

DIABETES SERIES
Number 2

National Diabetes Register

**Statistical Profile
December 2000**

September 2001

Australian Institute of Health and Welfare
Canberra

AIHW cat. no. CVD 18

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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 Publications Unit, Australian Institute of Health and Welfare, GPO Box 570, Canberra ACT 2601, or via the Institute's web site (<http://www.aihw.gov.au>).

ISSN 1444-8033

ISBN 1 74024 141 X

Suggested citation

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.

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Published by Australian Institute of Health and Welfare

Printed by National Capital Printing

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Acknowledgments

Diabetes is a National Health Priority Area. The National Diabetes Register has been funded by the Commonwealth Department of Health and Aged Care as one of the initiatives under the National Diabetes Strategy to address the impact of diabetes on the health of Australians.

This report was prepared by Ilona Brockway and Phil Trickett of the Australian Institute of Health and Welfare, with input from the National Diabetes Register Management Committee.

The assistance of Diabetes Australia and the Australasian Paediatric Endocrine Group (APEG) in the provision of data and the ongoing development of the Register is greatly appreciated.

For further information on the Register and the statistics in this report, please contact Mr Phil Trickett on ph (02) 6244 1097 or e-mail phil.trickett@aihw.gov.au .

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Foreword

This seminal report from the Australian Institute of Health and Welfare (AIHW) reports for the first time on the National Diabetes Register. It is an exciting milestone for statistical data on diabetes, specifically Type 1 diabetes.

The Register is the result of strong personal commitment from many people. Outside the Institute, these included the Commonwealth Minister for Health, Dr Michael Wooldridge; the Chair of the Ministerial Advisory Committee on Diabetes (MACOD) from 1996–1998, Dr John Carter; the members of MACOD; the Chair of the National Diabetes Register Management Committee, Associate Professor Peter Colman; the members of the Management Committee, Diabetes Australia; and the Australasian Paediatric Endocrine Group. To all of them is owed a strong debt of gratitude. Putting a new register of this nature in place is a major undertaking, with issues of confidentiality, consent, design and analysis to be solved. Issues remain, but the first report graphically illustrates the value of persistence with this endeavour.

Within the Institute, Ilona Brockway and Phil Trickett have steered the Register for the last two years. Paul Jelfs and John Harding have provided ongoing leadership in planning and implementation. Other AIHW staff who played a role in the developmental process of the Register include Bonnie Field, Michelle McPherson and Rebecca Bentley.

I commend this first report on the National Diabetes Register to all those interested in or affected by diabetes, as the first of an ongoing series of reports to guide policy and research in the future.

Richard Madden
Director

Abbreviations

ABS	Australian Bureau of Statistics
ADEA	Australian Diabetes Educators Association
AIHW	Australian Institute of Health and Welfare
APEG	Australasian Paediatric Endocrine Group
AusDiab	Australian Diabetes, Obesity and Lifestyle Study
DA	Diabetes Australia
DHAC	Commonwealth Department of Health and Aged Care
GDM	Gestational diabetes mellitus
IDI	International Diabetes Institute
ITDM	Insulin treated diabetes mellitus
JDRF	Juvenile Diabetes Research Foundation
MACOD	Ministerial Advisory Committee on Diabetes
Menzies Centre	The Menzies Centre for Population Health
NADC	National Association of Diabetes Centres
NDI	National Death Index
NDR	National Diabetes Register
NDS	National Diabetes Strategy
NDSS	National Diabetic Services Scheme
NHS	National Health Survey
NNS	National Nutrition Survey
Register	The National Diabetes Register
TITDR	Tasmania Insulin Treated Diabetes Register

Summary

The *National Diabetes Register Statistical Profile, December 2000* describes the 13,347 people who began to use insulin between 1 January 1999 and 31 December 2000, and consented to be on the National Diabetes Register. This information will assist planners of diabetes services, and government and non-government organisations. It will provide a statistical reference point for diabetes researchers wishing to access the Register for epidemiological studies, after obtaining appropriate peer review and ethics committee protocol approvals.

The main features of the people on the Register were:

- There were 6,847 males and 6,500 females who registered in 1999 and 2000.
- The sex ratio varied with age. For ages less than 25 years, numbers of males and females were similar. At ages 25–44 years, females strongly outnumbered males, reflecting the effect of gestational diabetes in women from this group. For older age groups (45–74 years), there were 37% more male registrants than females.
- More than 60% of registrants were aged 45 and over, compared with 10% aged under 15 years.
- The peak ages for diagnosis with insulin-treated diabetes for males were between 45 and 64 years (40% of all male registrants), whereas the effect of gestational diabetes made the ages between 25 and 64 years the peak ages for diagnosis for females (34% of all female registrants).
- The median age at diagnosis was 14.5 years for registrants diagnosed with Type 1 diabetes, and 53.7 years for registrants diagnosed with Type 2 diabetes.
- The number of registrants across metropolitan, rural and remote zones as a proportion of the population living in each zone was generally similar.
- Aboriginal and Torres Strait Islander records make up almost 2% of all records. However, this percentage does not reflect the higher prevalence of diabetes reported among the Indigenous population. This is largely because the Register is not currently sourcing information for many Indigenous people with diabetes who use Aboriginal Medical Services.
- Death rates for registrants in 1999 and 2000 were three and a half times that of the general Australian community.
- The incidence of diabetes among children aged 0–14 years (predominantly Type 1) in 2000 was estimated at 18.9 new cases per 100,000 population. The rates were similar for males and females, and between metropolitan and rural areas.
- Australian residents born in North Africa and the Middle East (Lebanon is the largest source country in this group), and Southern and Central Asia (India and Sri Lanka are the largest source countries in this group) have the highest registration rates among birthplace groups. Both groups have registration rates around 50% higher than the male Australian-born rate and more than double the female Australian-born rate.

1 Introduction

1.1 Background

Diabetes in Australia

In 1996, diabetes became the fifth National Health Priority Area in recognition of the increasing prevalence of the disease, its seriousness and its cost to the community. Data on the true incidence and prevalence of diabetes in Australia are limited, with the most recent estimates those published by the International Diabetes Institute in its report *Diabetes & Associated Disorders in Australia, 2000*.

