.0
80+	20	13	33	60.6	39.4	100.0
Not stated	25	17	42	59.5	40.5	100.0
State/territory of usual residence[(b)]						
NSW	314	124	438	71.7	28.3	100.0
Vic	145	52	197	73.6	26.4	100.0
Qld	103	27	130	79.2	20.8	100.0
WA	62	16	78	79.5	20.5	100.0
SA	36	17	53	67.9	32.1	100.0
Tas	15	4	19	78.9	21.1	100.0
ACT	14	2	16	87.5	12.5	100.0
NT	7	4	11	63.6	36.4	100.0
Region of birth						
Australian-born	2,557	935	3,492	73.2	26.8	100.0
Overseas-born	2,807	1,110	3,917	71.7	28.3	100.0
Not stated	1,587	384	1,971	80.5	19.5	100.0

Source: AIHW analysis of National Diabetes Services Scheme data.

10 Summary of results and discussion

The results presented in this paper indicate that NDSS ascertainment for the NDR has improved over time from 39% for NDR-eligible NDSS registrants who began using insulin in 1999 to 70% for those who began using insulin in 2005. Further, NDR-eligible NDSS registrants who registered with the NDSS since July 2003 have even higher ascertainment rates ranging from 81% for those registering over the period from August to December 2003 to 93% for those registering in the first half of 2005 (Table A4). This indicates that the introduction of the new NDSS registration form and NDSS consent arrangements for the NDR in July 2003 have significantly improved NDSS ascertainment rates for the NDR. Ascertainment rates for new NDR-eligible NDSS registrants should improve even further as old versions of the NDSS registration form cease to be used for NDSS registration.

However, there is still considerable room for improvement in ascertainment. As at 1 July 2005, the overall ascertainment rate for NDR-eligible NDSS registrants was only 55%. The main reason for this low rate is that most (86%) NDR-eligible NDSS registrants had registered with the NDSS on an old form. Old NDSS forms were previously found to be problematic for recruiting people to the NDR because they contained two separate sections requiring the NDSS registrant's signature.

Although NDSS ascertainment for the NDR is clearly improving markedly for new NDR-eligible NDSS registrants, rates will remain low for existing registrants who registered on an old NDSS form unless some attempt is made to raise ascertainment rates for this group. As stated above, 86% of registrants were registered on an old form as at 1 July 2005. Of these, only 48% are on the NDR (Table A4). One possible mechanism for improving ascertainment for this group is the Diabetes Australia back-capture project targeted at updating information for all NDSS registrants. A pilot of this back-capture project is due to start in late 2006 and will target NDSS registrants who registered with the NDSS between 1 January 1999 and 31 July 2003. The proposed second phase of the back-capture project will start once the results from the first phase have been finalised. As well as possibly improving NDSS ascertainment for the NDR, the back-capture project should also help improve the completeness of NDSS data items, such as date of diagnosis and date of first insulin use, that are crucial variables for the NDR's data quality.

As well as varying by year of first insulin use and year of NDSS registration, NDSS ascertainment for the NDR was found to vary considerably by type of diabetes and sociodemographic characteristics of NDR-eligible NDSS registrants. The major differentials in ascertainment rate are summarised below:

- Ascertainment rates by age at first insulin use were highest for NDR-eligible NDSS registrants aged 0–14 years (85.7%), then fell with increasing age of first insulin use to 49.0% for 70–79 year olds but increased slightly again for people aged 80 years and over (50.4%).
- 71.7% of registrants with Type 1 diabetes were on the NDR compared with only 51.4% of registrants with Type 2 diabetes.
- 74.1% of women with gestational diabetes who were registered on the NDSS were also on the NDR.

