

# **National Diabetes Register**

**Impact of changed consent arrangements  
on ascertainment from the  
National Diabetes Services Scheme**

The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is *better health and wellbeing for Australians through better health and welfare statistics and information.*

Please note that as with all statistical reports there is the potential for minor revisions of data in this report over its life. Please refer to the online version at [www.aihw.gov.au](http://www.aihw.gov.au). Other statistics and information on diabetes and the National Diabetes Register can be found at <http://www.aihw.gov.au/diabetes/index.cfm>.

DIABETES SERIES

Number 5

# **National Diabetes Register**

**Impact of changed consent arrangements  
on ascertainment from the  
National Diabetes Services Scheme**

**December 2006**

Australian Institute of Health and Welfare  
Canberra

AIHW cat. no. CVD 35

© The Australian Institute of Health and Welfare 2006

This work is copyright. Apart from any use as permitted under the *Copyright Act 1968*, no part may be reproduced without prior written permission from the Australian Institute of Health and Welfare. Requests and enquiries concerning reproduction and rights should be directed to the Head, Business Promotion and Media Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601.

This publication is part of the Australian Institute of Health and Welfare's Diabetes Series. A complete list of the Institute's publications is available from the Institute's website <[www.aihw.gov.au](http://www.aihw.gov.au)>.

ISSN: 1444 8033

ISBN-10: 1 74024 6373

ISBN-13: 978 1 74024 637 8

### **Suggested citation**

Australian Institute of Health and Welfare (AIHW) 2006. National Diabetes Register: impact of changed consent arrangements on ascertainment from the National Diabetes Services Scheme. Diabetes Series Number 5. Cat. no. CVD 35. Canberra: AIHW.

### **Australian Institute of Health and Welfare**

Board Chair  
Hon. Peter Collins, AM, QC

Director  
Penny Allbon

Any enquiries about or comments on this publication should be directed to:

National Centre for Monitoring Diabetes  
Australian Institute of Health and Welfare  
GPO Box 570  
Canberra ACT 2601  
Phone: (02) 6244 1000  
Email: [diabetes@aihw.gov.au](mailto:diabetes@aihw.gov.au)

Published by the Australian Institute of Health and Welfare

Printed by Union Offset

# Contents

Acknowledgments.....	vi
Abbreviations.....	vi
Glossary of terms.....	vi
Executive summary .....	1
1 Introduction.....	4
2 Purpose .....	5
3 Methods.....	6
4 All NDR-eligible NDSS registrants.....	9
5 Type 1 diabetes: 0–14 year olds.....	18
6 Type 1 diabetes: 15–39 year olds.....	22
7 Type 2 diabetes .....	26
8 Gestational diabetes.....	31
9 Other types of diabetes .....	35
10 Summary of results and discussion .....	39
11 Recommendations .....	43
Appendix A: Statistical tables.....	44
Appendix B: Definitions and algorithms .....	80
Appendix C: NDSS registration forms.....	82
References.....	89
List of tables .....	90
List of figures .....	93

## Acknowledgments

This information paper has been prepared by Anne-Marie Waters of the Australian Institute of Health and Welfare. Significant contributions were made by Louise Catanzariti, Lynelle Moon and Kathryn Webbie.

Valuable comments on drafts of this information paper were received from Jonathon Shaw, Cathy Teager, David Cummins and Colin Nelson. Their input is gratefully acknowledged.

Funding from the Australian Government Department of Health and Ageing contributed to the production of this information paper.

## Abbreviations

<b>AIHW</b>	Australian Institute of Health and Welfare
<b>APEG</b>	Australasian Paediatric Endocrine Group
<b>CDE</b>	credentialed diabetes educator
<b>NDR</b>	National Diabetes Register
<b>NDSS</b>	National Diabetes Services Scheme

## Glossary of terms

<b>NDR-eligible NDSS registrant</b>	An NDSS registrant who began using insulin to manage his or her diabetes on or after 1 January 1999 and is therefore eligible to be on the NDR.
<b>NDSS ascertainment for the NDR</b>	The number of NDR-eligible NDSS registrants on the NDR compared with the total number of NDR-eligible NDSS registrants.
<b>New NDSS registration form</b>	The NDSS registration form introduced in July 2003 that had the separate NDR consent section removed (see Old NDSS registration form).
<b>Old NDSS registration form</b>	A version of the NDSS registration form that included a separate NDR consent section.

# Executive summary

## Background

The National Diabetes Register (NDR) is a register of people living in Australia with insulin-treated diabetes. People are eligible to be on the NDR only if they use insulin to treat their diabetes and their insulin use began on or after 1 January 1999.

The NDR has two main sources of data:

- the National Diabetes Services Scheme (NDSS) database, administered by Diabetes Australia
- the Australasian Paediatric Endocrine Group's (APEG) state and territory databases.

The NDSS has been operating since 1987. When the NDR was established in 1999, the NDSS registration form was updated to include a section for NDSS registrants to consent to be included on the NDR. In July 2003, Diabetes Australia introduced a new NDSS registration form that changed the NDSS consent arrangements for the NDR by removing the NDR opt-in consent section. This meant that, from August 2003, all people registering for the NDSS on the new form who are eligible to be on the NDR are automatically included on the NDR unless they specifically ask not to be. As a result, NDSS ascertainment for the NDR has improved since August 2003 and therefore notification of new cases of insulin-treated diabetes to the NDR from the NDSS has increased since that time. However, NDSS ascertainment for the NDR has not yet reached 100% for two reasons:

- old versions of the NDSS form are still being used to register people on the NDSS
- changes in insulin status for existing NDSS registrants are not always being notified to the NDSS by completion of a new version of the NDSS registration form.

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.

## Purpose

This information paper describes the phasing in of the new NDSS registration form since August 2003 and the resulting improvement in NDSS ascertainment for the NDR.

When interpreting trends over time in the incidence of insulin-treated diabetes based on data from the NDR, it is important to be able to differentiate between the underlying trend and the effect of the changed NDSS consent arrangements for the NDR on any increase in incidence. Therefore, this information paper also provides information to help users of NDR data understand the impact of the changed consent arrangements on NDSS ascertainment for the NDR so that the data can be appropriately used and interpreted, particularly with respect to comparisons over time.

## Highlights

Of all people registering with the NDSS who were eligible to be on the NDR – that is, people who began using insulin on or after 1 January 1999 – the proportion on the NDR improved from 73% for those registering with the NDSS in January to July 2003 to 81% for those registering in August to December 2003. NDSS ascertainment for the NDR then further improved to 92% for those registering with the NDSS in 2004 and 93% for those registering in the first half of 2005.

Overall, as at 1 July 2005, 55% of NDSS registrants who were eligible to be on the NDR were registered on it. However, NDSS ascertainment rates for the NDR (that is, the proportion of NDSS registrants eligible to be on the NDR who are on it) varied considerably by year of first insulin use, type of diabetes and the sociodemographic characteristics of NDR-eligible NDSS registrants:

- Despite the overall low NDSS ascertainment rate for the NDR, the rate 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.
- 72% of NDR-eligible NDSS registrants with Type 1 diabetes were on the NDR compared with only 51% of NDR-eligible NDSS registrants with Type 2 diabetes.
- 74% of NDR-eligible women with gestational diabetes who were registered on the NDSS were also on the NDR.
- Ascertainment rates by age at first insulin use were highest for NDR-eligible NDSS registrants aged 0–14 years (86%), then fell with increasing age to 49% for 70–79 year olds but increased slightly again for people aged 80 years and over (50%).
- 86% of NDR-eligible NDSS registrants with Type 1 diabetes who were aged 0–14 years at first insulin use were on the NDR compared with 67% of those aged 15–39 years at first insulin use.
- 75% of NDR-eligible NDSS registrants living in Western Australia were on the NDR compared with 40% of those living in the Northern Territory and 40% of those living in South Australia.
- 72% of NDR-eligible NDSS registrants who were born in Australia were on the NDR compared with 65% of those born overseas.

## 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, which are crucial variables for the NDR's data quality.

# 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

Year of registration	Type of NDSS registration form					
	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
<b>Total</b>	<b>103,995</b>	<b>16,566</b>	<b>120,561</b>	<b>86.3</b>	<b>13.7</b>	<b>100.0</b>

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**

Sociodemographic characteristic	Old form		New form		All forms	
	Number	Per cent	Number	Per cent	Number	Per cent
<b>Total</b>	<b>103,995</b>	<b>100.0</b>	<b>16,566</b>	<b>100.0</b>	<b>120,561</b>	<b>100.0</b>
<b>Sex</b>						
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
<b>Age at first insulin use (years)</b>						
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
<b>Age at diagnosis (years)</b>						
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
<b>State/territory of usual residence</b>						
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
<b>Region of birth</b>						
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

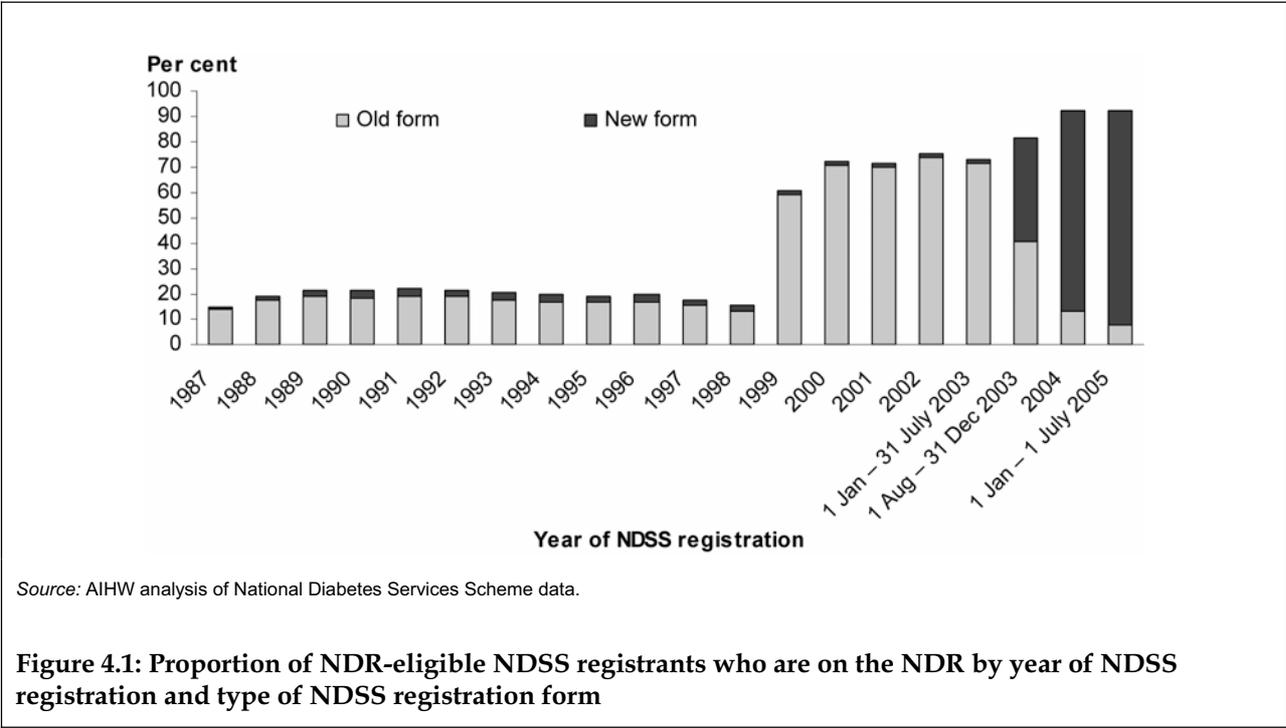
Source: AIHW analysis of National Diabetes Services Scheme data.

### 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.

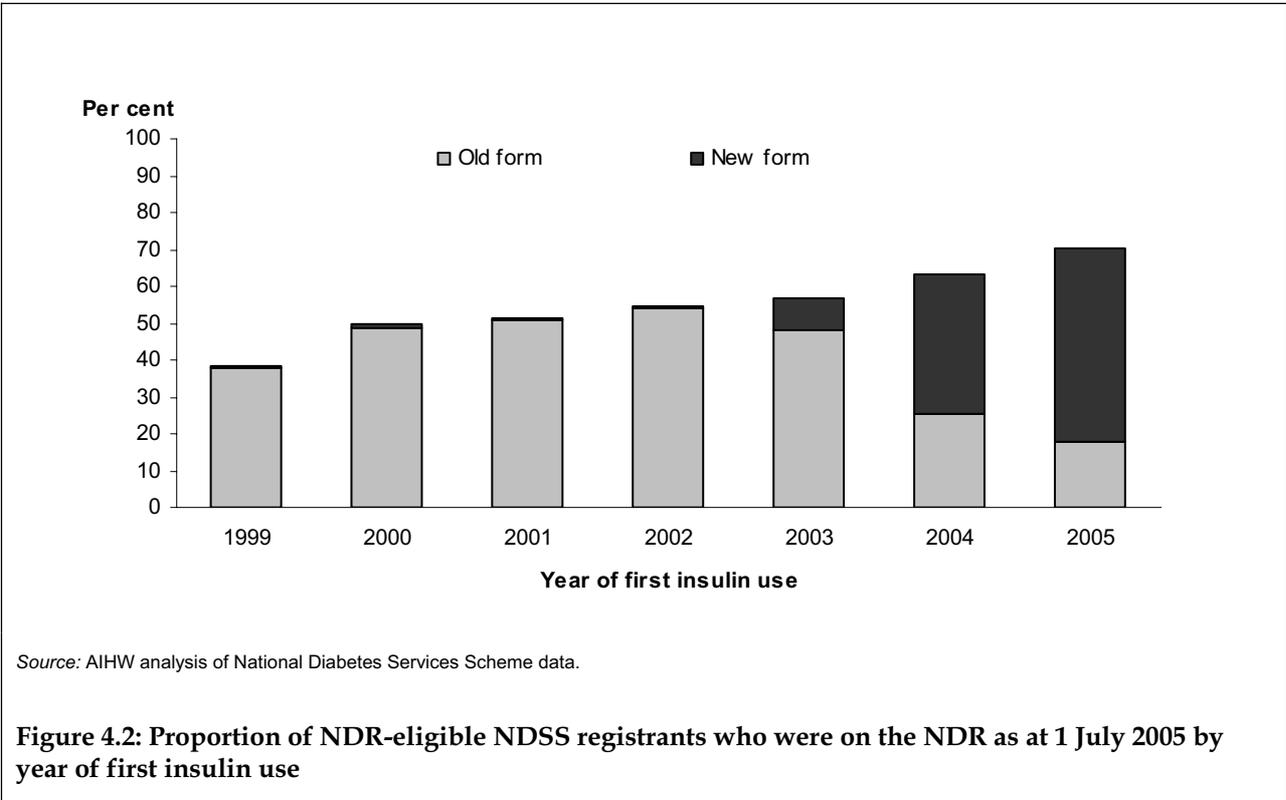
These results indicate that the introduction of the new NDSS form and consent arrangements for the NDR from August 2003 have significantly improved NDSS ascertainment rates for the NDR. Further, as old versions of the NDSS registration form cease to be used and the majority of all NDR-eligible NDSS registrants 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.