What is known about diabetes in Australia includes the following:

- In 1995, an estimated 2.4% of Australians (430,700 people) reported through the National Health Survey that they had been diagnosed with diabetes at some stage during their life (ABS 1997).
- Findings from the Australian Diabetes, Obesity and Lifestyle Study (AusDiab) conducted during 1999 and 2000 indicate that there are about 940,000 Australians (7.5% of the population aged over 25 years) with diabetes. The AusDiab study estimated that 8.0% of males over 25 years and 7.0% of females over 25 years currently have diabetes (Dunstan et al. 2000). AusDiab findings also showed that for each person with diagnosed diabetes, there was another person with diabetes not yet diagnosed.
- Diabetes is the eighth most common problem managed by doctors each year in general practice (Britt et al. 2001).
- People with diabetes have higher rates of cardiovascular, kidney and eye disease. The risk of heart disease and stroke is two to five times higher among people with diabetes than among people without diabetes (AIHW 1999).
- Diabetes-related deaths accounted for 18,982 deaths (7.4% of all deaths) in the two years 1997 and 1998. Diabetes-related deaths are substantially higher among Aboriginal and Torres Strait Islander people, representing 16.4% of deaths among Indigenous Australians in South Australia, Western Australia and the Northern Territory in 1997 and 1998 (AIHW: Mathur et al. 2000).
- Between 1986 and 1997 there was a significant increase in the death rate from diabetes among both males and females, although more so among males. For the period 1993–1997, the age-standardised death rate from diabetes mellitus among males was 172.0 per 100,000 population, compared with 119.9 per 100,000 population among females.
- The estimated annual total health system costs of diabetes were \$0.7 billion in 1993–94 compared with \$3.7 billion for cardiovascular disease and \$1.9 billion for all cancers (AIHW: Mathers & Penm 1999). More than half of the \$0.7 billion was attributed to morbidity from cardiovascular complications, eye and kidney diseases, and limb amputation caused by diabetes.

- Type 1 diabetes ranks as one of the most common serious childhood diseases, being more common than cancer and cystic fibrosis. There is evidence that the incidence among under 15 year olds is increasing in Australia (Craig et al. 2000).
- The incidence of Type 1 diabetes in Australia ranks in the middle range, when compared with the rest of the world. In the *Diabetes Atlas 2000* Scandinavian countries experience the highest estimated rates (Finland – 45 per 100,000 children aged 0–14 years, Sweden – 25.8). Countries in the African region are estimated to have the lowest incidence, with rates around 1 per 100,000 children. The Atlas estimated the Australian rate at 13 per 100,000 children in 2000 (International Diabetes Federation 2000). In fact, this report shows that, from data collected on the NDR, the rate was 18.9 per 100,000 children in 2000.
- Indigenous Australians have one of the highest prevalence of Type 2 diabetes in the world. In 1995, self-reported diabetes was 7 to 8 times higher among Indigenous Australians than for other Australians aged 25–55 years (AIHW 1999).
- Gestational diabetes is estimated to occur in 4 to 6% of pregnancies and its incidence is increasing (AIHW 1999). Diabetes in pregnancy increases the risk of birth complications to both the mother and child.

Establishment of the National Diabetes Register as part of the National Diabetes Strategy and Implementation Plan

Following the inclusion of diabetes as a National Health Priority Area in 1996, the Ministerial Advisory Committee On Diabetes (MACOD) was established. The major output from MACOD was the publication of the *National Diabetes Strategy and Implementation Plan* (Colagiuri et al. 1998) launched by the Australian Federal Health Minister, Dr Michael Wooldridge, in June 1998. In this report, one of the major developmental activities towards improving information about people with diabetes was to ‘establish the National Diabetes Register for people with insulin treated diabetes and consider expanding it into a comprehensive National Diabetes Register’ (p. 43).

Other strategies identified as part of the establishment of the National Diabetes Register were to:

- expand the Register to include women with GDM (gestational diabetes mellitus) in pregnancy (pages 90–92);
- ensure that data on the occurrence and outcomes of pregnancy in women with pre-existing diabetes are collected by the Register (page 97); and
- quantify the impact of diabetes upon children and adolescents (page 196).

The decision to establish a register of people with insulin-treated diabetes was largely based on the ease with which the use of insulin among people with diabetes can be identified. By contrast, developing a register based solely on the type of diabetes was seen as more difficult to establish (at least initially), because a person’s type of diabetes is not as easily defined as a person’s insulin-using status.

The Australian Institute of Health and Welfare (the Institute) submitted a tender application to establish the National (insulin-treated) Diabetes Register in August 1997, and was notified as the successful tenderer in February 1998. After several months, negotiation and refinement of the tasks required in establishing the Register, the Institute signed a Schedule under the Memorandum of Understanding with the Commonwealth Department of Health and Aged Care in August 1998. The charter of the Institute under the Memorandum of

Understanding was to establish and maintain a National Insulin-Treated Diabetes Register (commonly referred to as the 'National Diabetes Register' or in this report as 'the Register').

The Institute subsequently established contracts with Diabetes Australia and the Australasian Paediatric Endocrine Group (APEG) to provide records to the Register of consenting adults and children who started using insulin for the first time from 1 January 1999.

During 2001, the Institute will develop a contract with the Menzies Centre for Population Health in Tasmania as a third source of data for the Register. The Menzies Centre has operated a register of insulin-treated people in Tasmania since 1984.

1.2 Objectives and scope of the Register

Deficiencies in national information systems which would enable the monitoring of the incidence and prevalence of diabetes in Australia have long been identified. Mechanisms to enable research about people with diabetes. This research would lead to the improved management of the condition, further insight into associated risk factors and increased efficiency of services for those affected by diabetes. The Register seeks to address some of these deficiencies in current information systems and, importantly, to facilitate research on diabetes.