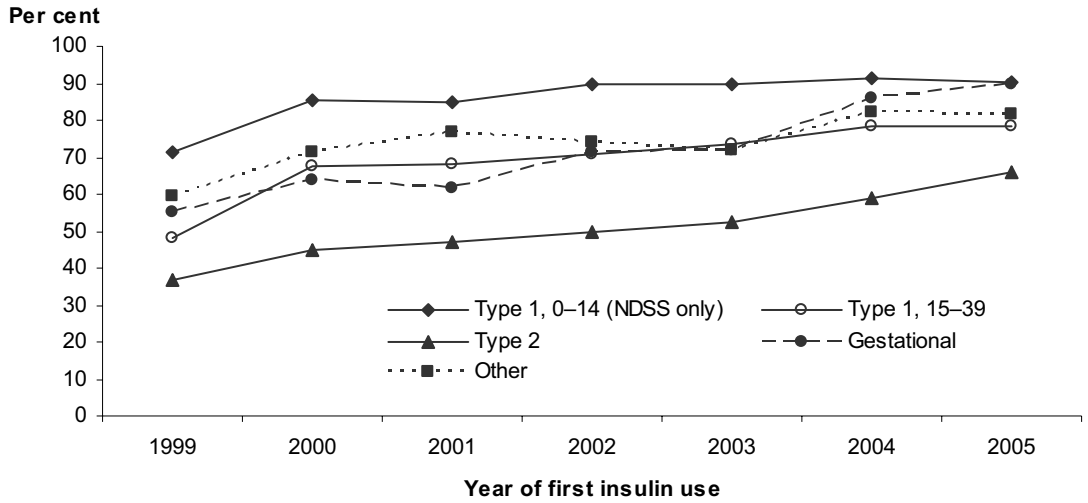
- 86.2% of registrants with Type 1 diabetes who were aged 0–14 years at first insulin use were on the NDR compared with 67.0% of those aged 15–39 years at first insulin use.
- 75.1% of registrants living in Western Australia were on the NDR compared with 40.1% of those living in the Northern Territory and 40.3% of those living in South Australia.
- 72.0% of registrants who were born in Australia were on the NDR compared with 65.2% of those born overseas.

When interpreting patterns in the incidence of insulin-treated diabetes based on data from the NDR it is important to take into consideration the bias resulting from under-ascertainment. To help with this, the major findings with respect to NDSS ascertainment for the NDR for Type 1 and Type 2 diabetes are discussed below.

10.1 Type 1 diabetes: 0–14 years

As at 1 July 2005, 77.8% of NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes had registered with the NDSS on an old registration form. However, since the introduction of the new form, the proportion registered on an old form has fallen considerably from 83.1% for those who began using insulin in 2003 to 22.9% for those who began using insulin in 2005.

The overall NDSS ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes was 86.2%. Since 1999, ascertainment rates in this group had improved from 71.4% for those who began using insulin in 1999 to 90.5% for those who began using insulin in 2005 (Figure 10.1).



Source: AIHW analysis of National Diabetes Services Scheme data.

Figure 10.1: Proportion of NDR-eligible NDSS registrants who were on the NDR as at 1 July 2005 by type of diabetes and year of first insulin use

There was no difference in the ascertainment rate between males and females aged 0–14 years at first insulin use with Type 1 diabetes, with 86% of both NDR-eligible males and NDR-eligible females registered on the NDR. However, older NDR-eligible NDSS registrants were somewhat less likely than their younger counterparts to be on the NDR, with ascertainment rates falling from 88.1% for 0–4 year olds and 5–9 year olds to 84.0% for 10–14 year olds. This finding is interesting given that there was little difference in the proportion registered on an old NDSS form by age (77.6% for 0–4 year olds; 76.5% for 5–9 year olds; and 79.0% for 10–14 year olds), suggesting that the lower NDSS ascertainment rate for the NDR for 10–14 year olds was independent of whether an old or new NDSS form was used.

10.2 Type 1 diabetes: 15–39 years

More than four-fifths (82.6%) of NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes had registered with the NDSS on an old form. However, the proportion of people registered on an old form has reduced markedly since 2003, falling from 83.6% for those who began using insulin in 2003 to 28.5% for those who began using insulin in 2005.