### 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.



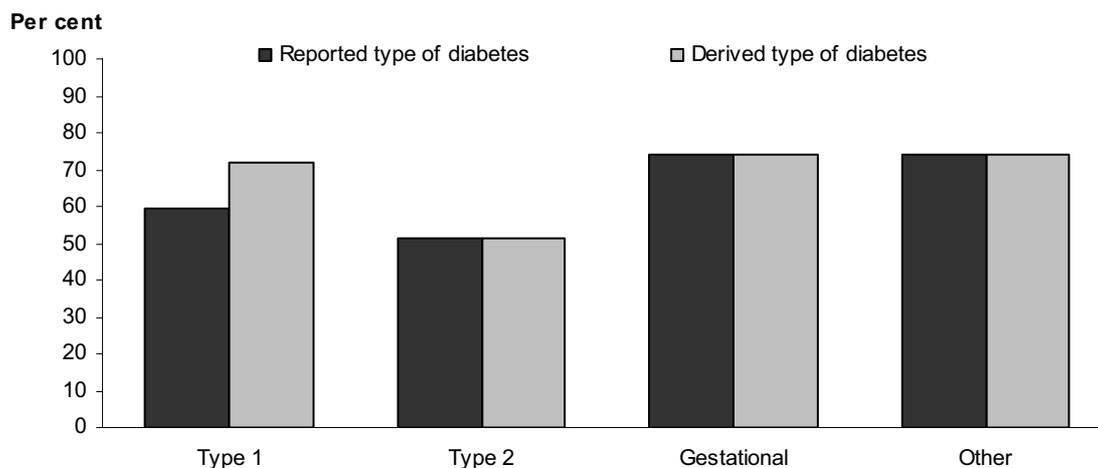
## Type of diabetes

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

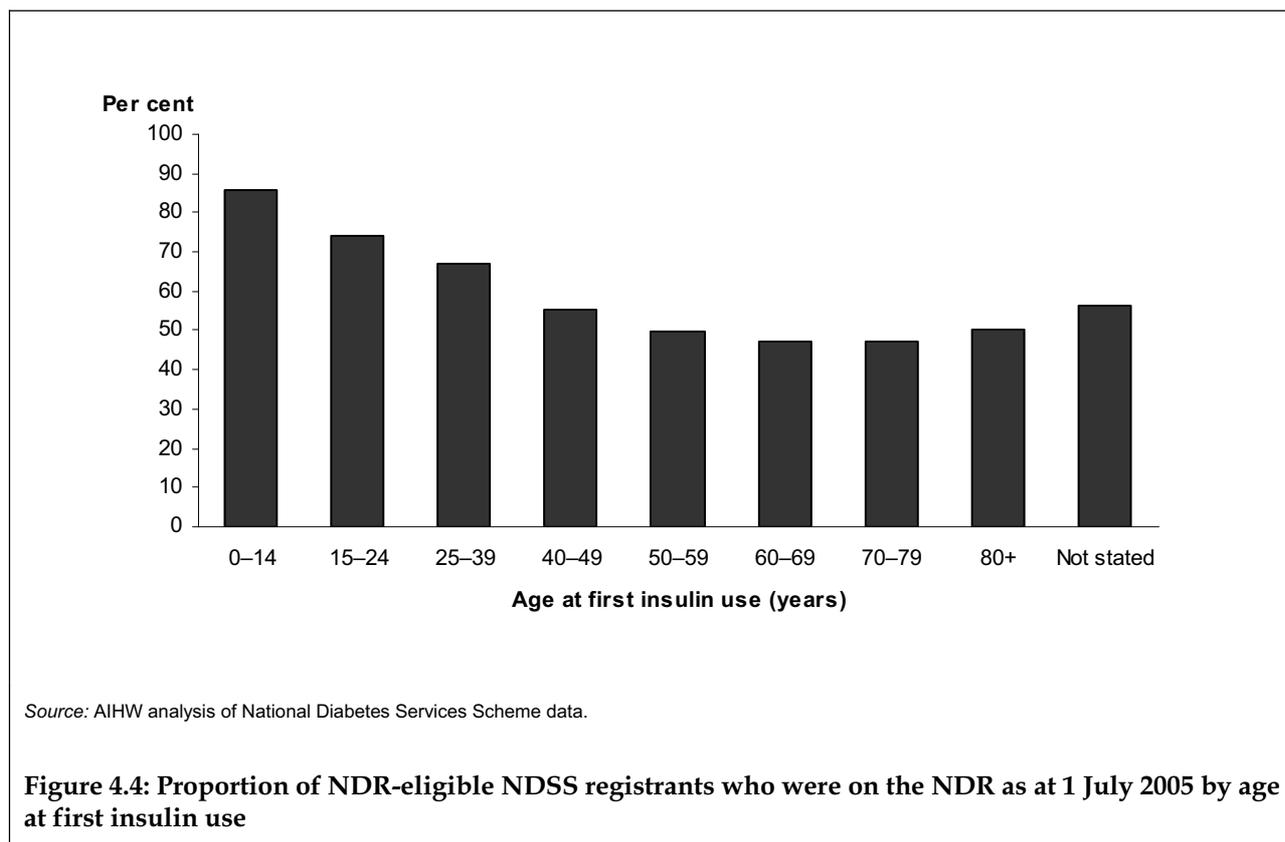
**Figure 4.3: Proportion of NDR-eligible NDSS registrants who were on the NDR as at 1 July 2005 by type of diabetes**

## 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.



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		
<b>Total</b>	<b>66,226</b>	<b>54,335</b>	<b>120,561</b>	<b>54.9</b>	<b>45.1</b>	<b>100.0</b>
<b>Sex<sup>(a)</sup></b>						
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
<b>Age at first insulin use (years)</b>						
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
<b>Age at diagnosis (years)</b>						
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
<b>State/territory of usual residence<sup>(b)</sup></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
<b>Region of birth</b>						
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**

Sociodemographic characteristic	Old form		New form		All forms	
	Number	Per cent	Number	Per cent	Number	Per cent
<b>Total</b>	<b>4,657</b>	<b>100.0</b>	<b>1,326</b>	<b>100.0</b>	<b>5,983</b>	<b>100.0</b>
<b>Sex</b>						
Male	2,381	51.1	681	51.4	3,062	51.2
Female	2,276	48.9	645	48.6	2,921	48.8
<b>Age at first insulin use (years)</b>						
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
<b>Age at diagnosis (years)</b>						
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
<b>State/territory of usual residence</b>						
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
<b>Region of birth</b>						
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.

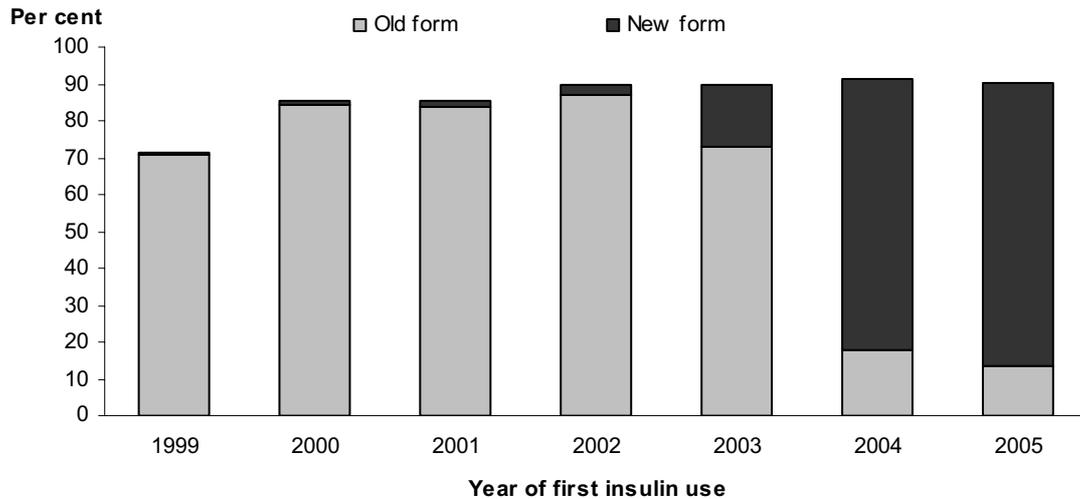
Just over 60% of NDR-eligible NDSS registrants aged 0–14 years with Type 1 diabetes were born in Australia and 10% were born overseas. However, country of birth was not recorded for 29%.

## 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		
<b>Total</b>	<b>5,157</b>	<b>826</b>	<b>5,983</b>	<b>86.2</b>	<b>13.8</b>	<b>100.0</b>
<b>Sex</b>						
Male	2,647	415	3,062	86.4	13.6	100.0
Female	2,510	411	2,921	85.9	14.1	100.0
<b>Age at first insulin use (years)</b>						
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
<b>State/territory of usual residence<sup>(a)</sup></b>						
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
<b>Region of birth</b>						
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.

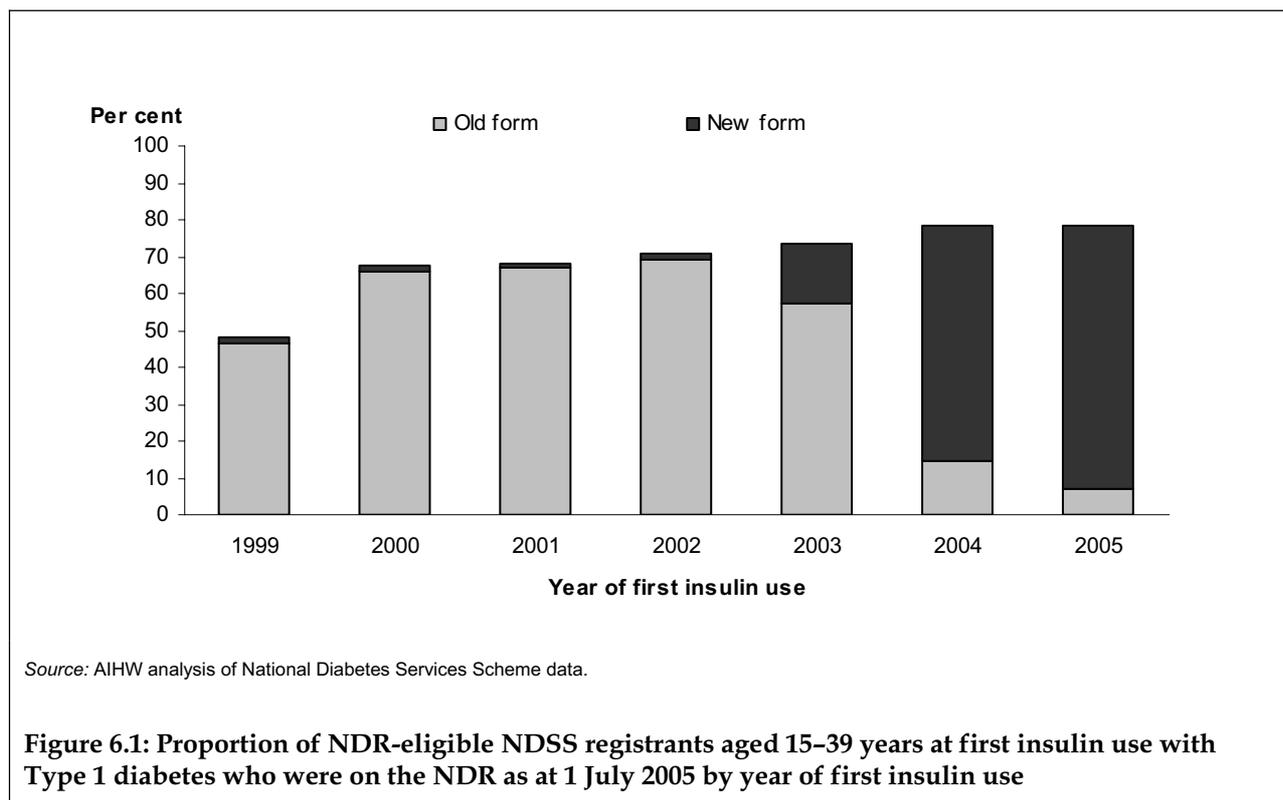
As expected, the contribution of the old NDSS form to ascertainment rates by year of first insulin use has been falling since 2003. For example, for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes who began using insulin in 2003, old form registrations contributed 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**

Sociodemographic characteristic	Old form		New form		All forms	
	Number	Per cent	Number	Per cent	Number	Per cent
<b>Total</b>	<b>6,122</b>	<b>100.0</b>	<b>1,291</b>	<b>100.0</b>	<b>7,413</b>	<b>100.0</b>
<b>Sex</b>						
Male	3,474	56.7	832	64.4	4,306	58.1
Female	2,648	43.3	459	35.6	3,107	41.9
<b>Age at first insulin use (years)</b>						
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
<b>Age at diagnosis (years)</b>						
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
<b>State/territory of usual residence</b>						
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
<b>Region of birth</b>						
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.



## 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		
<b>Total</b>	<b>4,967</b>	<b>2,446</b>	<b>7,413</b>	<b>67.0</b>	<b>33.0</b>	<b>100.0</b>
<b>Sex</b>						
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
<b>Age at first insulin use (years)</b>						
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
<b>State/territory of usual residence</b>						
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
<b>Region of birth</b>						
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**

Sociodemographic characteristic	Old form		New form		All forms	
	Number	Per cent	Number	Per cent	Number	Per cent
<b>Total</b>	<b>76,351</b>	<b>100.0</b>	<b>10,301</b>	<b>100.0</b>	<b>86,652</b>	<b>100.0</b>
<b>Sex</b>						
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
<b>Age at first insulin use (years)</b>						
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
<b>Age at diagnosis (years)</b>						
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
<b>State/territory of usual residence</b>						
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
<b>Region of birth</b>						
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

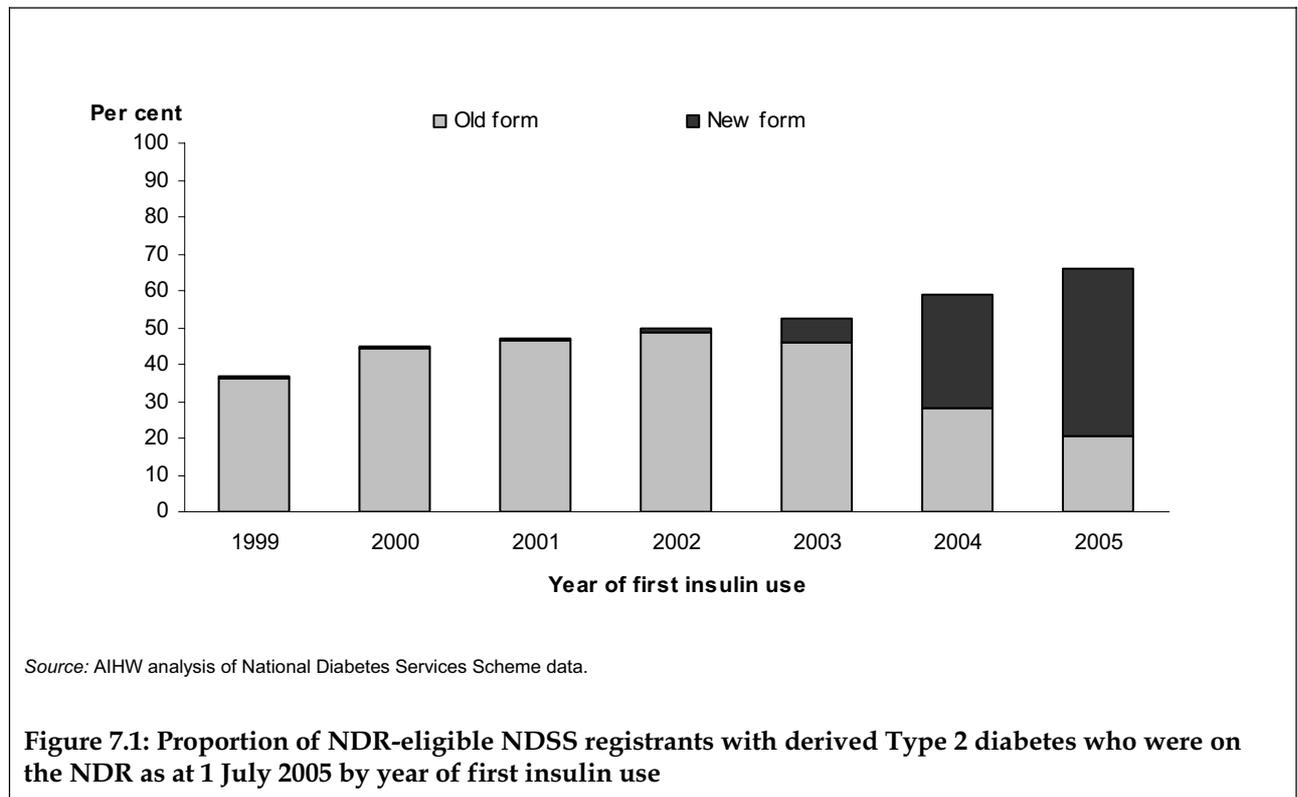
Source: AIHW analysis of National Diabetes Services Scheme data.