Objectives

The current objectives of the Register are to:

- collect information about new cases of insulin-treated diabetes mellitus (ITDM) (includes all Type 1 cases, and Type 2, gestational and other types of diabetes treated with insulin);
- provide a sampling frame for scientifically valid and ethically approved epidemiological and clinical studies of ITDM and Type 1 diabetes;
- monitor and report on the incidence of ITDM and Type 1 diabetes;
- assess the feasibility and cost of estimating the prevalence of ITDM and Type 1 diabetes;
- provide information to health service providers and planners at Commonwealth, State and local levels; and
- provide assistance in monitoring national diabetes indicators.

Scope

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

A person is not eligible for the Register if:

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

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

1.3 Register content

The data items collected on the Register were chosen to meet the following needs:

- the information needs of the strategies identified in the National Diabetes Strategy;
- information on a range of priority populations referred to in the National Diabetes Strategy, including:
 - Indigenous Australians;
 - people from non-English speaking backgrounds;
 - people living in rural and remote Australia; and
 - the elderly;
- the objectives of the Register; and
- the ability to provide mechanisms to facilitate record linkage to ensure that accurate and comprehensive diabetes data are collected on diabetes mortality and end-stage complications (cardiovascular disease, amputation, blindness and end-stage renal disease) (National Diabetes Strategy, p. 43).

The following data items are contained on the Register:

- name;
- address;
- sex;
- date of birth;
- country of birth;
- Aboriginal and/or Torres Strait Islander origin;
- type of diabetes;
- date of diagnosis;
- postcode at diagnosis;
- date of first insulin injection;
- in respect of the diagnosing doctor, doctor type and contact information; and
- carer's contact details when supplied and relevant.

The Register does not collect other clinical information about the person with diabetes.

1.4 Main data sources

There are two main suppliers of data for the Register – the National Diabetic Services Scheme (NDSS) database, administered by Diabetes Australia, and APEG State-based databases. The NDSS database collects information about people with diabetes in all age groups, whereas the APEG data focus on people with Type 1 diabetes who are under 15 years of age. It is anticipated that in 2001 the Menzies Centre for Population Health will also begin to provide data for people living in Tasmania.

National Diabetic Services Scheme

The NDSS is a Commonwealth government program that provides the products needed for the self-management of diabetes at subsidised prices. It was introduced in 1987 and collects information about people with all types of diabetes. Diabetes Australia believes the coverage to be over 90%.

The NDSS registration form contains a Register consent section, which was introduced to coincide with the introduction of the Register on 1 January 1999. The form also contains information about the Register, including its aims and the rights of registrants. Only NDSS records for registrants who consent to participate in the Register are transferred from Diabetes Australia to AIHW.

Australasian Paediatric Endocrine Group

APEG is the professional organisation for paediatric endocrinologists. APEG is actively involved in setting standards of care for children and adolescents with diabetes. One aspect of this care is APEG's State-based databases, which collect diagnosis information on children aged 15 years and under with Type 1 diabetes. Each State has established its database independently, and at varying times since 1985, but all collect the same minimum data set.

The APEG registration form contains a consent section which refers to registration with both APEG and the Register. Therefore, when the carer of a child signs the consent section of the APEG registration form, this record is automatically transferred to AIHW for loading onto the Register. As with the NDSS form, a revised APEG registration form containing information about the Register was introduced to coincide with its introduction.

Tasmanian Diabetes Register

The Tasmanian Diabetes Register has been identified as a source of case ascertainment for the Register, and from 2001 will be used as an additional source of data. Established in May 1984, the Tasmanian register is a collaborative effort by the Menzies Centre for Population Health in Hobart and the International Diabetes Institute in Melbourne.

2 Statistical results

2.1 Register holdings

The Register contains information about 13,347 people who began to use insulin between 1 January 1999 and 31 December 2000. The number of records provided by each data source for each State and Territory is shown in Table 2.1. It is important to note that data from APEG only relate to younger people, with most APEG registrants registered at age 15 years and under.

Table 2.1: NDR registrants: age at diagnosis by data source, States and Territories, 1999 and 2000

Data source	NSW	Vic	Qld	SA	WA	Tas	NT	ACT	Australia	%
Diagnosed at age under 15 years										
Both NDSS & APEG	160	143	74	67	129	22	2	8	605	41.6
NDSS only	270	156	183	35	10	13	6	15	688	47.3
APEG only	27	56	20	28	26	1	—	5	163	11.2
<i>Total</i>	<i>457</i>	<i>355</i>	<i>277</i>	<i>130</i>	<i>165</i>	<i>36</i>	<i>8</i>	<i>28</i>	<i>1,456</i>	<i>100.0</i>
Diagnosed at age 15 years or over										
Both NDSS & APEG	—	—	1	—	—	—	—	1	2	0.1
NDSS only	3,895	3,119	2,180	538	1,341	384	51	175	11,683	100.0
APEG only	—	—	—	—	—	—	—	—	—	0.0
<i>Total</i>	<i>3,895</i>	<i>3,119</i>	<i>2,181</i>	<i>538</i>	<i>1,341</i>	<i>384</i>	<i>51</i>	<i>176</i>	<i>11,685</i>	<i>100.0</i>
Age at diagnosis not stated										
Both NDSS & APEG	—	—	—	—	—	—	—	—	—	—
NDSS only	106	51	25	7	11	3	3	—	206	100.0
APEG only	—	—	—	—	—	—	—	—	—	—
<i>Total</i>	<i>106</i>	<i>51</i>	<i>25</i>	<i>7</i>	<i>11</i>	<i>3</i>	<i>3</i>	<i>—</i>	<i>206</i>	<i>100.0</i>
All records	4,458	3,525	2,483	675	1,517	423	62	204	13,347	

2.2 Concordance of NDSS and APEG data

Many records for children originate from both NDSS and APEG. The level of concordance between the two data providers for children's records varies among States and Territories (Table 2.2).

Overall 42.4% of children's records on the Register were provided by both NDSS and APEG. A further 46.1% were contributed solely by NDSS, with APEG contributing the remaining 11.4% solely. Western Australia had the strongest concordance between NDSS and APEG records, with 79% of children's records common to both data sources. Of the remaining 22% of records, APEG contributed 16% and NDSS 6%. In contrast, very low proportions of children's records were common to NDSS and APEG for Queensland, the Northern

Territory and the Australian Capital Territory. In these States and Territories, NDSS contributed most of the children's records on the Register.