The overall NDSS ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes was 67.0%, which was considerably lower than the ascertainment rate for their counterparts aged 0–14 years at first insulin use. However, ascertainment has improved over time, from 48.0% for those who began using insulin in 1999 to 78.6% for those who began using insulin in 2005.

Ascertainment rates for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes declined with increasing age at first insulin use. In fact, the age-related fall in ascertainment was quite dramatic, from 77.2% for 15–19 year olds to 56.7% for 35–39 year olds. The lower ascertainment rate in the older age groups may, to some extent, reflect the higher proportion of old NDSS form registrations among this group, with 86.1% of 35–39 year olds registered on an old form compared with 80.2% of 15–19 year olds.

Surprisingly, male registrants aged 15–39 years at first insulin use with Type 1 diabetes were significantly more likely to be on the NDR than their female counterparts (72.7% compared with 59.1%). This finding is interesting given that proportionately more registrants aged 15–39 years at first insulin use with Type 1 diabetes were male than female (58.1% compared with 41.9%). That is, not only were there proportionately more NDR-eligible males than females aged 15–39 years at first insulin use with Type 1 diabetes on the NDSS but these NDR-eligible males were more likely than their female counterparts to be on the NDR.

10.3 Type 2 diabetes

As at 1 July 2005, 88.1% of all NDR-eligible NDSS registrants with derived Type 2 diabetes had registered with the NDSS on an old form. However, the proportion of people registering on an old form has reduced markedly since 2003 (from 93.6% for those who began using insulin in 2003 to 54.6% for those who began using insulin in 2005).

The overall NDSS ascertainment for NDR-eligible NDSS registrants with derived Type 2 diabetes was 51.4%, which was considerably lower than the ascertainment rates for 0–14 year olds and 15–39 year olds with Type 1 diabetes. However, ascertainment has improved over

time for registrants with derived Type 2 diabetes from 36.9% for those who began using insulin in 1999 to 65.9% for those who began using insulin in 2005.

Of those with Type 2 diabetes, males were only slightly more likely than females to be on the NDR (52.0% compared with 50.7%). However, ascertainment rates for people with Type 2 diabetes fell with increasing age at first insulin use up to age 79 (from 69.4% for 0–14 year olds to 48.3% for 70–79 year olds) but then increased slightly for people aged 80 years and over (62.1%).

10.4 Summary

The NDSS ascertainment rate for the NDR has improved over time from 39% for NDR-eligible NDSS registrants who began using insulin in 1999 to 70% for those who began using insulin in 2005. Ascertainment rates are even higher for NDSS registrants who registered with the NDSS since July 2003, indicating that the new NDSS registration form and NDSS consent arrangements for the NDR introduced in July 2003 have substantially improved NDSS ascertainment rates for the NDR. The impact of this improvement in ascertainment needs to be considered when interpreting trends and patterns in the incidence of insulin-treated diabetes based on NDR data.

11 Recommendations

There is clearly scope to improve NDSS ascertainment for the NDR. The following actions, aimed at further improving NDSS ascertainment for the NDR, are therefore recommended:

- Old versions of the NDSS registration form should no longer be used for NDSS registration.
- Changes in insulin status for existing NDSS registrants should be notified to the NDSS by completion of a new NDSS registration form.
- NDR-eligible NDSS registrants, who registered with the NDSS on an old form and did not complete the separate NDR consent section, need to be encouraged to join the NDR. Note that Diabetes Australia's proposed back-capture project should help with this.
- Attention should be given to raising the NDSS ascertainment rate for the NDR in all states, but particularly in the Northern Territory and South Australia where ascertainment rates are lower than 50%.
- Appropriate steps should be taken to improve the completeness of NDSS data items, such as date of diagnosis and date of first insulin use, that are crucial variables for the NDR's data quality.