## 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.



### 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**

Sociodemographic characteristic	On NDR	Not on NDR	Total	On NDR	Not on NDR	Total
	Number			Per cent		
<b>Total</b>	<b>44,508</b>	<b>42,144</b>	<b>86,652</b>	<b>51.4</b>	<b>48.6</b>	<b>100.0</b>
<b>Sex<sup>(a)</sup></b>						
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
<b>Age at first insulin use (years)</b>						
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
<b>Age at diagnosis (years)</b>						
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
<b>State/territory of usual residence<sup>(b)</sup></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
<b>Region of birth</b>						
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

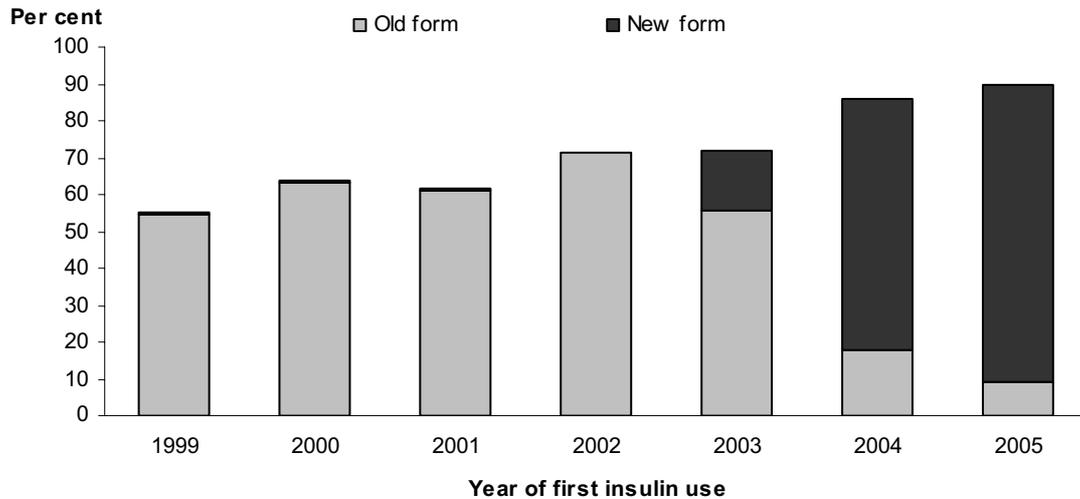
Ascertainment rates for the NDR by year of first insulin use for NDR-eligible NDSS registrants with gestational diabetes ranged from 55% in 1999 to 90% in 2005 (Figure 8.1, Table A31). Between 2000 and 2001, the ascertainment rate decreased slightly from 64% to 62%, but it then increased again to 72%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

Sociodemographic characteristic	Old form		New form		All forms	
	Number	Per cent	Number	Per cent	Number	Per cent
<b>Total (females)</b>	<b>6,528</b>	<b>100.0</b>	<b>2,852</b>	<b>100.0</b>	<b>9,380</b>	<b>100.0</b>
<b>Age at first insulin use (years)</b>						
< 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
<b>Age at diagnosis (years)</b>						
< 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
<b>State/territory of usual residence</b>						
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
<b>Region of birth</b>						
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**

Sociodemographic characteristic	On NDR	Not on NDR	Total	On NDR	Not on NDR	Total
	Number			Per cent		
<b>Total (females)</b>	<b>6,951</b>	<b>2,429</b>	<b>9,380</b>	<b>74.1</b>	<b>25.9</b>	<b>100.0</b>
<b>Age at first insulin use (years)</b>						
< 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
<b>State/territory of usual residence</b>						
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
<b>Region of birth</b>						
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

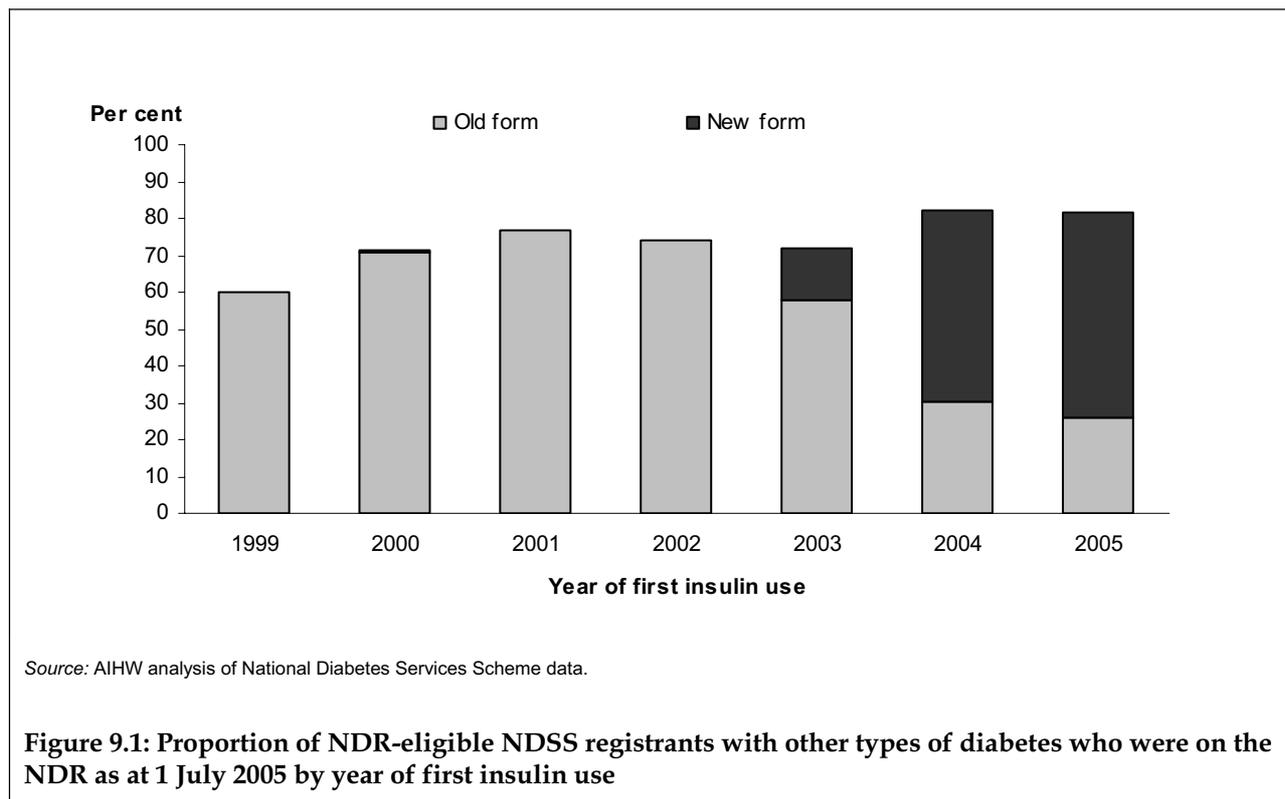
### Year of first insulin use

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**

Sociodemographic characteristic	Old form		New form		All forms	
	Number	Per cent	Number	Per cent	Number	Per cent
<b>Total</b>	<b>809</b>	<b>100.0</b>	<b>133</b>	<b>100.0</b>	<b>942</b>	<b>100.0</b>
<b>Sex</b>						
Male	450	55.6	78	58.6	528	56.1
Female	359	44.4	55	41.4	414	43.9
<b>Age at first insulin use (years)</b>						
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
<b>Age at diagnosis (years)</b>						
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
<b>State/territory of usual residence</b>						
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
<b>Region of birth</b>						
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.



## 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**

Sociodemographic characteristic	On NDR	Not on NDR	Total	On NDR	Not on NDR	Total
	Number			Per cent		
<b>Total</b>	<b>696</b>	<b>246</b>	<b>942</b>	<b>73.9</b>	<b>26.1</b>	<b>100.0</b>
<b>Sex<sup>(a)</sup></b>						
Male	387	141	528	73.3	26.7	100.0
Female	309	105	414	74.6	25.4	100.0
<b>Age at first insulin use (years)</b>						
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
<b>State/territory of usual residence<sup>(b)</sup></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
<b>Region of birth</b>						
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.

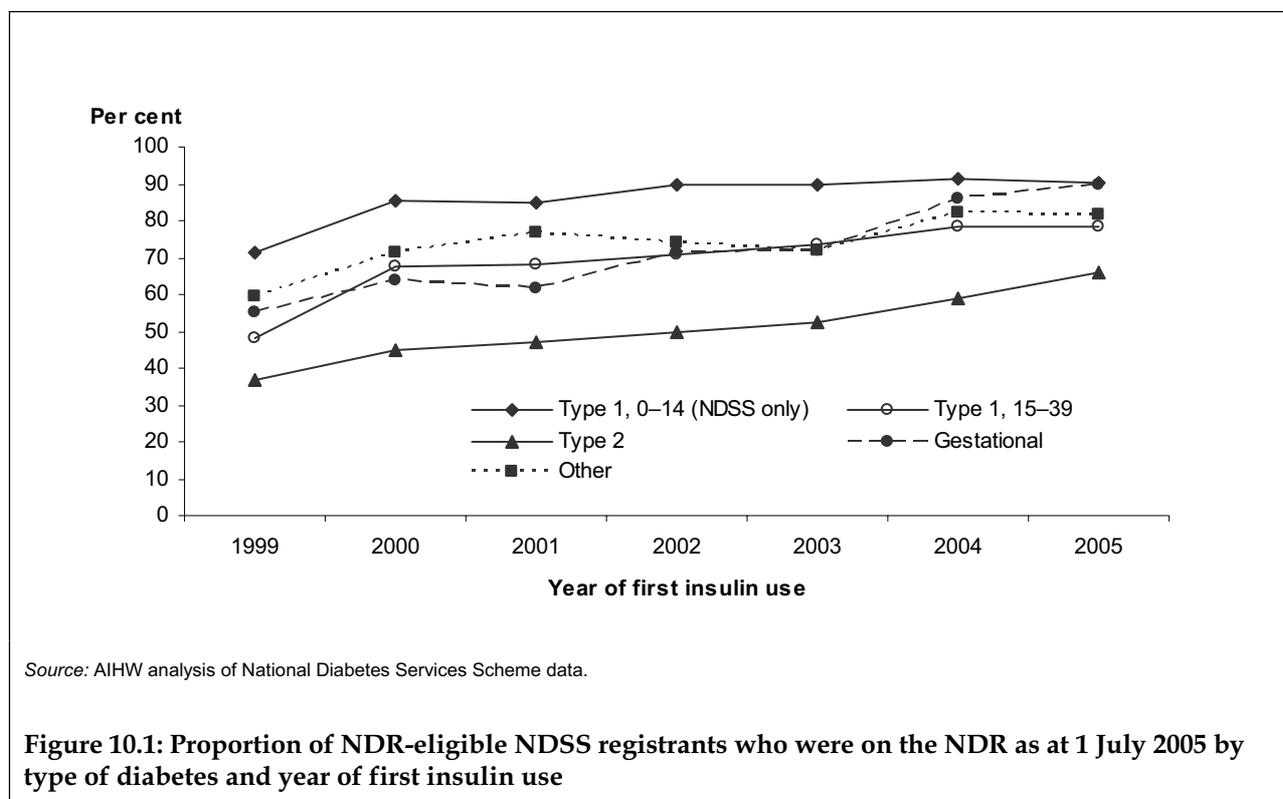
- 86.2% of registrants with Type 1 diabetes who were aged 0–14 years at first insulin use were on the NDR compared with 67.0% of those aged 15–39 years at first insulin use.
- 75.1% of registrants living in Western Australia were on the NDR compared with 40.1% of those living in the Northern Territory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



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.

# Appendix A: Statistical tables

**Table A1: Proportion of NDSS registrants eligible to be on the NDR who are on the NDR by year of NDSS registration and year of first insulin use**

Year of NDSS registration	Year of first insulin use							Not stated	Total
	1999	2000	2001	2002	2003	2004	2005		
1987	10.4	20.2	17.2	18.2	14.8	8.7	13.5	62.5	<b>14.9</b>
1988	12.9	20.0	21.0	27.1	20.4	17.5	21.2	50.0	<b>19.5</b>
1989	20.2	20.3	22.1	24.6	20.7	20.1	21.5	33.3	<b>21.3</b>
1990	14.7	25.2	24.1	20.8	24.3	15.7	30.2	25.0	<b>21.3</b>
1991	14.8	26.3	22.2	22.1	22.8	20.9	32.3	80.0	<b>22.2</b>
1992	17.1	25.1	23.9	20.6	23.1	17.3	23.9	0.0	<b>21.4</b>
1993	12.3	23.3	22.5	19.0	22.6	18.0	31.6	50.0	<b>20.5</b>
1994	12.1	22.2	20.3	20.6	21.6	18.4	26.4	25.0	<b>19.7</b>
1995	12.7	20.8	19.4	18.4	24.3	16.1	27.5	20.0	<b>19.4</b>
1996	12.9	20.3	23.0	17.5	24.0	18.4	29.5	50.0	<b>20.3</b>
1997	8.1	18.7	21.5	17.5	19.5	17.1	27.4	25.0	<b>18.0</b>
1998	6.1	16.4	17.4	17.9	19.4	14.1	24.3	33.3	<b>15.1</b>
1999	62.5	58.9	58.4	60.6	65.0	59.1	64.2	40.8	<b>60.9</b>
2000	72.6	72.6	72.1	70.8	74.3	74.2	77.7	58.4	<b>72.5</b>
2001	76.4	72.3	72.1	69.3	73.1	71.3	76.4	58.3	<b>71.7</b>
2002	91.9	75.8	70.9	75.8	76.5	74.7	79.6	68.6	<b>75.6</b>
2003	71.4	82.8	59.0	70.6	76.2	78.4	78.4	63.4	<b>76.3</b>
2004	96.8	93.0	94.3	100.0	87.5	92.4	93.0	98.2	<b>92.4</b>
2005	81.8	93.8	90.0	95.7	82.6	94.5	92.6	90.3	<b>92.6</b>
<b>Total</b>	<b>38.5</b>	<b>49.6</b>	<b>51.4</b>	<b>54.8</b>	<b>56.5</b>	<b>63.4</b>	<b>70.2</b>	<b>56.4</b>	<b>54.9</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A2: Contribution of old form registrations to NDR ascertainment rates by year of NDSS registration and year of first insulin use**

Year of NDSS registration	Year of first insulin use							Not stated	Total
	1999	2000	2001	2002	2003	2004	2005		
1987	10.4	19.8	16.8	18.2	14.8	6.6	1.8	62.5	<b>13.6</b>
1988	12.0	20.0	19.9	27.1	20.4	12.0	4.5	50.0	<b>17.4</b>
1989	19.8	19.9	22.1	24.1	20.3	14.4	5.4	33.3	<b>19.1</b>
1990	14.1	24.9	23.4	20.3	24.3	11.4	2.8	25.0	<b>18.7</b>
1991	14.6	25.9	21.7	21.3	22.6	13.5	8.4	80.0	<b>19.4</b>
1992	16.9	24.9	23.0	20.6	22.6	12.0	8.6	0.0	<b>19.2</b>
1993	11.1	22.9	22.2	18.5	22.1	13.6	8.1	25.0	<b>17.8</b>
1994	11.6	21.8	20.0	20.1	21.5	12.0	5.7	25.0	<b>17.1</b>
1995	11.6	20.5	18.9	18.2	24.0	11.8	5.1	20.0	<b>16.7</b>
1996	12.4	19.8	22.6	17.4	23.5	11.6	6.2	16.7	<b>17.0</b>
1997	7.9	18.7	20.9	17.2	19.2	12.5	2.4	25.0	<b>15.2</b>
1998	5.8	15.8	17.1	17.4	19.0	9.6	5.0	33.3	<b>12.7</b>
1999	62.0	58.3	58.2	60.3	64.8	54.3	42.1	40.2	<b>59.3</b>
2000	72.6	72.1	71.7	70.5	73.4	68.6	57.7	57.3	<b>70.8</b>
2001	76.4	71.6	71.6	68.9	72.7	66.4	55.2	58.0	<b>70.0</b>
2002	90.3	73.7	70.7	75.1	75.9	70.0	60.1	68.3	<b>73.7</b>
2003	48.6	65.6	45.9	66.6	59.6	53.6	53.3	48.8	<b>58.7</b>
2004	6.5	18.6	28.6	10.9	24.3	13.0	10.0	5.3	<b>13.1</b>
2005	18.2	12.5	40.0	8.7	17.4	13.4	7.3	6.5	<b>7.7</b>
<b>Total</b>	<b>37.7</b>	<b>48.8</b>	<b>50.7</b>	<b>53.8</b>	<b>48.2</b>	<b>25.4</b>	<b>17.7</b>	<b>50.7</b>	<b>41.2</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A3: Contribution of new form registrations to NDR ascertainment rates by year of NDSS registration and year of first insulin use**

Year of NDSS registration	Year of first insulin use							Not stated	Total
	1999	2000	2001	2002	2003	2004	2005		
1987	0.0	0.4	0.4	0.0	0.0	2.1	11.7	0.0	<b>1.3</b>
1988	0.9	0.0	1.1	0.0	0.0	5.5	16.7	0.0	<b>2.1</b>
1989	0.4	0.4	0.0	0.5	0.5	5.7	16.1	0.0	<b>2.2</b>
1990	0.6	0.3	0.7	0.4	0.0	4.3	27.4	0.0	<b>2.6</b>
1991	0.2	0.4	0.4	0.8	0.2	7.4	23.9	0.0	<b>2.8</b>
1992	0.2	0.2	0.9	0.0	0.6	5.3	15.2	0.0	<b>2.2</b>
1993	1.2	0.5	0.3	0.5	0.5	4.4	23.5	25.0	<b>2.8</b>
1994	0.5	0.4	0.3	0.5	0.1	6.4	20.7	0.0	<b>2.6</b>
1995	1.1	0.2	0.5	0.3	0.4	4.3	22.5	0.0	<b>2.7</b>
1996	0.5	0.5	0.5	0.1	0.5	6.8	23.3	33.3	<b>3.3</b>
1997	0.2	0.0	0.6	0.4	0.3	4.6	24.9	0.0	<b>2.8</b>
1998	0.3	0.6	0.3	0.6	0.4	4.5	19.3	0.0	<b>2.4</b>
1999	0.5	0.6	0.2	0.3	0.2	4.8	22.1	0.6	<b>1.6</b>
2000	0.0	0.5	0.3	0.3	0.9	5.6	20.0	1.1	<b>1.7</b>
2001	0.0	0.7	0.5	0.4	0.4	4.9	21.1	0.3	<b>1.7</b>
2002	1.6	2.0	0.3	0.7	0.6	4.7	19.6	0.3	<b>1.9</b>
2003	22.9	17.2	13.1	4.0	16.6	24.8	25.1	14.6	<b>17.5</b>
2004	90.3	74.4	65.7	89.1	63.2	79.4	83.0	93.0	<b>79.3</b>
2005	63.6	81.3	50.0	87.0	65.2	81.1	85.3	83.9	<b>84.9</b>
<b>Total</b>	<b>0.8</b>	<b>0.8</b>	<b>0.7</b>	<b>0.9</b>	<b>8.3</b>	<b>37.9</b>	<b>52.6</b>	<b>5.7</b>	<b>13.7</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A4: NDR ascertainment for all NDR-eligible NDSS registrants by year of NDSS registration**