Table 2.2: Concordance between NDSS and APEG records, registrants first diagnosed in 1999 or 2000 and aged under 15 years at time of diagnosis

State	Both APEG and NDSS	NDSS only	APEG only	Total
Number				
NSW	160	258	27	445
Vic	143	148	56	347
Qld	74	179	20	273
SA	67	32	28	127
WA	129	9	26	164
Tas	22	12	1	35
NT	2	6	—	8
ACT	8	14	5	27
Australia	605	658	163	1,426
Per cent				
NSW	36.0	58.0	6.1	100.0
Vic	41.2	42.7	16.1	100.0
Qld	27.1	65.6	7.3	100.0
SA	52.8	25.2	22.0	100.0
WA	78.7	5.5	15.9	100.0
Tas	62.9	34.3	2.9	100.0
NT	25.0	75.0	—	100.0
ACT	29.6	51.9	18.5	100.0
Australia	42.4	46.1	11.4	100.0

Note: This table excludes people diagnosed with diabetes before 1999. Therefore the numbers in this table differ from those in Table 2.1.

At time of writing, the Institute was waiting to receive APEG records for the final quarter of data for 2000 from Queensland.

2.3 Demographic analysis

This section analyses registrants for 1999 and 2000 by a range of demographic characteristics, including age, sex, State and Territory, geographical location/zones, and country of birth.

Age and sex

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

There is a slightly higher proportion of male records on the REGISTER (51.0%) compared to female records (49.0%). However, these proportions vary considerably with age. For the younger age groups, the ratio of male to female records are similar. In the 25–34 and 35–44 age groups, females strongly outnumber males, reflecting the effect of gestational diabetes in women from these age groups.

For older age groups (45–74 years), males strongly outnumber females, with 37% more male registrants than females. This may be attributed to lifestyle differences between males and females. The 1995 National Nutrition Survey showed that at every adult age, men were more likely than women to be overweight or obese, a major risk factor for diabetes (ABS 1998). Mean waist-to-hip ratios were also higher in men than women and increased with age. High waist-to-hip ratios indicate excessive abdominal fat which is associated with increased risk of diabetes. For the ages 75 and over, the number of males and females on the Register become similar, though this narrowing of the difference reflects the substantially lower proportion of males in the population in this age group due to the higher female life expectancy.

Table 2.3: NDR registrants: age and sex, 1999 and 2000

Age at 1 January 2001	Males	Females	Total	% Male
Number				
0–4	121	99	220	55.0
5–9	241	238	479	50.3
10–14	325	306	634	51.3
15–24	398	358	753	52.9
25–34	475	978	1,453	32.7
35–44	568	809	1,377	41.2
45–54	1,075	730	1,805	59.6
55–64	1,311	959	2,270	57.8
65–74	1,302	1,020	2,322	56.1
75 and over	718	781	1,499	47.9
Total	6,534	6,278	12,812	51.0
Per cent				
0–4	0.9	0.8	1.7	
5–9	1.9	1.9	3.7	
10–14	2.5	2.4	4.9	
15–24	3.1	2.8	5.9	
25–34	3.7	7.6	11.3	
35–44	4.4	6.3	10.7	
45–54	8.4	5.7	14.1	
55–64	10.2	7.5	17.7	
65–74	10.2	8.0	18.1	
75 and over	5.6	6.1	11.7	
Total	51.0	49.0	100.0	

Note: Statistics about 537 deceased registrants have been excluded from this table.

Geographical location

The distribution of registrants across geographical areas shows generally consistent coverage across metropolitan, rural and remote zones (Table 2.4). This indicates that the NDSS has good penetration across metropolitan, rural and remote areas in all States and Territories, apart from the Northern Territory and remote areas of South Australia. In the Northern Territory and South Australia, Indigenous people who are diagnosed with diabetes often use the services of Health Service Centres and Aboriginal Community Councils to treat their condition.

Caution should be used in comparing rates between zones and States and Territories, as any differences may be due to the small numbers involved, or differences in NDSS consent rates between areas, rather than due to real differences in incidence.

Table 2.4: NDR registrants: geographical locations, States and Territories, 2000

	Metropolitan	Rural	Remote	Total
State	Number			
NSW	1,984	633	28	2,645
Vic	1,483	536	6	2,025
Qld	842	487	96	1,425
SA	298	116	6	420
WA	550	179	90	819
Tas	93	149	2	244
NT	18	3	13	34
ACT	101	—	—	101
Total	5,369	2,103	241	7,713
	Age-standardised number per 100,000 population ^(a)			
NSW	39.0	38.6	48.6	38.9
Vic	39.3	43.5	35.1	40.2
Qld	39.7	36.2	51.7	39.1
SA	26.6	28.1	20.0	26.8
WA	39.2	52.6	54.9	43.1
Tas	44.1	50.5	107.7	48.1
NT	22.7	35.2	15.1	20.0
ACT	34.1	—	—	34.0
Total	38.0	39.7	46.5	38.7

(a) Age standardisation is to the Australian population at 30 June 1991. The direct method of standardisation is used—see Section 6.3.

Notes

1. Registrants are classified into metropolitan, rural and remote zones according to the Rural, Remote and Metropolitan Areas Classification.
2. Data for 1999 have not been used because of low registration rates for some States in the first six months of that year.

Age at diagnosis

The distribution of registrants by age at diagnosis in 1999 and 2000 is similar across all States and Territories (Table 2.5), apart from the Northern Territory and South Australia. In the Northern Territory, there is a large proportion of female registrants diagnosed in the 15–24-year age group, and in South Australia there is an under-representation of NDSS registrants. For South Australia, this causes inflated percentages for registrants aged 0–14 years, which are mainly sourced from APEG. The under-representation of NDSS registrants in South Australia was caused by delays in the use of the new NDSS registration forms, which were introduced throughout Australia in 1999. This new form included a NDR consent section where registrants could provide permission for their NDSS information to be provided to the Register, whereas the previous form did not include a consent section.