Year of NDSS registration	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	Number						
1987	207	1,292	1,499	20	227	1,292	1,519
1988	206	953	1,159	25	231	953	1,184
1989	279	1,152	1,431	32	311	1,152	1,463
1990	345	1,451	1,796	48	393	1,451	1,844
1991	533	2,134	2,667	76	609	2,134	2,743
1992	658	2,693	3,351	77	735	2,693	3,428
1993	712	3,185	3,897	111	823	3,185	4,008
1994	756	3,552	4,308	117	873	3,552	4,425
1995	846	4,088	4,934	136	982	4,088	5,070
1996	919	4,304	5,223	178	1,097	4,304	5,401
1997	873	4,718	5,591	160	1,033	4,718	5,751
1998	896	5,985	6,881	169	1,065	5,985	7,050
1999	7,817	5,155	12,972	208	8,025	5,155	13,180
2000	8,973	3,491	12,464	214	9,187	3,491	12,678
2001	8,704	3,524	12,228	208	8,912	3,524	12,436
2002	8,697	2,874	11,571	224	8,921	2,874	11,795
2003: 1 Jan–1 Jul	4,635	1,763	6,398	100	4,735	1,763	6,498
2003: 1 Aug–31 Dec	1,825	847	2,672	1,828	3,653	847	4,500
2004	1,406	818	2,224	8,524	9,930	818	10,748
2005: 1 Jan–1 Jul	373	356	729	4,111	4,484	356	4,840
<b>Total</b>	<b>49,660</b>	<b>54,335</b>	<b>103,995</b>	<b>16,566</b>	<b>66,226</b>	<b>54,335</b>	<b>120,561</b>

(continued)

**Table A4 (continued): NDR ascertainment for all NDR-eligible NDSS registrants by year of NDSS registration**

Year of NDSS registration	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	Per cent						
1987	13.8	86.2	100.0	100.0	14.9	85.1	100.0
1988	17.8	82.2	100.0	100.0	19.5	80.5	100.0
1989	19.5	80.5	100.0	100.0	21.3	78.7	100.0
1990	19.2	80.8	100.0	100.0	21.3	78.7	100.0
1991	20.0	80.0	100.0	100.0	22.2	77.8	100.0
1992	19.6	80.4	100.0	100.0	21.4	78.6	100.0
1993	18.3	81.7	100.0	100.0	20.5	79.5	100.0
1994	17.5	82.5	100.0	100.0	19.7	80.3	100.0
1995	17.1	82.9	100.0	100.0	19.4	80.6	100.0
1996	17.6	82.4	100.0	100.0	20.3	79.7	100.0
1997	15.6	84.4	100.0	100.0	18.0	82.0	100.0
1998	13.0	87.0	100.0	100.0	15.1	84.9	100.0
1999	60.3	39.7	100.0	100.0	60.9	39.1	100.0
2000	72.0	28.0	100.0	100.0	72.5	27.5	100.0
2001	71.2	28.8	100.0	100.0	71.7	28.3	100.0
2002	75.2	24.8	100.0	100.0	75.6	24.4	100.0
2003: 1 Jan–1 Jul	72.4	27.6	100.0	100.0	72.9	27.1	100.0
2003: 1 Aug–31 Dec	68.3	31.7	100.0	100.0	81.2	18.8	100.0
2004	63.2	36.8	100.0	100.0	92.4	7.6	100.0
2005: 1 Jan–1 Jul	51.2	48.8	100.0	100.0	92.6	7.4	100.0
<b>Total</b>	<b>47.8</b>	<b>52.2</b>	<b>100.0</b>	<b>100.0</b>	<b>54.9</b>	<b>45.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A5: NDR ascertainment for all NDR-eligible NDSS registrants by year of first insulin use**

Year of first insulin use	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
1999	5,531	9,032	14,563	112	5,643	9,032	14,675
2000	7,930	8,191	16,121	129	8,059	8,191	16,250
2001	8,591	8,236	16,827	113	8,704	8,236	16,940
2002	9,411	7,901	17,312	165	9,576	7,901	17,477
2003	9,658	8,705	18,363	1,657	11,315	8,705	20,020
2004	5,778	8,327	14,105	8,624	14,402	8,327	22,729
2005	1,906	3,208	5,114	5,669	7,575	3,208	10,783
Not stated	855	735	1,590	97	952	735	1,687
<b>Total</b>	<b>49,660</b>	<b>54,335</b>	<b>103,995</b>	<b>16,566</b>	<b>66,226</b>	<b>54,335</b>	<b>120,561</b>
	<b>Per cent</b>						
1999	38.0	62.0	100.0	100.0	38.5	61.5	100.0
2000	49.2	50.8	100.0	100.0	49.6	50.4	100.0
2001	51.1	48.9	100.0	100.0	51.4	48.6	100.0
2002	54.4	45.6	100.0	100.0	54.8	45.2	100.0
2003	52.6	47.4	100.0	100.0	56.5	43.5	100.0
2004	41.0	59.0	100.0	100.0	63.4	36.6	100.0
2005	37.3	62.7	100.0	100.0	70.2	29.8	100.0
Not stated	53.8	46.2	100.0	100.0	56.4	43.6	100.0
<b>Total</b>	<b>47.8</b>	<b>52.2</b>	<b>100.0</b>	<b>100.0</b>	<b>54.9</b>	<b>45.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A6: NDR ascertainment for all NDR-eligible NDSS registrants by reported type of diabetes**

	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
<b>Reported type of diabetes</b>	<b>Number</b>						
Type 1	12,530	10,881	23,411	3,352	15,882	10,881	26,763
Type 2	32,457	40,773	73,230	10,223	42,680	40,773	83,453
Gestational	4,110	2,435	6,545	2,858	6,968	2,435	9,403
Other	563	246	809	133	696	246	942
<b>Total</b>	<b>49,660</b>	<b>54,335</b>	<b>103,995</b>	<b>16,566</b>	<b>66,226</b>	<b>54,335</b>	<b>120,561</b>
	<b>Per cent</b>						
Type 1	53.5	46.5	100.0	100.0	59.3	40.7	100.0
Type 2	44.3	55.7	100.0	100.0	51.1	48.9	100.0
Gestational	62.8	37.2	100.0	100.0	74.1	25.9	100.0
Other	69.6	30.4	100.0	100.0	73.9	26.1	100.0
<b>Total</b>	<b>47.8</b>	<b>52.2</b>	<b>100.0</b>	<b>100.0</b>	<b>54.9</b>	<b>45.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A7: NDR ascertainment for all NDR-eligible NDSS registrants by derived type of diabetes**

	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
<b>Derived type of diabetes</b>	<b>Number</b>						
Type 1	10,117	5,147	15,264	3,098	13,215	5,147	18,362
Type 2	34,207	42,144	76,351	10,301	44,508	42,144	86,652
Gestational	4,099	2,429	6,528	2,852	6,951	2,429	9,380
Other	563	246	809	133	696	246	942
Not able to derive	674	4,369	5,043	182	856	4,369	5,225
<b>Total</b>	<b>49,660</b>	<b>54,335</b>	<b>103,995</b>	<b>16,566</b>	<b>66,226</b>	<b>54,335</b>	<b>120,561</b>
	<b>Per cent</b>						
Type 1	66.3	33.7	100.0	100.0	72.0	28.0	100.0
Type 2	44.8	55.2	100.0	100.0	51.4	48.6	100.0
Gestational	62.8	37.2	100.0	100.0	74.1	25.9	100.0
Other	69.6	30.4	100.0	100.0	73.9	26.1	100.0
Not able to derive	13.4	86.6	100.0	100.0	16.4	83.6	100.0
<b>Total</b>	<b>47.8</b>	<b>52.2</b>	<b>100.0</b>	<b>100.0</b>	<b>54.9</b>	<b>45.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A8: NDR ascertainment for all NDR-eligible NDSS registrants by sex**

	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
<b>Sex</b>	<b>Number</b>						
Male	24,926	27,612	52,538	7,841	32,767	27,612	60,379
Female	24,734	26,718	51,452	8,725	33,459	26,718	60,177
Unknown	0	5	5	0	0	5	5
<b>Total</b>	<b>49,660</b>	<b>54,330</b>	<b>103,990</b>	<b>16,566</b>	<b>66,226</b>	<b>54,330</b>	<b>120,556</b>
	<b>Per cent</b>						
Male	47.4	52.6	100.0	100.0	54.3	45.7	100.0
Female	48.1	51.9	100.0	100.0	55.6	44.4	100.0
Unknown	0.0	100.0	100.0	100.0	0.0	100.0	100.0
<b>Total</b>	<b>47.8</b>	<b>52.2</b>	<b>100.0</b>	<b>100.0</b>	<b>54.9</b>	<b>45.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A9: NDR ascertainment for all NDR-eligible NDSS registrants by age at first insulin use**

	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
<b>Age at first insulin use (years)</b>	<b>Number</b>						
0–14	3,951	886	4,837	1,376	5,327	886	6,213
15–24	2,206	1,091	3,297	935	3,141	1,091	4,232
25–39	8,266	6,026	14,292	4,073	12,339	6,026	18,365
40–49	5,777	6,117	11,894	1,757	7,534	6,117	13,651
50–59	9,180	11,816	20,996	2,606	11,786	11,816	23,602
60–69	9,512	13,479	22,991	2,568	12,080	13,479	25,559
70–79	7,240	10,584	17,824	2,163	9,403	10,584	19,987
80+	2,673	3,601	6,274	990	3,663	3,601	7,264
Not stated	855	735	1,590	98	953	735	1,688
<b>Total</b>	<b>49,660</b>	<b>54,335</b>	<b>103,995</b>	<b>16,566</b>	<b>66,226</b>	<b>54,335</b>	<b>120,561</b>
	<b>Per cent</b>						
0–14	81.7	18.3	100.0	100.0	85.7	14.3	100.0
15–24	66.9	33.1	100.0	100.0	74.2	25.8	100.0
25–39	57.8	42.2	100.0	100.0	67.2	32.8	100.0
40–49	48.6	51.4	100.0	100.0	55.2	44.8	100.0
50–59	43.7	56.3	100.0	100.0	49.9	50.1	100.0
60–69	41.4	58.6	100.0	100.0	47.3	52.7	100.0
70–79	40.6	59.4	100.0	100.0	47.0	53.0	100.0
80+	42.6	57.4	100.0	100.0	50.4	49.6	100.0
Not stated	53.8	46.2	100.0	100.0	56.5	43.5	100.0
<b>Total</b>	<b>47.8</b>	<b>52.2</b>	<b>100.0</b>	<b>100.0</b>	<b>54.9</b>	<b>45.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A10: NDR ascertainment for all NDR-eligible NDSS registrants by age at diagnosis**

Age at diagnosis (years)	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
0–14	4,011	924	4,935	1,369	5,380	924	6,304
15–24	2,625	1,230	3,855	949	3,574	1,230	4,804
25–39	10,404	6,337	16,741	4,058	14,462	6,337	20,799
40–49	8,610	5,594	14,204	1,856	10,466	5,594	16,060
50–59	9,132	6,517	15,649	1,904	11,036	6,517	17,553
60–69	6,541	4,987	11,528	1,454	7,995	4,987	12,982
70–79	3,394	2,549	5,943	840	4,234	2,549	6,783
80+	1,041	763	1,804	292	1,333	763	2,096
Not stated	3,902	25,434	29,336	3,844	7,746	25,434	33,180
<b>Total</b>	<b>49,660</b>	<b>54,335</b>	<b>103,995</b>	<b>16,566</b>	<b>66,226</b>	<b>54,335</b>	<b>120,561</b>
	<b>Per cent</b>						
0–14	81.3	18.7	100.0	100.0	85.3	14.7	100.0
15–24	68.1	31.9	100.0	100.0	74.4	25.6	100.0
25–39	62.1	37.9	100.0	100.0	69.5	30.5	100.0
40–49	60.6	39.4	100.0	100.0	65.2	34.8	100.0
50–59	58.4	41.6	100.0	100.0	62.9	37.1	100.0
60–69	56.7	43.3	100.0	100.0	61.6	38.4	100.0
70–79	57.1	42.9	100.0	100.0	62.4	37.6	100.0
80+	57.7	42.3	100.0	100.0	63.6	36.4	100.0
Not stated	13.3	86.7	100.0	100.0	23.3	76.7	100.0
<b>Total</b>	<b>47.8</b>	<b>52.2</b>	<b>100.0</b>	<b>100.0</b>	<b>54.9</b>	<b>45.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A11: NDR ascertainment for all NDR-eligible NDSS registrants by state/territory of usual residence**

State/territory of usual residence	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
NSW	16,429	22,759	39,188	6,890	23,319	22,759	46,078
Vic	12,597	12,988	25,585	3,801	16,398	12,988	29,386
Qld	9,993	7,933	17,926	3,105	13,098	7,933	21,031
WA	5,769	2,238	8,007	974	6,743	2,238	8,981
SA	2,536	5,668	8,204	1,294	3,830	5,668	9,498
Tas	1,486	1,573	3,059	120	1,606	1,573	3,179
ACT	599	542	1,141	208	807	542	1,349
NT	248	630	878	173	421	630	1,051
Unknown	3	4	7	1	4	4	8
<b>Total</b>	<b>49,660</b>	<b>54,335</b>	<b>103,995</b>	<b>16,566</b>	<b>66,226</b>	<b>54,335</b>	<b>120,561</b>
	<b>Per cent</b>						
NSW	41.9	58.1	100.0	100.0	50.6	49.4	100.0
Vic	49.2	50.8	100.0	100.0	55.8	44.2	100.0
Qld	55.7	44.3	100.0	100.0	62.3	37.7	100.0
WA	72.0	28.0	100.0	100.0	75.1	24.9	100.0
SA	30.9	69.1	100.0	100.0	40.3	59.7	100.0
Tas	48.6	51.4	100.0	100.0	50.5	49.5	100.0
ACT	52.5	47.5	100.0	100.0	59.8	40.2	100.0
NT	28.2	71.8	100.0	100.0	40.1	59.9	100.0
Unknown	42.9	57.1	100.0	100.0	50.0	50.0	100.0
<b>Total</b>	<b>47.8</b>	<b>52.2</b>	<b>100.0</b>	<b>100.0</b>	<b>54.9</b>	<b>45.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A12: NDR ascertainment for all NDR-eligible NDSS registrants by region of birth**

Region of birth	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
Australian-born	24,917	11,180	36,097	3,808	28,725	11,180	39,905
Overseas-born	16,783	12,525	29,308	6,676	23,459	12,525	35,984
Not stated	7,960	30,630	38,590	6,082	14,042	30,630	44,672
<b>Total</b>	<b>49,660</b>	<b>54,335</b>	<b>103,995</b>	<b>16,566</b>	<b>66,226</b>	<b>54,335</b>	<b>120,561</b>
	<b>Per cent</b>						
Australian-born	69.0	31.0	100.0	100.0	72.0	28.0	100.0
Overseas-born	57.3	42.7	100.0	100.0	65.2	34.8	100.0
Not stated	20.6	79.4	100.0	100.0	31.4	68.6	100.0
<b>Total</b>	<b>47.8</b>	<b>52.2</b>	<b>100.0</b>	<b>100.0</b>	<b>54.9</b>	<b>45.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A13: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by year of first insulin use**

Year of first insulin use	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
1999	593	239	832	4	597	239	836
2000	699	121	820	10	709	121	830
2001	738	131	869	13	751	131	882
2002	814	97	911	22	836	97	933
2003	741	104	845	172	913	104	1,017
2004	184	90	274	748	932	90	1,022
2005	62	44	106	357	419	44	463
<b>Total</b>	<b>3,831</b>	<b>826</b>	<b>4,657</b>	<b>1,326</b>	<b>5,157</b>	<b>826</b>	<b>5,983</b>
	<b>Per cent</b>						
1999	71.3	28.7	100.0	100.0	71.4	28.6	100.0
2000	85.2	14.8	100.0	100.0	85.4	14.6	100.0
2001	84.9	15.1	100.0	100.0	85.1	14.9	100.0
2002	89.4	10.6	100.0	100.0	89.6	10.4	100.0
2003	87.7	12.3	100.0	100.0	89.8	10.2	100.0
2004	67.2	32.8	100.0	100.0	91.2	8.8	100.0
2005	58.5	41.5	100.0	100.0	90.5	9.5	100.0
<b>Total</b>	<b>82.3</b>	<b>17.7</b>	<b>100.0</b>	<b>100.0</b>	<b>86.2</b>	<b>13.8</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A14: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by sex**

	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
<b>Sex</b>	<b>Number</b>						
Male	1,966	415	2,381	681	2,647	415	3,062
Female	1,865	411	2,276	645	2,510	411	2,921
<b>Total</b>	<b>3,831</b>	<b>826</b>	<b>4,657</b>	<b>1,326</b>	<b>5,157</b>	<b>826</b>	<b>5,983</b>
	<b>Per cent</b>						
Male	82.6	17.4	100.0	100.0	86.4	13.6	100.0
Female	81.9	18.1	100.0	100.0	85.9	14.1	100.0
<b>Total</b>	<b>82.3</b>	<b>17.7</b>	<b>100.0</b>	<b>100.0</b>	<b>86.2</b>	<b>13.8</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A15: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by age at first insulin use**

	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
<b>Age at first insulin use (years)</b>	<b>Number</b>						
0–4	811	147	958	276	1,087	147	1,234
5–9	1,345	255	1,600	491	1,836	255	2,091
10–14	1,675	424	2,099	559	2,234	424	2,658
<b>Total</b>	<b>3,831</b>	<b>826</b>	<b>4,657</b>	<b>1,326</b>	<b>5,157</b>	<b>826</b>	<b>5,983</b>
	<b>Per cent</b>						
0–4	84.7	15.3	100.0	100.0	88.1	11.9	100.0
5–9	84.1	15.9	100.0	100.0	87.8	12.2	100.0
10–14	79.8	20.2	100.0	100.0	84.0	16.0	100.0
<b>Total</b>	<b>82.3</b>	<b>17.7</b>	<b>100.0</b>	<b>100.0</b>	<b>86.2</b>	<b>13.8</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A16: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by age at diagnosis**

Age at diagnosis (years)	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
0–4	810	160	970	271	1,081	160	1,241
5–9	1,331	246	1,577	470	1,801	246	2,047
10–14	1,658	349	2,007	536	2,194	349	2,543
Not stated	32	71	103	49	81	71	152
<b>Total</b>	<b>3,831</b>	<b>826</b>	<b>4,657</b>	<b>1,326</b>	<b>5,157</b>	<b>826</b>	<b>5,983</b>
	<b>Per cent</b>						
0–4	83.5	16.5	100.0	100.0	87.1	12.9	100.0
5–9	84.4	15.6	100.0	100.0	88.0	12.0	100.0
10–14	82.6	17.4	100.0	100.0	86.3	13.7	100.0
Not stated	31.1	68.9	100.0	100.0	53.3	46.7	100.0
<b>Total</b>	<b>82.3</b>	<b>17.7</b>	<b>100.0</b>	<b>100.0</b>	<b>86.2</b>	<b>13.8</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A17: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by state/territory of usual residence**

State/territory of usual residence	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
NSW	1,118	266	1,384	503	1,621	266	1,887
Vic	943	259	1,202	344	1,287	259	1,546
Qld	792	128	920	245	1,037	128	1,165
WA	471	43	514	65	536	43	579
SA	295	79	374	115	410	79	489
Tas	137	26	163	13	150	26	176
ACT	54	13	67	30	84	13	97
NT	20	12	32	11	31	12	43
Unknown	1	0	1	0	1	0	1
<b>Total</b>	<b>3,831</b>	<b>826</b>	<b>4,657</b>	<b>1,326</b>	<b>5,157</b>	<b>826</b>	<b>5,983</b>
	<b>Per cent</b>						
NSW	80.8	19.2	100.0	100.0	85.9	14.1	100.0
Vic	78.5	21.5	100.0	100.0	83.2	16.8	100.0
Qld	86.1	13.9	100.0	100.0	89.0	11.0	100.0
WA	91.6	8.4	100.0	100.0	92.6	7.4	100.0
SA	78.9	21.1	100.0	100.0	83.8	16.2	100.0
Tas	84.0	16.0	100.0	100.0	85.2	14.8	100.0
ACT	80.6	19.4	100.0	100.0	86.6	13.4	100.0
NT	62.5	37.5	100.0	100.0	72.1	27.9	100.0
Unknown	100.0	0.0	100.0	—	100.0	0.0	100.0
<b>Total</b>	<b>82.3</b>	<b>17.7</b>	<b>100.0</b>	<b>100.0</b>	<b>86.2</b>	<b>13.8</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A18: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by region of birth**

Region of birth	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
Australian-born	2,685	509	3,194	434	3,119	509	3,628
Overseas-born	318	67	385	214	532	67	599
Not stated	828	250	1,078	678	1,506	250	1,756
<b>Total</b>	<b>3,831</b>	<b>826</b>	<b>4,657</b>	<b>1,326</b>	<b>5,157</b>	<b>826</b>	<b>5,983</b>
	<b>Per cent</b>						
Australian-born	84.1	15.9	100.0	100.0	86.0	14.0	100.0
Overseas-born	82.6	17.4	100.0	100.0	88.8	11.2	100.0
Not stated	76.8	23.2	100.0	100.0	85.8	14.2	100.0
<b>Total</b>	<b>82.3</b>	<b>17.7</b>	<b>100.0</b>	<b>100.0</b>	<b>86.2</b>	<b>13.8</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A19: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by year of first insulin use**

Year of first insulin use	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
1999	756	841	1,597	20	776	841	1,617
2000	736	363	1,099	18	754	363	1,117
2001	750	358	1,108	14	764	358	1,122
2002	634	267	901	14	648	267	915
2003	607	278	885	174	781	278	1,059
2004	160	239	399	717	877	239	1,116
2005	33	100	133	334	367	100	467
<b>Total</b>	<b>3,676</b>	<b>2,446</b>	<b>6,122</b>	<b>1,291</b>	<b>4,967</b>	<b>2,446</b>	<b>7,413</b>
	<b>Per cent</b>						
1999	47.3	52.7	100.0	100.0	48.0	52.0	100.0
2000	67.0	33.0	100.0	100.0	67.5	32.5	100.0
2001	67.7	32.3	100.0	100.0	68.1	31.9	100.0
2002	70.4	29.6	100.0	100.0	70.8	29.2	100.0
2003	68.6	31.4	100.0	100.0	73.7	26.3	100.0
2004	40.1	59.9	100.0	100.0	78.6	21.4	100.0
2005	24.8	75.2	100.0	100.0	78.6	21.4	100.0
<b>Total</b>	<b>60.0</b>	<b>40.0</b>	<b>100.0</b>	<b>100.0</b>	<b>67.0</b>	<b>33.0</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A20: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by sex**

	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
<b>Sex</b>	<b>Number</b>						
Male	2,299	1,175	3,474	832	3,131	1,175	4,306
Female	1,377	1,271	2,648	459	1,836	1,271	3,107
<b>Total</b>	<b>3,676</b>	<b>2,446</b>	<b>6,122</b>	<b>1,291</b>	<b>4,967</b>	<b>2,446</b>	<b>7,413</b>
	<b>Per cent</b>						
Male	66.2	33.8	100.0	100.0	72.7	27.3	100.0
Female	52.0	48.0	100.0	100.0	59.1	40.9	100.0
<b>Total</b>	<b>60.0</b>	<b>40.0</b>	<b>100.0</b>	<b>100.0</b>	<b>67.0</b>	<b>33.0</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A21: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by age at first insulin use**

	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
<b>Age at first insulin use (years)</b>	<b>Number</b>						
15–19	907	360	1,267	312	1,219	360	1,579
20–24	713	374	1,087	283	996	374	1,370
25–29	749	554	1,303	254	1,003	554	1,557
30–34	712	555	1,267	248	960	555	1,515
35–39	595	603	1,198	194	789	603	1,392
<b>Total</b>	<b>3,676</b>	<b>2,446</b>	<b>6,122</b>	<b>1,291</b>	<b>4,967</b>	<b>2,446</b>	<b>7,413</b>
	<b>Per cent</b>						
15–19	71.6	28.4	100.0	100.0	77.2	22.8	100.0
20–24	65.6	34.4	100.0	100.0	72.7	27.3	100.0
25–29	57.5	42.5	100.0	100.0	64.4	35.6	100.0
30–34	56.2	43.8	100.0	100.0	63.4	36.6	100.0
35–39	49.7	50.3	100.0	100.0	56.7	43.3	100.0
<b>Total</b>	<b>60.0</b>	<b>40.0</b>	<b>100.0</b>	<b>100.0</b>	<b>67.0</b>	<b>33.0</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A22: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by age at diagnosis**

Age at diagnosis (years)	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
0–4	8	12	20	5	13	12	25
5–9	6	18	24	8	14	18	32
10–14	14	34	48	9	23	34	57
15–19	922	313	1,235	303	1,225	313	1,538
20–24	733	317	1,050	273	1,006	317	1,323
25–29	749	378	1,127	236	985	378	1,363
30–34	677	345	1,022	202	879	345	1,224
35–39	495	224	719	159	654	224	878
Not stated	72	805	877	96	168	805	973
<b>Total</b>	<b>3,676</b>	<b>2,446</b>	<b>6,122</b>	<b>1,291</b>	<b>4,967</b>	<b>2,446</b>	<b>7,413</b>
	<b>Per cent</b>						
0–4	40.0	60.0	100.0	100.0	52.0	48.0	100.0
5–9	25.0	75.0	100.0	100.0	43.8	56.3	100.0
10–14	29.2	70.8	100.0	100.0	40.4	59.6	100.0
15–19	74.7	25.3	100.0	100.0	79.6	20.4	100.0
20–24	69.8	30.2	100.0	100.0	76.0	24.0	100.0
25–29	66.5	33.5	100.0	100.0	72.3	27.7	100.0
30–34	66.2	33.8	100.0	100.0	71.8	28.2	100.0
35–39	68.8	31.2	100.0	100.0	74.5	25.5	100.0
Not stated	8.2	91.8	100.0	100.0	17.3	82.7	100.0
<b>Total</b>	<b>60.0</b>	<b>40.0</b>	<b>100.0</b>	<b>100.0</b>	<b>67.0</b>	<b>33.0</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A23: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by state/territory of usual residence**

State/territory of usual residence	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
NSW	1,045	772	1,817	447	1,492	772	2,264
Vic	902	614	1,516	306	1,208	614	1,822
Qld	787	458	1,245	273	1,060	458	1,518
WA	495	159	654	115	610	159	769
SA	244	277	521	102	346	277	623
Tas	108	101	209	11	119	101	220
ACT	70	32	102	22	92	32	124
NT	25	33	58	15	40	33	73
<b>Total</b>	<b>3,676</b>	<b>2,446</b>	<b>6,122</b>	<b>1,291</b>	<b>4,967</b>	<b>2,446</b>	<b>7,413</b>
	<b>Per cent</b>						
NSW	57.5	42.5	100.0	100.0	65.9	34.1	100.0
Vic	59.5	40.5	100.0	100.0	66.3	33.7	100.0
Qld	63.2	36.8	100.0	100.0	69.8	30.2	100.0
WA	75.7	24.3	100.0	100.0	79.3	20.7	100.0
SA	46.8	53.2	100.0	100.0	55.5	44.5	100.0
Tas	51.7	48.3	100.0	100.0	54.1	45.9	100.0
ACT	68.6	31.4	100.0	100.0	74.2	25.8	100.0
NT	43.1	56.9	100.0	100.0	54.8	45.2	100.0
<b>Total</b>	<b>60.0</b>	<b>40.0</b>	<b>100.0</b>	<b>100.0</b>	<b>67.0</b>	<b>33.0</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A24: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by region of birth**

	Old form		Total	New form	All forms		Total
	On NDR	Not on NDR		On NDR	On NDR	Not on NDR	
<b>Region of birth</b>	<b>Number</b>						
Australian-born	2,302	871	3,173	305	2,607	871	3,478
Overseas-born	688	401	1,089	355	1,043	401	1,444
Not stated	686	1,174	1,860	631	1,317	1,174	2,491
<b>Total</b>	<b>3,676</b>	<b>2,446</b>	<b>6,122</b>	<b>1,291</b>	<b>4,967</b>	<b>2,446</b>	<b>7,413</b>
	<b>Per cent</b>						
Australian-born	72.5	27.5	100.0	100.0	75.0	25.0	100.0
Overseas-born	63.2	36.8	100.0	100.0	72.2	27.8	100.0
Not stated	36.9	63.1	100.0	100.0	52.9	47.1	100.0
<b>Total</b>	<b>60.0</b>	<b>40.0</b>	<b>100.0</b>	<b>100.0</b>	<b>67.0</b>	<b>33.0</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A25: NDR ascertainment for all eligible NDSS registrants with derived Type 2 diabetes by year of first insulin use**

Year of first insulin use	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
1999	2,964	5,202	8,166	75	3,039	5,202	8,241
2000	5,184	6,465	11,649	86	5,270	6,465	11,735
2001	5,617	6,366	11,983	75	5,692	6,366	12,058
2002	6,336	6,584	12,920	112	6,448	6,584	13,032
2003	7,095	7,339	14,434	979	8,074	7,339	15,413
2004	4,923	7,169	12,092	5,321	10,244	7,169	17,413
2005	1,628	2,708	4,336	3,605	5,233	2,708	7,941
Not stated	460	311	771	48	508	311	819
<b>Total</b>	<b>34,207</b>	<b>42,144</b>	<b>76,351</b>	<b>10,301</b>	<b>44,508</b>	<b>42,144</b>	<b>86,652</b>
	<b>Per cent</b>						
1999	36.3	63.7	100.0	100.0	36.9	63.1	100.0
2000	44.5	55.5	100.0	100.0	44.9	55.1	100.0
2001	46.9	53.1	100.0	100.0	47.2	52.8	100.0
2002	49.0	51.0	100.0	100.0	49.5	50.5	100.0
2003	49.2	50.8	100.0	100.0	52.4	47.6	100.0
2004	40.7	59.3	100.0	100.0	58.8	41.2	100.0
2005	37.5	62.5	100.0	100.0	65.9	34.1	100.0
Not stated	59.7	40.3	100.0	101.0	62.0	38.0	100.0
<b>Total</b>	<b>44.8</b>	<b>55.2</b>	<b>100.0</b>	<b>100.0</b>	<b>51.4</b>	<b>48.6</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A26: NDR ascertainment for NDR-eligible NDSS registrants with derived Type 2 diabetes by sex**

Sex	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
Male	18,462	22,482	40,944	5,857	24,319	22,482	46,801
Female	15,745	19,659	35,404	4,444	20,189	19,659	39,848
Unknown	0	3	3	0	0	3	3
<b>Total</b>	<b>34,207</b>	<b>42,144</b>	<b>76,351</b>	<b>10,301</b>	<b>44,508</b>	<b>42,144</b>	<b>86,652</b>
	<b>Per cent</b>						
Male	45.1	54.9	100.0	100.0	52.0	48.0	100.0
Female	44.5	55.5	100.0	100.0	50.7	49.3	100.0
Unknown	0.0	100.0	100.0	100.0	0.0	100.0	100.0
<b>Total</b>	<b>44.8</b>	<b>55.2</b>	<b>100.0</b>	<b>100.0</b>	<b>51.4</b>	<b>48.6</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A27: NDR ascertainment for NDR-eligible NDSS registrants with derived Type 2 diabetes by age at first insulin use**

Age at first insulin use (years)	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
0–14	65	44	109	35	100	44	144
15–24	249	186	435	124	373	186	559
25–39	2,666	2,254	4,920	921	3,587	2,254	5,841
40–49	4,495	4,596	9,091	1,302	5,797	4,596	10,393
50–59	8,322	10,275	18,597	2,419	10,741	10,275	21,016
60–69	8,832	11,901	20,733	2,450	11,282	11,901	23,183
70–79	6,717	9,404	16,121	2,076	8,793	9,404	18,197
80+	2,401	3,173	5,574	925	3,326	3,173	6,499
Not stated	460	311	771	49	509	311	820
<b>Total</b>	<b>34,207</b>	<b>42,144</b>	<b>76,351</b>	<b>10,301</b>	<b>44,508</b>	<b>42,144</b>	<b>86,652</b>
	<b>Per cent</b>						
0–14	59.6	40.4	100.0	100.0	69.4	30.6	100.0
15–24	57.2	42.8	100.0	100.0	66.7	33.3	100.0
25–39	54.2	45.8	100.0	100.0	61.4	38.6	100.0
40–49	49.4	50.6	100.0	100.0	55.8	44.2	100.0
50–59	44.7	55.3	100.0	100.0	51.1	48.9	100.0
60–69	42.6	57.4	100.0	100.0	48.7	51.3	100.0
70–79	41.7	58.3	100.0	100.0	48.3	51.7	100.0
80+	43.1	56.9	100.0	100.0	51.2	48.8	100.0
Not stated	59.7	40.3	100.0	100.0	62.1	37.9	100.0
<b>Total</b>	<b>44.8</b>	<b>55.2</b>	<b>100.0</b>	<b>100.0</b>	<b>51.4</b>	<b>48.6</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A28: NDR ascertainment for NDR-eligible NDSS registrants with derived Type 2 diabetes by age at diagnosis**