Table 2.5: NDR registrants: age at diagnosis of diabetes and sex, States and Territories, 1999 and 2000

Age at diagnosis	NSW	Vic	Qld	SA	WA	Tas	NT	ACT	Australia
	Per cent								
Males									
0–4	2.4	2.0	2.5	5.8	2.4	0.9	—	3.1	2.4
5–9	3.3	3.3	4.0	5.5	3.3	4.1	4.3	5.1	3.6
10–14	5.0	4.5	4.6	10.0	4.7	3.7	4.3	2.0	4.9
15–24	6.1	5.2	6.7	5.5	7.2	6.8	13.0	13.3	6.2
25–34	7.9	9.1	9.7	8.8	11.5	11.0	4.3	12.2	9.2
35–44	14.4	15.2	15.9	15.8	19.0	12.3	17.4	18.4	15.5
45–54	20.0	22.4	22.2	15.5	24.0	19.6	17.4	15.3	21.2
55–64	19.0	18.4	18.5	15.5	17.8	16.4	26.1	16.3	18.3
65–74	13.4	13.5	9.8	10.6	7.0	15.1	8.7	7.1	11.8
75 and over	5.9	4.6	5.1	6.1	2.7	10.0	—	6.1	5.1
Not stated	2.5	1.8	1.1	0.9	0.4	—	4.3	1.0	1.6
Total males	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
Females									
0–4	2.2	1.8	2.5	2.0	2.8	2.5	—	2.4	2.2
5–9	3.4	4.0	3.7	8.3	4.6	2.5	3.0	3.2	4.0
10–14	4.6	4.4	4.9	7.2	4.1	3.0	9.1	5.6	4.7
15–24	6.3	4.9	8.0	6.3	8.4	6.6	30.3	8.7	6.6
25–34	18.3	15.6	19.0	18.7	18.7	16.2	9.1	27.8	17.9
35–44	15.7	15.7	16.2	14.9	17.3	14.6	18.2	26.2	16.1
45–54	14.1	16.0	17.5	8.9	17.3	16.2	12.1	6.3	15.2
55–64	14.8	16.2	13.1	13.5	15.7	19.2	9.1	9.5	14.8
65–74	11.7	12.6	9.9	11.8	6.8	10.1	—	4.8	10.8
75 and over	6.9	7.6	4.4	6.9	3.2	7.6	3.0	5.6	6.2
Not stated	2.1	1.2	0.8	1.4	1.2	1.5	6.1	—	1.5
Total females	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

All States and Territories show a pattern of gradually increasing numbers with age. For males, the peak ages for diagnosis are those between age 35 and 74 years, whereas for females the peak ages commence earlier (at age 25 years), reflecting the effect of gestational diabetes.

Two thirds (66.8%) of male registrants in 1999 and 2000 reported an age at diagnosis between 35–74 years, with a third of these reporting first diagnosis between 45–54 years. Similar proportions of males and females reported age at diagnosis less than 24 years (17.1% and 17.5% respectively).

Indigenous status

Almost 2% of records on the Register are from registrants of Aboriginal or Torres Strait Islander origin (Table 2.6). While this percentage is consistent with the proportion of Indigenous people in the Australian population (2.2% in 1999), it does not reflect the much higher diabetes prevalence and mortality per 100,000 population among the Indigenous population (see Section 1.1). Proportions of Indigenous registrants on the Register vary by State and Territory, with the highest in the Northern Territory (34%), and the lowest in Victoria (0.3%).

Table 2.6: NDR registrants: age at diagnosis and Indigenous status, States and Territories, 1999 and 2000

Age at diagnosis	NSW	Vic	Qld	SA	WA	Tas	NT	ACT	Australia
0–14 years									
Indigenous	8	2	—	—	5	—	—	—	15
Non-Indigenous	438	148	204	124	160	34	4	24	1,136
Not stated	19	202	73	7	1	1	2	—	305
15–34 years									
Indigenous	15	3	28	—	40	4	11	—	101
Non-Indigenous	780	595	500	130	292	71	6	71	2,445
Not stated	60	10	7	4	11	9	—	—	101
35–54 years									
Indigenous	24	4	33	1	36	6	5	3	112
Non-Indigenous	1,304	1,191	860	177	540	116	11	70	4,269
Not stated	93	27	7	8	22	9	2	1	169
55 and over									
Indigenous	7	2	5	5	5	1	1	—	26
Non-Indigenous	1,488	1,254	752	197	387	146	10	53	4,287
Not stated	94	25	5	16	16	17	1	1	175
Age of diagnosis not stated									
Indigenous	—	—	5	—	2	—	2	—	9
Non-Indigenous	88	51	20	6	9	2	—	1	177
Not stated	15	1	—	2	—	1	1	—	20
Total									
Indigenous	54	11	71	6	88	11	19	3	263
Non-Indigenous	4,098	3,239	2,336	634	1,388	369	31	219	12,314
Not stated	281	265	92	37	50	37	6	2	770

Higher proportions of non-Indigenous registrants than Indigenous registrants are diagnosed with diabetes before the age of 15 years (9.2% compared with 5.7% of Indigenous registrants). Nearly all non-Indigenous registrants diagnosed under 15 years have Type 1 diabetes (96.9%). In comparison, 73.3% of Indigenous registrants in the same age group are recorded as having Type 1 diabetes.

The proportion of the Indigenous population registered with the Register at the end of 2000 varies substantially across States and Territories, ranging from 19 registrants per 100,000 population for South Australia to 108 registrants per 100,000 population for Western Australia (Table 2.7). However, these numbers are unlikely to reflect actual differences in diabetes prevalence among States and Territories. Instead, they are more likely to indicate the extent to which the Indigenous population uses services other than the NDSS to manage their condition. In the Northern Territory and South Australia, for example, many Indigenous people visit Health Service Centres and Aboriginal Community Councils for treatment, rather than joining the NDSS.

Table 2.7: Age-standardised NDR registrants per 100,000 population by Indigenous status, States and Territories, 1999 and 2000

Average annual registrations per 100,000 population	NSW	Vic	Qld	SA ^(a)	WA	Tas	NT	ACT	Australia
Indigenous	20.6	36.6	48.0	18.7	107.9	46.8	25.4	48.7	59.9
Non-Indigenous	34.3	36.9	35.5	21.6	40.7	43.7	18.9	36.2	34.9

(a) South Australian rates are reduced due to the low consent rate in 1999, caused by the delays in implementing the new NDSS form in South Australia.