Age at diagnosis (years)	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
0–14	113	60	173	45	158	60	218
15–24	541	350	891	150	691	350	1,041
25–39	4,653	3,071	7,724	1,126	5,779	3,071	8,850
40–49	7,499	4,944	12,340	1,470	8,969	4,944	13,913
50–59	8,430	6,081	14,388	1,765	10,195	6,081	16,276
60–69	5,940	4,556	10,462	1,373	7,313	4,556	11,869
70–79	2,971	2,210	5,308	788	3,759	2,210	5,969
80+	824	600	1,557	257	1,081	600	1,681
Not stated	3,236	20,272	23,508	3,327	6,563	20,272	26,835
<b>Total</b>	<b>34,207</b>	<b>42,144</b>	<b>76,351</b>	<b>10,301</b>	<b>44,508</b>	<b>42,144</b>	<b>86,652</b>
	<b>Per cent</b>						
0–14	65.3	34.7	100.0	100.0	72.5	27.5	100.0
15–24	60.7	39.3	100.0	100.0	66.4	33.6	100.0
25–39	60.2	39.8	100.0	100.0	65.3	34.7	100.0
40–49	60.8	40.1	100.0	100.0	64.5	35.5	100.0
50–59	58.6	42.3	100.0	100.0	62.6	37.4	100.0
60–69	56.8	43.5	100.0	100.0	61.6	38.4	100.0
70–79	56.0	41.6	100.0	100.0	63.0	37.0	100.0
80+	52.9	38.5	100.0	100.0	64.3	35.7	100.0
Not stated	13.8	86.2	100.0	100.0	24.5	75.5	100.0
<b>Total</b>	<b>44.8</b>	<b>55.2</b>	<b>100.0</b>	<b>100.0</b>	<b>51.4</b>	<b>48.6</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A29: NDR ascertainment for NDR-eligible NDSS registrants with derived Type 2 diabetes by state/territory of usual residence**

State/territory of usual residence	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
NSW	11,313	17,982	29,295	4,239	15,552	17,982	33,534
Vic	8,723	10,292	19,015	2,348	11,071	10,292	21,363
Qld	7,078	6,101	13,179	1,988	9,066	6,101	15,167
WA	4,171	1,584	5,755	671	4,842	1,584	6,426
SA	1,446	4,159	5,605	749	2,195	4,159	6,354
Tas	971	1,186	2,157	85	1,056	1,186	2,242
ACT	338	372	710	110	448	372	820
NT	165	464	629	110	275	464	739
Unknown	2	4	6	1	3	4	7
<b>Total</b>	<b>34,207</b>	<b>42,144</b>	<b>76,351</b>	<b>10,301</b>	<b>44,508</b>	<b>42,144</b>	<b>86,652</b>
	<b>Per cent</b>						
NSW	38.6	61.4	100.0	100.0	46.4	53.6	100.0
Vic	45.9	54.1	100.0	100.0	51.8	48.2	100.0
Qld	53.7	46.3	100.0	100.0	59.8	40.2	100.0
WA	72.5	27.5	100.0	100.0	75.4	24.6	100.0
SA	25.8	74.2	100.0	100.0	34.5	65.5	100.0
Tas	45.0	55.0	100.0	100.0	47.1	52.9	100.0
ACT	47.6	52.4	100.0	100.0	54.6	45.4	100.0
NT	26.2	73.8	100.0	100.0	37.2	62.8	100.0
Unknown	33.3	66.7	100.0	100.0	42.9	57.1	100.0
<b>Total</b>	<b>44.8</b>	<b>55.2</b>	<b>100.0</b>	<b>100.0</b>	<b>51.4</b>	<b>48.6</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A30: NDR ascertainment for NDR-eligible NDSS registrants with derived Type 2 diabetes by region of birth**

	Old form		Total	New form	All forms		Total
	On NDR	Not on NDR		On NDR	On NDR	Not on NDR	
<b>Region of birth</b>	<b>Number</b>						
Australian-born	15,955	7,754	23,709	2,315	18,270	7,754	26,024
Overseas-born	12,945	9,803	22,748	4,474	17,419	9,803	27,222
Not stated	5,307	24,587	29,894	3,512	8,819	24,587	33,406
<b>Total</b>	<b>34,207</b>	<b>42,144</b>	<b>76,351</b>	<b>10,301</b>	<b>44,508</b>	<b>42,144</b>	<b>86,652</b>
	<b>Per cent</b>						
Australian-born	67.3	32.7	100.0	100.0	70.2	29.8	100.0
Overseas-born	56.9	43.1	100.0	100.0	64.0	36.0	100.0
Not stated	17.8	82.2	100.0	100.0	26.4	73.6	100.0
<b>Total</b>	<b>44.8</b>	<b>55.2</b>	<b>100.0</b>	<b>100.0</b>	<b>51.4</b>	<b>48.6</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A31: NDR ascertainment for all eligible NDSS registrants with gestational diabetes by year of first insulin use**

Year of first insulin use	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
1999	378	312	690	2	380	312	692
2000	579	332	911	6	585	332	917
2001	711	447	1,158	5	716	447	1,163
2002	1,086	434	1,520	6	1,092	434	1,526
2003	786	400	1,186	228	1,014	400	1,414
2004	363	286	649	1,411	1,774	286	2,060
2005	137	150	287	1,186	1,323	150	1,473
Not stated	59	68	127	8	67	68	135
<b>Total</b>	<b>4,099</b>	<b>2,429</b>	<b>6,528</b>	<b>2,852</b>	<b>6,951</b>	<b>2,429</b>	<b>9,380</b>
	<b>Per cent</b>						
1999	54.8	45.2	100.0	100.0	54.9	45.1	100.0
2000	63.6	36.4	100.0	100.0	63.8	36.2	100.0
2001	61.4	38.6	100.0	100.0	61.6	38.4	100.0
2002	71.4	28.6	100.0	100.0	71.6	28.4	100.0
2003	66.3	33.7	100.0	100.0	71.7	28.3	100.0
2004	55.9	44.1	100.0	100.0	86.1	13.9	100.0
2005	47.7	52.3	100.0	100.0	89.8	10.2	100.0
Not stated	46.5	53.5	100.0	101.0	49.6	50.4	100.0
<b>Total</b>	<b>62.8</b>	<b>37.2</b>	<b>100.0</b>	<b>100.0</b>	<b>74.1</b>	<b>25.9</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A32: NDR ascertainment for NDR-eligible NDSS registrants with gestational diabetes by age at first insulin use**

Age at first insulin use (years)	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
< 20	27	27	54	24	51	27	78
20–24	248	130	378	176	424	130	554
25–29	970	509	1,479	580	1,550	509	2,059
30–34	1,466	848	2,314	1,049	2,515	848	3,363
35–39	1,017	655	1,672	810	1,827	655	2,482
40–44	284	184	468	190	474	184	658
45+	28	8	36	15	43	8	51
Not stated	59	68	127	8	67	68	135
<b>Total</b>	<b>4,099</b>	<b>2,429</b>	<b>6,528</b>	<b>2,852</b>	<b>6,951</b>	<b>2,429</b>	<b>9,380</b>
	<b>Per cent</b>						
< 20	50.0	50.0	100.0	100.0	65.4	34.6	100.0
20–24	65.6	34.4	100.0	100.0	76.5	23.5	100.0
25–29	65.6	34.4	100.0	100.0	75.3	24.7	100.0
30–34	63.4	36.6	100.0	100.0	74.8	25.2	100.0
35–39	60.8	39.2	100.0	100.0	73.6	26.4	100.0
40–44	60.7	39.3	100.0	100.0	72.0	28.0	100.0
45+	77.8	22.2	100.0	100.0	84.3	15.7	100.0
Not stated	46.5	53.5	100.0	100.0	49.6	50.4	100.0
<b>Total</b>	<b>62.8</b>	<b>37.2</b>	<b>100.0</b>	<b>100.0</b>	<b>74.1</b>	<b>25.9</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A33: NDR ascertainment for NDR-eligible NDSS registrants with gestational diabetes by age at diagnosis**

Age at diagnosis (years)	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
< 20	39	36	75	26	65	36	101
20–24	278	161	439	174	452	161	613
25–29	1,042	549	1,591	569	1,611	549	2,160
30–34	1,431	829	2,260	984	2,415	829	3,244
35–39	929	565	1,494	725	1,654	565	2,219
40–44	240	140	380	166	406	140	546
45+	22	6	28	12	34	6	40
Not stated	118	143	261	196	314	143	457
<b>Total</b>	<b>4,099</b>	<b>2,429</b>	<b>6,528</b>	<b>2,852</b>	<b>6,951</b>	<b>2,429</b>	<b>9,380</b>
	<b>Per cent</b>						
< 20	52.0	48.0	100.0	100.0	64.4	35.6	100.0
20–24	63.3	36.7	100.0	100.0	73.7	26.3	100.0
25–29	65.5	34.5	100.0	100.0	74.6	25.4	100.0
30–34	63.3	36.7	100.0	100.0	74.4	25.6	100.0
35–39	62.2	37.8	100.0	100.0	74.5	25.5	100.0
40–44	63.2	36.8	100.0	100.0	74.4	25.6	100.0
45+	78.6	21.4	100.0	100.0	85.0	15.0	100.0
Not stated	45.2	54.8	100.0	100.0	68.7	31.3	100.0
<b>Total</b>	<b>62.8</b>	<b>37.2</b>	<b>100.0</b>	<b>100.0</b>	<b>74.1</b>	<b>25.9</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A34: NDR ascertainment for NDR-eligible NDSS registrants with gestational diabetes by state/territory of usual residence**

State/territory of usual residence	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
NSW	1,450	1,172	2,622	1,420	2,870	1,172	4,042
Vic	1,097	393	1,490	588	1,685	393	2,078
Qld	861	426	1,287	483	1,344	426	1,770
WA	206	48	254	53	259	48	307
SA	226	199	425	241	467	199	666
Tas	141	74	215	5	146	74	220
ACT	101	62	163	38	139	62	201
NT	17	55	72	24	41	55	96
<b>Total</b>	<b>4,099</b>	<b>2,429</b>	<b>6,528</b>	<b>2,852</b>	<b>6,951</b>	<b>2,429</b>	<b>9,380</b>
	<b>Per cent</b>						
NSW	55.3	44.7	100.0	100.0	71.0	29.0	100.0
Vic	73.6	26.4	100.0	100.0	81.1	18.9	100.0
Qld	66.9	33.1	100.0	100.0	75.9	24.1	100.0
WA	81.1	18.9	100.0	100.0	84.4	15.6	100.0
SA	53.2	46.8	100.0	100.0	70.1	29.9	100.0
Tas	65.6	34.4	100.0	100.0	66.4	33.6	100.0
ACT	62.0	38.0	100.0	100.0	69.2	30.8	100.0
NT	23.6	76.4	100.0	100.0	42.7	57.3	100.0
<b>Total</b>	<b>62.8</b>	<b>37.2</b>	<b>100.0</b>	<b>100.0</b>	<b>74.1</b>	<b>25.9</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A35: NDR ascertainment for NDR-eligible NDSS registrants with gestational diabetes by region of birth**

	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
<b>Region of birth</b>	<b>Number</b>						
Australian-born	1,965	935	2,900	592	2,557	935	3,492
Overseas-born	1,473	1,110	2,583	1,334	2,807	1,110	3,917
Not stated	661	384	1,045	926	1,587	384	1,971
<b>Total</b>	<b>4,099</b>	<b>2,429</b>	<b>6,528</b>	<b>2,852</b>	<b>6,951</b>	<b>2,429</b>	<b>9,380</b>
	<b>Per cent</b>						
Australian-born	67.8	32.2	100.0	100.0	73.2	26.8	100.0
Overseas-born	57.0	43.0	100.0	100.0	71.7	28.3	100.0
Not stated	63.3	36.7	100.0	100.0	80.5	19.5	100.0
<b>Total</b>	<b>62.8</b>	<b>37.2</b>	<b>100.0</b>	<b>100.0</b>	<b>74.1</b>	<b>25.9</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A36: NDR ascertainment for all eligible NDSS registrants with other types of diabetes by year of first insulin use**

Year of first insulin use	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
1999	46	31	77	0	46	31	77
2000	94	38	132	1	95	38	133
2001	149	45	194	0	149	45	194
2002	110	39	149	0	110	39	149
2003	79	38	117	19	98	38	136
2004	44	26	70	75	119	26	145
2005	17	12	29	37	54	12	66
Not stated	24	17	41	1	25	17	42
<b>Total</b>	<b>563</b>	<b>246</b>	<b>809</b>	<b>133</b>	<b>696</b>	<b>246</b>	<b>942</b>
	<b>Per cent</b>						
1999	59.7	40.3	100.0	100.0	59.7	40.3	100.0
2000	71.2	28.8	100.0	100.0	71.4	28.6	100.0
2001	76.8	23.2	100.0	100.0	76.8	23.2	100.0
2002	73.8	26.2	100.0	100.0	73.8	26.2	100.0
2003	67.5	32.5	100.0	100.0	72.1	27.9	100.0
2004	62.9	37.1	100.0	100.0	82.1	17.9	100.0
2005	58.6	41.4	100.0	100.0	81.8	18.2	100.0
Not stated	58.5	41.5	100.0	101.0	59.5	40.5	100.0
<b>Total</b>	<b>69.6</b>	<b>30.4</b>	<b>100.0</b>	<b>100.0</b>	<b>73.9</b>	<b>26.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A37: NDR ascertainment for NDR-eligible NDSS registrants with other types of diabetes by sex**

Sex	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
Male	309	141	450	78	387	141	528
Female	254	105	359	55	309	105	414
<b>Total</b>	<b>563</b>	<b>246</b>	<b>809</b>	<b>133</b>	<b>696</b>	<b>246</b>	<b>942</b>
	<b>Per cent</b>						
Male	68.7	31.3	100.0	100.0	73.3	26.7	100.0
Female	70.8	29.2	100.0	100.0	74.6	25.4	100.0
<b>Total</b>	<b>69.6</b>	<b>30.4</b>	<b>100.0</b>	<b>100.0</b>	<b>73.9</b>	<b>26.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A38: NDR ascertainment for NDR-eligible NDSS registrants with other types of diabetes by age at first insulin use**

	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
<b>Age at first insulin use (years)</b>	<b>Number</b>						
0–14	55	16	71	14	69	16	85
15–24	62	14	76	17	79	14	93
25–39	91	48	139	17	108	48	156
40–49	72	35	107	25	97	35	132
50–59	104	37	141	18	122	37	159
60–69	92	38	130	25	117	38	155
70–79	49	28	77	10	59	28	87
80+	14	13	27	6	20	13	33
Not stated	24	17	41	1	25	17	42
<b>Total</b>	<b>563</b>	<b>246</b>	<b>809</b>	<b>133</b>	<b>696</b>	<b>246</b>	<b>942</b>
	<b>Per cent</b>						
0–14	77.5	22.5	100.0	100.0	81.2	18.8	100.0
15–24	81.6	18.4	100.0	100.0	84.9	15.1	100.0
25–39	65.5	34.5	100.0	100.0	69.2	30.8	100.0
40–49	67.3	32.7	100.0	100.0	73.5	26.5	100.0
50–59	73.8	26.2	100.0	100.0	76.7	23.3	100.0
60–69	70.8	29.2	100.0	100.0	75.5	24.5	100.0
70–79	63.6	36.4	100.0	100.0	67.8	32.2	100.0
80+	51.9	48.1	100.0	100.0	60.6	39.4	100.0
Not stated	58.5	41.5	100.0	100.0	59.5	40.5	100.0
<b>Total</b>	<b>69.6</b>	<b>30.4</b>	<b>100.0</b>	<b>100.0</b>	<b>73.9</b>	<b>26.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A39: NDR ascertainment for NDR-eligible NDSS registrants with other types of diabetes by age at diagnosis**

Age at diagnosis (years)	Old form			New form	All forms		
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
0–14	55	17	72	13	68	17	85
15–24	65	15	80	16	81	15	96
25–39	97	52	149	16	113	52	165
40–49	80	39	119	25	105	39	144
50–59	110	41	151	16	126	41	167
60–69	82	37	119	23	105	37	142
70–79	34	25	59	7	41	25	66
80+	10	10	20	6	16	10	26
Not stated	30	10	40	11	41	10	51
<b>Total</b>	<b>563</b>	<b>246</b>	<b>809</b>	<b>133</b>	<b>696</b>	<b>246</b>	<b>942</b>
	<b>Per cent</b>						
0–14	76.4	23.6	100.0	100.0	80.0	20.0	100.0
15–24	81.3	18.8	100.0	100.0	84.4	15.6	100.0
25–39	65.1	34.9	100.0	100.0	68.5	31.5	100.0
40–49	67.2	32.8	100.0	100.0	72.9	27.1	100.0
50–59	72.8	27.2	100.0	100.0	75.4	24.6	100.0
60–69	68.9	31.1	100.0	100.0	73.9	26.1	100.0
70–79	57.6	42.4	100.0	100.0	62.1	37.9	100.0
80+	50.0	50.0	100.0	100.0	61.5	38.5	100.0
Not stated	75.0	25.0	100.0	100.0	80.4	19.6	100.0
<b>Total</b>	<b>69.6</b>	<b>30.4</b>	<b>100.0</b>	<b>100.0</b>	<b>73.9</b>	<b>26.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A40: NDR ascertainment for NDR-eligible NDSS registrants with other types of diabetes by state/territory of usual residence**

State/territory of usual residence	Old form			New form		All forms	
	On NDR	Not on NDR	Total	On NDR	On NDR	Not on NDR	Total
	<b>Number</b>						
NSW	281	124	405	33	314	124	438
Vic	108	52	160	37	145	52	197
Qld	82	27	109	21	103	27	130
WA	43	16	59	19	62	16	78
SA	25	17	42	11	36	17	53
Tas	13	4	17	2	15	4	19
ACT	8	2	10	6	14	2	16
NT	3	4	7	4	7	4	11
<b>Total</b>	<b>563</b>	<b>246</b>	<b>809</b>	<b>133</b>	<b>696</b>	<b>246</b>	<b>942</b>
	<b>Per cent</b>						
NSW	69.4	30.6	100.0	100.0	71.7	28.3	100.0
Vic	67.5	32.5	100.0	100.0	73.6	26.4	100.0
Qld	75.2	24.8	100.0	100.0	79.2	20.8	100.0
WA	72.9	27.1	100.0	100.0	79.5	20.5	100.0
SA	59.5	40.5	100.0	100.0	67.9	32.1	100.0
Tas	76.5	23.5	100.0	100.0	78.9	21.1	100.0
ACT	80.0	20.0	100.0	100.0	87.5	12.5	100.0
NT	42.9	57.1	100.0	100.0	63.6	36.4	100.0
<b>Total</b>	<b>69.6</b>	<b>30.4</b>	<b>100.0</b>	<b>100.0</b>	<b>73.9</b>	<b>26.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

**Table A41: NDR ascertainment for NDR-eligible NDSS registrants with other types of diabetes by region of birth**

Region of birth	Old form		Total	New form	All forms		Total
	On NDR	Not on NDR		On NDR	On NDR	Not on NDR	
<b>Number</b>							
Australian-born	307	123	430	26	333	123	456
Overseas-born	182	88	270	44	226	88	314
Not stated	74	35	109	63	137	35	172
<b>Total</b>	<b>563</b>	<b>246</b>	<b>809</b>	<b>133</b>	<b>696</b>	<b>246</b>	<b>942</b>
<b>Per cent</b>							
Australian-born	71.4	28.6	100.0	100.0	73.0	27.0	100.0
Overseas-born	67.4	32.6	100.0	100.0	72.0	28.0	100.0
Not stated	67.9	32.1	100.0	100.0	79.7	20.3	100.0
<b>Total</b>	<b>69.6</b>	<b>30.4</b>	<b>100.0</b>	<b>100.0</b>	<b>73.9</b>	<b>26.1</b>	<b>100.0</b>

Source: AIHW analysis of National Diabetes Services Scheme data.

# Appendix B: Definitions and algorithms

## Eligible to be on the NDR

An NDSS registrant was identified as eligible to be on the NDR according to the following sequence of criteria:

1. if the date of first insulin injection was recorded and the year of first insulin injection was 1999 or later; or
2. if the date of first insulin injection was not recorded but the date of first syringe purchase was recorded and the year of first syringe purchase was 1999 or later; or
3. if neither the date of first insulin injection nor the date of first syringe purchase was recorded but the registrant's doctor or CDE has certified that insulin is required and the year of diagnosis was 1999 or later; or
4. if neither the date of first insulin injection nor the date of first syringe purchase was recorded but the registrant was recorded as having Type 1 diabetes and the year of diagnosis was 1999 or later.

If none of these criteria was met, the registrant was deemed not to be eligible to be on the NDR.

## Derivation of diabetes type

### People reporting Type 1

To obtain a more accurate measure of type of diabetes, the following algorithm was developed which reclassifies registrants believed to be incorrectly recorded as having Type 1 diabetes to Type 2 diabetes.

#### **For persons reporting Type 1 only:**

*If age at diagnosis is less than or equal to 40 years, or age at diagnosis is missing and age at first insulin use is less than or equal to 40 years, then diabetes type = 1 (that is, Type 1).*

*If age at diagnosis is over 40 years and the difference between the year of diagnosis with diabetes and the year of first insulin use is greater than 2 years, then diabetes type = 2 (that is, Type 2).*

*If age at diagnosis is over 40 years and the difference between the year of first insulin use and the year of diagnosis with diabetes is less than or equal to 2 years, then diabetes type = 1.*

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

## **Gestational diabetes mellitus**

The following algorithm was used to reclassify women aged 50 years and over who were recorded as having gestational diabetes mellitus (GDM) to Type 2 diabetes.

**For women reporting gestational diabetes mellitus only:**

*If age at diagnosis is less than 50 years, or age at diagnosis is missing and age at NDSS registration is less than 50 years, then diabetes type = 3 (that is, GDM).*

*If age at diagnosis is 50 years or over, or age at diagnosis is missing and age at NDSS registration is 50 years or over, then diabetes type = 2 (that is, Type 2).*

# **Appendix C: NDSS registration forms**

## **C.1 New NDSS registration form—July 2003**

# National Diabetes Services Scheme (NDSS) REGISTRATION FOR NDSS

The National Diabetes Services Scheme is a Commonwealth Government initiative administered by Diabetes Australia Ltd.

**Please read the explanatory notes before completing this form.**

## Section 1 – Details of Person with Diabetes *(This section **must** be completed before NDSS registration can be processed)*

Title:	Given Name(s):		Family Name:		Male <input type="checkbox"/>	Female <input type="checkbox"/>
Date of birth: DD / MM / YYYY	Maiden name:	Daytime/mobile phone number: ( )	Medicare No. <input type="checkbox"/> <i>(please tick one)</i>	OR DVA File No.:		
Address: House number		Street name	Suburb or town	State	Postcode	
Postal address: <i>(if different from above)</i>						
Country of birth:	Main language spoken at home:	Are you of Aboriginal or Torres Strait Islander origin? No <input type="checkbox"/> Yes (Aboriginal) <input type="checkbox"/> Yes (Torres Strait Islander) <input type="checkbox"/>				
<b>Detail relating to diagnosis:</b>		MM / YYYY	<i>(if the date is not known please tick a category to provide an indication)</i>			
When did a doctor first diagnose your diabetes?		Last year <input type="checkbox"/>	1-2 years ago <input type="checkbox"/>	3-5 years ago <input type="checkbox"/>	more than 5 years ago <input type="checkbox"/>	
Residence at time of diagnosis: Suburb or town Postcode Country						
I certify that I require NDSS products and services for the management of my diabetes. (Signature) <b>X</b>						

## Section 2 – Details of Person in charge/carer *If the person with diabetes is under 15 years of age or is an adult receiving continuing care, this section should be completed by a parent or person responsible for care (person in charge).*

Title:	Given Name(s):		Family Name:		Date of birth: DD / MM / YYYY
Address: House number		Street name	Suburb or town	State	Postcode
Is this mailing address to be used for the person with diabetes? Yes <input type="checkbox"/> No <input type="checkbox"/>			Daytime telephone number: ( )		
Relationship to person with diabetes:		I certify that NDSS products and services are required for the management of diabetes for the person in my charge/care. (Signature) <b>X</b>			

## Section 3 – Certification by a Health Professional *(This section **must** be completed and signed by a Medical Practitioner or Credentialed Diabetes Educator–RN (CDE–RN) before NDSS registration can be completed.)*

Type of Diabetes: <i>(See tear-off opposite for diabetes definitions)</i>	
<input type="checkbox"/> Type 1	<input type="checkbox"/> Gestational Diabetes
<input type="checkbox"/> Type 2 insulin requiring	Other Diabetes <i>(please specify)</i>
<input type="checkbox"/> Type 2 non insulin requiring	
Are insulin injections required? Yes <input type="checkbox"/> No <input type="checkbox"/>	If Yes, date of first insulin injection: MM / YYYY
<i>(if the date is not known please tick a category to provide an indication)</i> Last year <input type="checkbox"/> 1-2 years ago <input type="checkbox"/> 3-5 years ago <input type="checkbox"/> more than 5 years ago <input type="checkbox"/>	
Medical practitioner or Credentialed Diabetes Educator - RN's name: <i>(please print)</i>	
Business address:	
Phone number: ( )	
Type of Health Professional <input type="checkbox"/> GP <input type="checkbox"/> Endocrinologist <input type="checkbox"/> Other medical practitioner <input type="checkbox"/> CDE-RN	
<b>I confirm that I have performed the diagnosis or sighted written documentation relating to the diagnosis of diabetes for this applicant (refer to the attached notes for further information).</b>	
Signature <b>X</b>	
Doctor Provider number <i>or</i> CDE Registered Nurse number	

## Section 4 - Research Opportunities *From time to time, opportunities will arise for people with diabetes to participate in research activities related to diabetes, its management and the prospects of finding a cure.*

Would you like to receive information about these opportunities as they arise? Yes  No

## Section 5 – Diabetes Australia *Diabetes Australia has member organisations in each State and Territory. Their role is to help people manage diabetes through information and products and actively support research into diabetes. Registration with NDSS does not automatically provide membership of Diabetes Australia.*

Are you currently a subscribing member of a Diabetes Australia State or Territory Association? Yes  No

If you have ticked 'No' above would you like to receive information about the benefits of membership of Diabetes Australia? Yes  No

## Office Use Only

NDSS card number:	Card issued by:	Date:
Checked by:	Date:	

If you have any queries regarding the completion of this form or the NDSS please call **1300 136 588**. Send the completed form to **Diabetes Australia - NDSS, GPO Box 9824** in your capital city, or hand to the staff member assisting you.

Diabetes Australia ABN 47 008 528 461  
Quality Assured Company AS/NZS ISO 9001:2000 registration no:431 (NDSS only)

## Overseas Visitors

If you are a visitor to Australia, and from a country with a Reciprocal Health Care Agreement with the Australian Government, you may be entitled to temporary registration with the NDSS. Please call Diabetes Australia on 1300 136 588 for further information.



DIABETES AUSTRALIA

## Diabetes Australia Membership Benefits

Diabetes Australia is a community and donor based organisation dedicated to assisting people with diabetes. Membership subscription helps the organisation to continue this vital work.

Ticking the appropriate box in section 5 will allow Diabetes Australia to make available information about becoming a member. Membership entitles you to:

- purchase blood glucose meters, books, blood letting devices, special injection systems and other products at **member prices**.
- quarterly copies of **Conquest**, our national magazine, plus the local Association's magazine. These publications provide the latest information on diabetes education, research, diet and lifestyle, along with advice about children's camps, support groups, branch meetings and information about everyday people meeting the challenge of living with diabetes.

Diabetes Australia represents the interests of people with diabetes at State/Territory and Commonwealth Government forums. With over 60 years service, Diabetes Australia is uniquely placed to meet the special needs of ALL people with diabetes.



DIABETES AUSTRALIA  
Research Trust

Diabetes Australia established a Research Trust (DART) in 1987 and now funds some 30 research projects each year. The projects are working towards a cure, or better management, of Type 1 and Type 2 diabetes.

**For further information contact The Office of Diabetes Research, Phone 02 6232 3800 or email [dart@diabetesaustralia.com.au](mailto:dart@diabetesaustralia.com.au)**



## Juvenile Diabetes Research Foundation (JDRF)

JDRF is dedicated to finding a cure for Type 1 diabetes and its complications through the support of medical research.

Recognising the special needs of children with diabetes, JDRF also provides practical support to families living with the disease.

**For information about JDRF please call 1300 363 126 or visit [www.jdrf.org.au](http://www.jdrf.org.au)**

---

## There is no cost to register for NDSS.

To qualify for NDSS benefits the applicant must first complete this Registration Form, have it signed by a medical practitioner or Credentialed Diabetes Educator - RN and either mail it to: **Diabetes Australia, GPO Box 9824 (insert your State/Territory capital city and its postcode)** OR visit the Diabetes Australia office in their capital city.

Phone 1300 136 588 to contact the nearest office.



DIABETES AUSTRALIA

## Explanatory Notes Completing the NDSS Registration Form

### Please use a separate form for each person with diabetes

Registration for NDSS benefits is free of charge and covers the registrant for life. The benefits of the NDSS are outlined on the reverse of this form.

#### Section 1 - Details of person with diabetes

Registration with the NDSS requires a certain amount of personal information. The information you provide is protected by Commonwealth laws, including the *Privacy Act 1988*. Diabetes Australia respects all aspects of your privacy and your personal information will not be accessed, other than as listed in this section, without your express permission.

The personal information you provide by completing this Registration Form helps ensure high quality NDSS products and services are delivered to the correct individuals.

The planning and development of high quality services to assist people with diabetes depends on understanding more about the effect diabetes has on these people, their families and their communities. In accordance with the strict requirements of the Commonwealth privacy legislation, NDSS information may be provided to legally authorised agencies for statistical and/or analytical activities to help us gain this understanding. At the present time, these activities are undertaken by the Australian Institute of Health and Welfare. You can be assured that your personal details will remain confidential at all times.

You may access the personal information we collect about you, at any stage, by contacting the Diabetes Australia office in your State/Territory, or by writing to:

**The Privacy Officer  
Diabetes Australia Ltd  
GPO Box 3156  
Canberra ACT 2601**

#### Section 2 - Details of person in charge/carer

If you are responsible for a child (or children) or for the care of an adult with diabetes, you may be the 'cardholder'. In these cases you must complete Section 2 of the form.

#### Section 3 - Certification by a Health Professional

Please make sure a Medical Practitioner or Credentialed Diabetes Educator - RN completes this section in full and signs it so that your application for registration can be processed without delay. (This is essential for NDSS registration.)

**Type 1 diabetes**, also known as insulin dependent diabetes mellitus, IDDM, or juvenile-onset diabetes mellitus. People with Type 1 diabetes have total insulin deficiency and require daily insulin injections. The condition is caused by autoimmune destruction of the insulin producing beta cells.

**Type 2 diabetes**, also known as non-insulin dependent diabetes mellitus, NIDDM, or adult-onset diabetes. This is by far the most common Type of diabetes. Although people with Type 2 diabetes have normal or even increased insulin secretion the condition is characterised by insulin resistance causing hyperglycaemia. **Up to 30% of patients eventually require insulin injections.**

**Gestational diabetes** or pregnancy-induced diabetes. This type of diabetes develops in a pregnant woman, and usually goes away after the birth of the child.

**"Other specific types"**. This category includes diabetes caused by a genetic defect, pancreatic diseases, hormonal abnormalities, or exposure to certain drugs or chemicals.

**NOTE - Impaired Glucose Tolerance (IGT).** Eligibility for registration with the NDSS does not extend to IGT.

**The National Diabetes Services Scheme is a Commonwealth Government initiative administered by Diabetes Australia Ltd.  
Contact Diabetes Australia on 1300 136 588**

## National Diabetes Services Scheme NDSS

### Explanatory Notes

**What is the NDSS?** – The National Diabetes Services Scheme, or NDSS, is a Commonwealth program that provides people who register with the Scheme with access to a range of Commonwealth-approved products including syringes, needles for special injection pens and blood and urine test strips, at subsidised prices. These prices are generally below those of other sources of supply.

Diabetes Australia has administered the Scheme since 1987.

#### Who can register for NDSS?-

People who reside in Australia and:

- Have been diagnosed as having diabetes, and
- Hold or are eligible to hold an Australian Medicare card are entitled to register for the NDSS.

**Registration** – There is no charge for registration for the NDSS. To qualify for NDSS benefits you must first complete this Registration Form and have it signed by a medical practitioner or Credentialed Diabetes Educator - RN. You should then either mail it to: Diabetes Australia, GPO Box 9824 in your State/Territory capital city, OR visit the Diabetes Australia office in your capital city. You can contact Diabetes Australia on 1300 136 588 if you have any questions.

**Information and Education** – From time to time, Diabetes Australia and/or the Commonwealth Department of Health and Ageing may send people who register for the Scheme, information that will assist them with the effective management of their diabetes and material that informs them about the operation of the NDSS. There are no charges for these services and personal details are kept confidential at all times.

#### For more information

**Call 1300 136 588 or write to Diabetes Australia, GPO Box 9824 (insert the name of your State/ Territory capital city and its postcode), or visit the internet site at [www.diabetesaustralia.com.au](http://www.diabetesaustralia.com.au)**

**After reading this leaflet,  
please tear it off  
and keep it for future reference**

## **C.2 Old NDSS registration form—January 2002**

*Note:* Older versions of the old NDSS registration form were also produced in July 1999, January 1999, February 1998, August 1997, November 1996, January 1996, June 1993, August 1989, November 1988 and July 1987.