Note: Age-standardisation is to the Australian population at 30 June 1991. The indirect method of standardisation is used—see Section 6.3.

Country of birth

There is substantial variation in the registration rate with the Register among birthplace groups (Table 2.8). The number of registrants per 100,000 population is highest among those born in North Africa and the Middle East (Lebanon is the largest source country in this group), and Southern and Central Asia (India and Sri Lanka are the largest source countries in this group). Both these groups have registration rates substantially higher than those of the Australian-born registrants, being 50% higher for males and more than double for females. All other birthplace groups show similar registration rates to those for the Australian-born population.

The median age at diagnosis is consistently around the mid-40s for all groups, apart from the North-West Europe and Southern and Eastern Europe groups, which have a median age at diagnosis in the mid-50s.

Table 2.8: NDR registrants aged 15 years and over at diagnosis: country of birth^(a), sex and median age at diagnosis, 1999 and 2000

Country of birth	Males		Females		Median age at diagnosis
	Number	Average annual rate ^(b)	Number	Average annual rate ^(b)	
Australia	4,083	40.3	3,843	34.7	48.1
Oceania and Antarctica (excluding Australia)	136	37.8	187	48.7	41.0
North-West Europe	728	37.1	556	31.3	55.7
Southern and Eastern Europe	618	37.8	537	37.6	57.0
North Africa and the Middle East	145	63.6	163	82.2	47.6
South-East Asia	133	47.2	195	47.9	45.0
North-East Asia	70	34.1	120	44.4	44.6
Southern and Central Asia	113	66.8	135	79.4	42.3
Americas	58	40.6	48	35.9	45.6
Sub-Saharan Africa	48	46.4	46	39.7	42.8

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

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

2.4 Type of diabetes

Reported type versus derived type

One of the data quality issues with the Register is the accuracy of the reporting of diabetes type by the doctor certifying a requirement for insulin on the NDSS registration form. The level of incorrect classification is illustrated by the higher than expected proportion of people on the Register who were diagnosed at age 65 years and over as having Type 1 rather than Type 2 diabetes (Table 2.9).

A survey conducted with registrants' certifying doctors in June 2000 (see also page 24) confirmed this misclassification. The results of this survey highlight a common misconception among people with diabetes and some health professionals that only people with Type 1 diabetes use insulin injections regularly to manage their condition. In fact, many insulin users have Type 2, gestational or other types of diabetes. In an effort to describe the distribution of registrants by type of diabetes more accurately, the NDR Management Committee recommended use of a data item on derived type of diabetes. Because of the high correlation between type of diabetes and age of diagnosis, this item is based on age at diagnosis, and the period between the date of diagnosis and the time when insulin use commenced. The formula used to calculate the derived type of diabetes data item is described in Section 6 Statistical Notes.

If registrants are classified using derived diabetes type, just over 1,600 records originally recorded as Type 1 are re-classified as Type 2, representing 29% of original Type 1 records (Table 2.9).

Although the new results show a significant shift between reported and derived type of diabetes, it is considered that more records should be re-classified to diabetes Type 2. The method used to calculate derived diabetes type does not re-classify some records because of suspected incorrect reporting of date of diagnosis by registrants. Analysis of this variable undertaken by the Institute shows that many registrants may be misinterpreting the question and instead recording date of registration with the NDSS scheme or date of first insulin use. This results in a number of cases of reported Type 1 diabetes where age of diagnosis is greater than 50 not being re-classified to Type 2. Type 1 diabetes can appear at any age, but it most commonly occurs at ages under 40 years, and occurs less commonly after 50 years of age.

Table 2.9: NDR registrants: reported and derived diabetes type by age, 1999 and 2000

Age at diagnosis	Reported diabetes type				Derived diabetes type				Not derived ^(a)
	Type 1	Type 2	Gestational	Other	Type 1	Type 2	Gestational	Other	
0–4	303	3	—	3	303	3	—	3	—
5–9	498	8	—	—	498	8	—	—	—
10–14	614	17	—	10	614	17	—	10	—
15–24	641	132	74	10	641	132	74	10	—
25–34	675	512	590	13	675	512	590	13	—
35–44	621	1,197	267	24	329	1,420	267	24	69
45–54	662	1,741	6	32	261	2,062	6	32	80
55–64	613	1,577	—	30	221	1,856	—	30	113
65–74	443	1,057	—	12	184	1,207	—	12	109
75 and over	266	480	—	10	137	531	—	10	78
Not stated	151	51	3	1	20	51	3	1	131
Total	5,487	6,774	941	145	3,883	7,798	941	145	580

(a) For some registrants, type of diabetes could not be derived due to missing information.

Median age at diagnosis

Median age at diagnosis differs markedly by derived diabetes type. As expected, those diagnosed with Type 1 diabetes are diagnosed at younger ages than registrants with other types of diabetes. The patterns of median age at diagnosis for each diabetes type remain consistent across the States and Territories (Table 2.10).

Table 2.10: NDR registrants: median age at diagnosis, derived type of diabetes, States and Territories, 1999 and 2000

Derived diabetes type	NSW	Vic	Qld	SA	WA	Tas	NT	ACT	Australia
Type 1 ^(a)	14.9	14.2	13.9	11.8	15.8	17.3	17.0	15.1	14.5
Type 2	55.0	54.4	52.4	53.0	50.2	57.0	48.5	53.0	53.7
Gestational	32.3	32.5	30.9	32.4	31.7	30.8	39.5	33.1	32.0
Other	49.4	52.0	42.0	53.5	50.5	53.0	24.5	37.0	49.2

(a) Median age for registrants with Type 1 diabetes is only calculated using those records for which date of diagnosis was less than 35 years.

2.5 Mortality

The Register's records for 1999 and 2000 were matched against the National Death Index (NDI). There were 537 registrants identified as having died in the years 1999 and 2000, representing 4% of all registrants on the Register. The age-standardised death rate for registrants is three and a half times that of the general population in these two years for both males and females (Table 2.11).