National Diabetes Services Scheme (NDSS)  
Registration for NDSS Card

The National Diabetes Services Scheme is a Commonwealth Government initiative administered by Diabetes Australia Ltd.  
Diabetes Australia ABN 47 008 528 461 Quality Assured Company AS/NZS ISO 9001:2000 registration no:431 (NDSS only)

**Section 1 Details of person with diabetes**

Date of birth Day  Month  Year   
 Mr  Mrs  Ms  Miss  Other   
 First name(s) (Please print all information clearly)  
  
 Surname  
  
 Other names (for example, maiden name)  
 Male  Female   
 Address  
  
 Postcode  
  
 Daytime contact phone  
 ( )  
  
 Country of birth  
  
 Are you of Aboriginal or Torres Strait Islander origin?  
 No  Yes, Aboriginal  Yes, Torres Strait Islander   
 Date diabetes first diagnosed Month  Year   
 Suburb/Town Postcode  
  
 Residence at time of diagnosis with diabetes  
  
 Do you need insulin injections? Yes  No   
 Date of first insulin injection Month  Year   
 Medicare number

**Details of person in charge/carer**

If the person with diabetes is under 18 years of age or is an adult receiving continuing care, a parent, carer or person responsible for care (person in charge) should complete and sign this section of the form.  
 Mr  Mrs  Ms  Miss  Other   
 First name(s) Surname  
  
 Address  
  
 Postcode  
  
 Daytime contact phone Relationship to person with diabetes  
 ( )  
  
 Signature of person in charge/carer

**Certification**

I certify that I require NDSS products for the treatment of diabetes for myself or my dependant.  
 Signature Date  
  
 Person with diabetes  Person in charge/carer

**Section 2 National Diabetes Register**

We would like your permission to include the information on this form in the National Diabetes Register. This will help show how many people are diagnosed with diabetes in Australia. It can also help research on the best ways to prevent and treat the problem. The staff at Diabetes Australia or the person helping you with this NDSS Registration Form can explain the register and its importance to you. Please read the tear-off brochure attached to this form. In signing this section, you agree that you have read and understood the brochure. If you do not want to take part in the register, this will not affect your NDSS eligibility and you will still receive an NDSS card.

**By signing this section I agree to the information on this form being included in the National Diabetes Register.**

Signature of person with diabetes or person in charge/carer Date

**Section 3 Declaration by Medical Practitioner / Credentialed Diabetes Educator - RN**

This section must be completed and signed by a Medical Practitioner or Credentialed Diabetes Educator -RN (CDE-RN) before NDSS registration can be completed.  
 Type 1 (Insulin Dependent Diabetes)  
 Type 2 (Insulin requiring)  Type 2 (Non Insulin requiring)  
 Gestational Diabetes  
 Other Diabetes

See the box on the reverse side of this form for diabetes definitions.  
 Are insulin injections required? Yes  No

Name - Medical practitioner or Credentialed Diabetes Educator - RN  
  
 Business address  
  
 Postcode

Doctor Provider number or CDE Registered Nurse number  
  
 Phone number ( )

GP  Endocrinologist  
 Specialist Physician  Other medical practitioner

I confirm that I have performed the diagnosis or sighted written documentation relating to the diagnosis of diabetes for this applicant (refer to the attached notes for further information).

**Section 4 Diabetes Australia information**

Are you a subscribing member of a Diabetes Australia State or Territory Association? Yes  No   
 Would you like to receive information about Diabetes Australia and diabetes management, research and education?  
 Yes  No

**Office use only** NDSS card number   
 Duplicate check Entered in database Card issued by  
 Initials   
 Date

Please send the completed form to **Diabetes Australia, GPO Box 9824** in your capital city. F70-0047 0102



**Completing the NDSS Registration Form**

**Section 1**

This section relates to your once-only registration for the benefits of the National Diabetes Services Scheme (NDSS). The benefits of the NDSS are outlined on the reverse side of the form.

Please use a separate form for each person with diabetes.

Section 1 requests personal identification information, including ethnicity. A person of both Aboriginal and Torres Strait Islander origin may tick both boxes under Are you of Aboriginal and Torres Strait Islander origin?. The personal information is very important for determining the impact of diabetes on different groups of people and the planning of printed material and services for them.

**Parents and persons in charge/carers**

If you are responsible for a child (or children) or for the care of an adult with diabetes, you may be the 'cardholder'. In these cases you must complete the **Details of person in charge/carer** section of the form.

**Section 2**

This section requests consent for your participation in the National Diabetes Register.

If you give your consent, your personal details will be included in the register. You may also be contacted by researchers to take part in a research project.

Please refer to the National Diabetes Register Information Brochure on the reverse of this page for more information.

Note: You are not required to sign Section 2 in order to register for NDSS benefits.

**Section 3**

Please make sure a Medical Practitioner or Credentialed Diabetes Educator completes this section in full and signs it so that your application for registration can be processed without delay. (This is essential for NDSS registration).

**Section 4**

This section asks whether you are a subscribing member of Diabetes Australia and whether you wish to receive information about managing diabetes from Diabetes Australia.

**Your privacy**

Diabetes Australia is obliged to meet Commonwealth privacy standards and information you provide on this form is kept strictly confidential.

**The NDSS and the National Diabetes Register**

The NDSS is a Commonwealth Government initiative administered by Diabetes Australia. The NDSS is separate from the National Diabetes Register. You will have access to NDSS benefits when you have completed the attached Registration Form, had a Medical Practitioner or Credentialed Diabetes Educator sign it and sent it to Diabetes Australia. Your NDSS card will be sent to you.

**Contact Diabetes Australia on 1300 136 588**



## National Diabetes Register Information Brochure

(After reading this leaflet, please tear it off the Registration Form and keep it for future reference)

### What is the National Diabetes Register?

The register is a record of people in Australia with diabetes who use insulin. For each person, the register includes:

- name and address
- date of birth
- country of birth
- type of diabetes
- when the diabetes was diagnosed
- if insulin is used, when this began.

### Why is the register important?

The register will help show how many people are diagnosed with diabetes in Australia each year and whether the disease is being controlled or not. Also, the register will help researchers find better ways to prevent and treat diabetes.

### Who runs the register?

The Australian Institute of Health and Welfare (AIHW) is funded by the Commonwealth Government to maintain the register. The AIHW was set up under Commonwealth legislation to collect important national information on health and welfare. This legislation sets conditions that strictly guard the privacy of people on the register.

### Who has access to information on the register?

First, people on the register can have access at any time to information about themselves.  
Second, staff at the AIHW must have access to the information so they can keep it up to date.  
Third, researchers may be allowed to use the information, but only under strict conditions.

### How is the register used in research?

Research that uses the register must be judged by scientific committees to be important and ethical. These committees will also ensure that the privacy of people on the register is protected.

Much of the research can be done without names. But where researchers need to gather more information, they may want to contact people on the register. In this case, the AIHW will not hand over your information unless it has been in contact with you and obtained your permission to do so.

### Do I have to take part in this register or in any research?

We strongly encourage you to be on the register. Without you, there will be a missing piece in the national diabetes picture. But the decision is yours and you are under no obligation.  
If you are approached to take part in a research project, you are free to decide whether to be in it or not.  
Finally, you can withdraw from the register, or any research project, at any time.

### How can I find out more about the register?

For more information on the National Diabetes Register (NDR) please call **1300 136 588**.

## National Diabetes Services Scheme NDSS

### What is the NDSS?

The NDSS is a Commonwealth Government program that provides blood and urine testing strips, syringes and needles for special injection systems at subsidised prices to people who register for its benefits.

Diabetes Australia has administered the NDSS for the Commonwealth since 1987.

### Who can register for the NDSS?

People who reside in Australia and  
– have been diagnosed as having diabetes and  
– hold or are eligible for an Australian Medicare card  
are entitled to register for Commonwealth Government subsidised products.

To qualify for NDSS benefits you must first complete this Registration Form, have it signed by your Medical Practitioner or Credentialed Diabetes Educator and either mail it to Diabetes Australia GPO Box 9824 (insert your State/Territory capital city and its postcode) OR visit the Diabetes Australia office in your capital city. Phone **1300 136 588** to contact your nearest office.

There is no cost to register for the NDSS.

### What are the benefits of the NDSS?

Approved products - syringes, needles for special injection pens and blood and urine test strips - are available at subsidised prices generally below those of other sources of supply.

### For more information

Call **1300 136 588** or write to Diabetes Australia, GPO Box 9824 (insert the name of your State/Territory capital city and its postcode), or visit the internet site at [www.diabetesaustralia.com.au](http://www.diabetesaustralia.com.au)

## Diabetes Australia Membership Benefits

Diabetes Australia is a community and donor based organisation dedicated to assisting people with diabetes. Membership subscription helps the organisation to continue this vital work.

Ticking the appropriate box in section 4 will allow Diabetes Australia to make available information about becoming a member. Membership entitles you to:

- purchase blood glucose meters, books, blood letting devices, special injection systems and other products at **member prices**.
- quarterly copies of **Conquest**, our national magazine, plus the local Association's magazine. These publications provide the latest information on diabetes education, research, diet and lifestyle, along with advice about children's camps, support groups, branch meetings and information about everyday people meeting the challenge of living with diabetes.
- details of Government policies that affect people with diabetes and their families.

Diabetes Australia represents the interests of people with diabetes at State/Territory and Commonwealth Government forums. With over 60 years service, Diabetes Australia is uniquely placed to meet the special needs of ALL people with diabetes, all of the time. At Diabetes Australia-we care.

### Types of diabetes (to assist with the completion of Section 3 overleaf):

**Type 1** (formerly known as Insulin Dependent Diabetes Mellitus or IDDM) is characterised by autoimmune mediated destruction of the insulin-secreting pancreatic beta cells. It does not include forms of beta cell failure for which a non-autoimmune specific cause can be assigned, for example cystic fibrosis or chronic pancreatitis.

**Type 2** (formerly known as Non-insulin Dependent Diabetes Mellitus or NIDDM) usually arises because of insulin resistance, in which the body fails to use insulin properly, combined with a relative deficiency in the production of insulin. Insulin injections may be required in Type 2 diabetes.

**Gestational diabetes** is any degree of glucose intolerance with onset or first recognition during pregnancy. After the pregnancy ends, the woman should be re-classified as having either diabetes, impaired glucose tolerance, or normal glucose tolerance based on the results of a 75 gram OGTT six weeks or more after delivery.

**Other diabetes** is a condition in which the underlying defect or disease process can be identified in a relatively specific manner. It includes, for example, Fibrocalculus pancreatopathy, Pancreatitis, Cystic Fibrosis, Trauma/pancreatectomy, genetic defects of beta-cell function (for example, MODY) and genetic defects of insulin action (for example, Type A insulin resistance).

# References

AIHW (Australian Institute of Health and Welfare) 2001. National diabetes register statistical profile, December 2000. AIHW cat. no. CVD 18 (Diabetes Series No. 2). Canberra: AIHW.

Colagiuri S, Colagiuri R & Ward J 1998. National diabetes strategy and implementation plan. Canberra: Diabetes Australia.

DoHA (Department of Health and Ageing) 2005. National Diabetes Services Scheme (NDSS). Viewed 23 November 2005,

<<http://www.health.gov.au/internet/wcms/publishing.nsf/content/health-pbs-healthpro-supply-ndss.htm>>.

Diabetes Australia 2005. Fact Sheet: National Diabetes Services Scheme (NDSS) 30th June 2005. Viewed 23 November 2005,

<[http://www.diabetesaustralia.com.au/ndss/doc\\_pdf/NDSS-Fact-Sheet.pdf](http://www.diabetesaustralia.com.au/ndss/doc_pdf/NDSS-Fact-Sheet.pdf)>.

WHO (World Health Organization) 1999. Definition, diagnosis and classification of diabetes mellitus and its complications: report of WHO consultation – Part 1: Diagnosis and classification of diabetes mellitus 1999. Geneva: WHO.

# List of tables

Table 4.1: Number of NDR-eligible NDSS registrants by year of registration and type of registration form as at 1 July 2005.....	9
Table 4.2: Sociodemographic profile of NDSS registrants eligible to be on the NDR as at 1 July 2005.....	11
Table 4.3: Ascertainment rates for the NDR as at 1 July 2005 for all NDR-eligible NDSS registrants by selected sociodemographic characteristics .....	17
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.....	18
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 .....	21
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.....	23
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 .....	25
Table 7.1: Sociodemographic profile of NDR-eligible NDSS registrants with derived Type 2 diabetes as at 1 July 2005 .....	27
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.....	29
Table 8.1: Sociodemographic profile of NDR-eligible NDSS registrants with gestational diabetes as at 1 July 2005 .....	32
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.....	34
Table 9.1: Sociodemographic profile of NDR-eligible NDSS registrants with other types of diabetes as at 1 July 2005.....	36
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.....	38
Table A1: Proportion of NDSS registrants eligible to be on the NDR who are on the NDR by year of NDSS registration and year of first insulin use .....	44
Table A2: Contribution of old form registrations to NDR ascertainment rates by year of NDSS registration and year of first insulin use.....	45
Table A3: Contribution of new form registrations to NDR ascertainment rates by year of NDSS registration and year of first insulin use.....	46

Table A4: NDR ascertainment for all NDR-eligible NDSS registrants by year of NDSS registration .....	47
Table A5: NDR ascertainment for all NDR-eligible NDSS registrants by year of first insulin use.....	49
Table A6: NDR ascertainment for all NDR-eligible NDSS registrants by reported type of diabetes .....	50
Table A7: NDR ascertainment for all NDR-eligible NDSS registrants by derived type of diabetes .....	50
Table A8: NDR ascertainment for all NDR-eligible NDSS registrants by sex .....	51
Table A9: NDR ascertainment for all NDR-eligible NDSS registrants by age at first insulin use.....	52
Table A10: NDR ascertainment for all NDR-eligible NDSS registrants by age at diagnosis....	53
Table A11: NDR ascertainment for all NDR-eligible NDSS registrants by state/territory of usual residence .....	54
Table A12: NDR ascertainment for all NDR-eligible NDSS registrants by region of birth .....	55
Table A13: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by year of first insulin use.....	55
Table A14: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by sex .....	56
Table A15: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by age at first insulin use .....	56
Table A16: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by age at diagnosis.....	57
Table A17: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by state/territory of usual residence.....	58
Table A18: NDR ascertainment for NDR-eligible NDSS registrants aged 0–14 years at first insulin use with Type 1 diabetes by region of birth.....	59
Table A19: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by year of first insulin use.....	59
Table A20: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by sex .....	60
Table A21: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by age at first insulin use .....	60
Table A22: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by age at diagnosis.....	61
Table A23: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by state/territory of usual residence.....	62
Table A24: NDR ascertainment for NDR-eligible NDSS registrants aged 15–39 years at first insulin use with Type 1 diabetes by region of birth.....	63

Table A25: NDR ascertainment for all eligible NDSS registrants with derived Type 2 diabetes by year of first insulin use.....	64
Table A26: NDR ascertainment for NDR-eligible NDSS registrants with derived Type 2 diabetes by sex.....	65
Table A27: NDR ascertainment for NDR-eligible NDSS registrants with derived Type 2 diabetes by age at first insulin use.....	66
Table A28: NDR ascertainment for NDR-eligible NDSS registrants with derived Type 2 diabetes by age at diagnosis.....	67
Table A29: NDR ascertainment for NDR-eligible NDSS registrants with derived Type 2 diabetes by state/territory of usual residence.....	68
Table A30: NDR ascertainment for NDR-eligible NDSS registrants with derived Type 2 diabetes by region of birth.....	69
Table A31: NDR ascertainment for all eligible NDSS registrants with gestational diabetes by year of first insulin use.....	70
Table A32: NDR ascertainment for NDR-eligible NDSS registrants with gestational diabetes by age at first insulin use.....	71
Table A33: NDR ascertainment for NDR-eligible NDSS registrants with gestational diabetes by age at diagnosis.....	72
Table A34: NDR ascertainment for NDR-eligible NDSS registrants with gestational diabetes by state/territory of usual residence.....	73
Table A35: NDR ascertainment for NDR-eligible NDSS registrants with gestational diabetes by region of birth.....	74
Table A36: NDR ascertainment for all eligible NDSS registrants with other types of diabetes by year of first insulin use.....	75
Table A37: NDR ascertainment for NDR-eligible NDSS registrants with other types of diabetes by sex.....	75
Table A38: NDR ascertainment for NDR-eligible NDSS registrants with other types of diabetes by age at first insulin use.....	76
Table A39: NDR ascertainment for NDR-eligible NDSS registrants with other types of diabetes by age at diagnosis.....	77
Table A40: NDR ascertainment for NDR-eligible NDSS registrants with other types of diabetes by state/territory of usual residence.....	78
Table A41: NDR ascertainment for NDR-eligible NDSS registrants with other types of diabetes by region of birth.....	79

# List of figures

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 .....	12
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 .....	13
Figure 4.3: Proportion of NDR-eligible NDSS registrants who were on the NDR as at 1 July 2005 by type of diabetes .....	15
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 .....	16
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 .....	20
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 .....	24
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 .....	28
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 .....	33
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 .....	37
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 .....	40