Table 2.11: NDR registrants: average annual age-standardised death rates, 1999 and 2000^(a)

	Males	Females
	Age standardised rate per 100,000 population	
NDR registrants	2,686	1,667
All Australia, 1999 ^(b)	737	483
Standardised mortality ratio	3.6	3.5

(a) The indirect method of standardisation is used, See Section 6.4 for method used to calculate death rates.

(b) Death rates for all Australia are not yet available for the year 2000.

Almost all of the deaths in the NDR population in 1999 and 2000 were people suffering Type 2 diabetes, as more than 90% of deaths occurred to registrants aged 50 and over (Table 2.12). Given that all registrants only commenced using insulin after 1 January 1999, it is estimated that very few of this 50 years and over group would be Type 1 cases, as this would imply that they were diagnosed with Type 1 diabetes at ages greater than 50.

At time of writing, cause of death was only available on the NDI for 1999. When 2000 cause data become available further analysis will be undertaken about causes of death of registrants on the Register.

Table 2.12: NDR registrants: deaths, 1999 and 2000

Age at death	Males		Females	
	Number	Percent	Number	Percent
0-49	29	9.2	16	7.2
50-59	37	11.7	26	11.7
60-69	78	24.8	46	20.7
70-79	104	33.0	76	34.2
80 and over	67	21.3	58	26.1
All ages	315	100.0	222	100.0

2.6 Incidence rates

One of the primary objectives of the Register is to report on incidence rates of insulin-treated diabetes in Australia. This section provides incidence rates (predominantly Type 1) in children for 2000. Only incidence rates for children are provided, as this is the only population group on the Register where coverage is considered to be close to 100%, and then only for year 2000 registrations. For adults, coverage is affected by the proportion of NDSS registrants who provide consent to join the Register, and the use by some Indigenous communities of Health Service Centres and Aboriginal Community Councils, rather than the NDSS, for their supply of diabetes products.

Table 2.13: Incidence of diabetes among 0–14 year olds: sex and age, State and Territories, 2000

Sex and age at diagnosis	NSW	Vic	Qld	SA	WA	Tas	NT	ACT	Australia
Number									
Males									
0–4	29	23	16	8	6	—	—	2	84
5–9	42	32	27	12	18	4	1	2	138
10–14	62	35	30	17	16	4	—	1	165
<i>Total males 0–14</i>	<i>133</i>	<i>90</i>	<i>73</i>	<i>37</i>	<i>40</i>	<i>8</i>	<i>1</i>	<i>5</i>	<i>387</i>
Females									
0–4	23	17	17	5	8	2	—	3	75
5–9	40	35	27	13	12	4	—	2	133
10–14	47	38	27	16	13	3	2	2	148
<i>Total females 0–14</i>	<i>110</i>	<i>90</i>	<i>71</i>	<i>34</i>	<i>33</i>	<i>9</i>	<i>2</i>	<i>7</i>	<i>356</i>
Rate per 100,000 population									
Males									
0–4	13.1	14.7	13.0	16.9	9.2	—	—	19.0	13.0
5–9	18.4	19.2	20.4	23.8	26.3	23.1	11.0	18.2	20.2
10–14	27.5	21.3	22.9	33.0	22.5	22.7	—	9.0	24.3
<i>Total males 0–14</i>	<i>19.7</i>	<i>18.5</i>	<i>18.9</i>	<i>24.8</i>	<i>19.6</i>	<i>15.8</i>	<i>3.8</i>	<i>15.3</i>	<i>19.2</i>
Females									
0–4	10.9	11.6	14.5	11.1	13.0	13.4	—	29.2	12.2
5–9	18.5	22.2	21.5	27.0	18.6	24.4	—	19.0	20.5
10–14	21.9	24.3	21.8	32.8	19.3	17.9	26.2	18.7	22.9
<i>Total females 0–14</i>	<i>17.1</i>	<i>19.5</i>	<i>19.3</i>	<i>23.9</i>	<i>17.1</i>	<i>18.7</i>	<i>8.2</i>	<i>22.2</i>	<i>18.6</i>

Caution needs to be exercised in comparing among States and Territories and between sexes because of the small numbers involved. The Australian incidence rates for 2000 are around 19 per 100,000 population for both males and females (Table 2.13), similar to the rate of 17.8 per 100,000 children estimated for New South Wales for the 1990–96 period (Craig et al. 2000). The incidence rates increase with increasing age, with the rates for ages 5–9 and 10–14 much higher than those for the 0–4 age group. There appears to be some evidence of a

higher incidence rate in South Australia, though more data needs to be collected on the Register before any conclusive State and Territory differences can be identified.

Again caution needs to be used in making comparisons between metropolitan, rural and remote areas because of the relatively small numbers currently held on the Register. Data for a number of years will need to be collected before accurate comparisons can be made for geographic categories. However, the incidence rates for 2000 do show a reasonably consistent pattern across metropolitan and rural zones of around 18 to 21 cases per 100,000 population (Table 2.14). Rates for the remote zones appear substantially lower than the metropolitan and rural zones. This is expected, given the higher proportion of the Indigenous population who live in these zones compared with the proportion living in metropolitan and rural zones, and the previously reported low incidence rates of Type 1 diabetes among the Indigenous population (McCarty et al. 1996) when compared to the non-Indigenous population.

Table 2.14: Incidence of diabetes among 0-14 year olds: geographical location, States and Territories, 2000

State	Metropolitan	Rural	Remote	Total
Numbers				
NSW	159	82	2	243
Vic	122	58	—	180
Qld	86	51	7	144
SA	55	16	—	71
WA	53	15	5	73
Tas	8	9	—	17
NT	3	—	—	3
ACT	12	—	—	12
Total	498	231	14	743
Age-standardised rate per 100,000 population				
NSW	16.4	24.1	12.4	18.4
Vic	17.5	22.8	—	18.9
Qld	20.1	18.0	14.0	19.0
SA	26.7	19.3	—	24.0
WA	19.0	19.6	10.5	18.2
Tas	19.4	15.2	—	16.8
NT	14.9	—	—	6.1
ACT	18.9	—	—	18.8
Total	18.4	21.0	9.4	18.8

3 Data collection issues

3.1 Proportion of eligible persons providing consent to be on the Register

For the Register to realise its objectives, it is important that the proportion of eligible persons providing consent to join the Register is maximised. Inclusion in the Register is voluntary but every effort is made to encourage those who are eligible to join the Register.

The Register relies on health professionals, such as general practitioners, diabetes educators and endocrinologists, to help inform the person filling in NDSS or APEG registration forms about the Register, and to encourage them to join. Where forms are presented in person to Diabetes Australia offices, the personnel in these offices also play a key role in encouraging registrants to provide consent to join the Register.

NDSS consent

There are two main types of registrant on the Register – those newly registered with NDSS and those already registered with NDSS but commencing insulin use.

When a new NDSS registrant fills in the NDSS registration form, signed consent to join the Register is sought. The Register consent section of the NDSS form was added to the revised 'green' NDSS form, which was introduced to coincide with the commencement of the Register on 1 January 1999. Information about the Register, including its aims and the rights of patients on the Register, and the privacy protection provided by the AIHW Act, is also included on the revised form.

In the Register's initial stages, the proportion of eligible NDSS registrants consenting to join the Register was very low, mainly due to the continuing use of superseded forms, which did not contain a NDR consent section. As these old forms were removed from use, consent rates increased, then stabilised after September 1999. Consent rates are calculated by comparing the number of NDSS registrants who consent to join the Register with the number of NDSS registrants who are eligible to join.

Rates of coverage on the Register have varied greatly by State and Territory. Western Australia and Queensland have consistently had the highest consent rates (Table 3.1). This reflects the continued commitment to the Register in these offices and the willingness of staff to promote and encourage new NDSS registrants to join the Register. Due to small numbers of potential registrants in Tasmania, the Northern Territory and the Australian Capital Territory, consent rates for these States and Territories show large fluctuations.

A substantial effort by the AIHW NDR team has been devoted to promoting the Register to staff in Diabetes Australia's State and Territory offices. This includes the dissemination of promotional material (magazine articles, brochures, posters etc.) and visits to offices where Institute staff provided training, presentations and discussions about Register activities. During State and Territory visits, the importance of lifting consent rates for the Register was discussed and the continued effort required in encouraging eligible people to join the register was emphasised. Procedures used in each State and Territory office (e.g. issue of change of status forms to existing registrants commencing to use insulin) were also

discussed, to help identify reasons for differences in consent rates among the States and Territories.

Consent rates for each monthly batch of NDSS records received continue to be lower than desired, but it is important to note that many additional records of new NDSS registrants are transferred to the Institute over time. Many of these records are of registrants who have joined the NDSS using the old registration form, or have not signed the consent section of the new form upon initial registration but have since elected to join the Register. Once additional records are incorporated on the Register, coverage improves to just over 70% (Table 3.1).

Table 3.1: Proportion of new NDSS registrations on the NDR, States and Territories, 1999 and 2000

Quarter	NSW	Vic	Qld	SA	WA	Tas	NT	ACT	Australia
Jan 99 – Mar 99	14.4	40.5	52.7	5.7	77.4	46.6	8.7	38.8	31.9
Apr 99 – Jun 99	57.1	66.8	66.5	26.9	83.7	50.0	50.0	51.2	60.2
Jul 99 – Sep 99	74.8	67.6	71.9	49.4	82.5	66.2	56.0	64.3	70.6
Oct 99 – Dec 99	72.1	70.6	74.9	77.2	84.5	66.0	35.3	54.1	72.8
Jan 00 – Mar 00	75.1	71.9	73.7	69.0	77.6	76.9	33.3	36.4	73.0
Apr 00 – Jun 00	73.2	71.8	79.3	57.8	74.4	60.9	110.0	74.1	72.8
Jul 00 – Sep 00	74.7	59.0	80.4	74.4	86.4	58.6	37.5	68.8	72.0
Oct 00 – Dec 00	74.1	62.3	76.5	59.7	82.7	94.9	73.3	76.0	71.0

Western Australian records indicate that, with strong follow-up procedures for those registrants eligible for the register in 1999 and 2000 but who had not joined during initial registration, a consistent rate of consent (between 75% and 85% each quarter) can be achieved.

The NDR Management Committee has recommended a back-capture program as an option in lifting coverage of the Register. This would involve contacting eligible persons newly registered with NDSS since 1 January 1999 who have not provided consent to join the register, and providing them with another opportunity to do so. A telephone survey of non-consenting eligible NDSS registrants was conducted in September 2000 to assess the feasibility of conducting a back-capture program (Appendix 2). Results from this survey indicated that many eligible registrants were unaware of the Register (58.5%). Of those who were aware of the Register, 57% thought they were already registered. Almost three-quarters of telephone survey respondents requested the opportunity to join the Register and asked to be provided with further information about the Register and a registration form. This survey indicated that a back-capture program would be very successful in substantially raising consent rates.

The Register also collects information about registrants who have been previously registered with NDSS but whose management of diabetes has changed to include insulin. If an existing registrant informs Diabetes Australia that they are now required to use insulin, the Diabetes Australia State office will send out a 'change of status' registration form. This form includes a section that requires certification from the registrant's doctor that insulin is required and a consent section for the Register. If a registrant does not inform Diabetes Australia of the change to insulin, a flag is triggered on the NDSS system if that registrant attempts to purchase syringes. Diabetes Australia will then send out the 'change of status' form. Data about that registrant can be transferred to the AIHW, once the signed form is returned to

Diabetes Australia, and signed consent has been obtained. Through discussions during visits to State and Territory offices, it was ascertained that many different processes are used in individual offices when an existing NDSS registrant commences to use insulin. These differences result in varying levels of capture of 'change of status' records on the Register. This issue is being addressed by the Diabetes Australia National Office.

From analysis of Register records using dates of first injection, first syringe purchase and registration with Diabetes Australia, it is estimated that approximately 70% of current registrants on the Register are new NDSS registrants, and 15% of registrants are existing NDSS registrants who have started to use insulin (Table 3.2). The remaining 15% could not be classified into new or existing.

Table 3.2: NDSS registrants: type of registration, States and Territories, 1999 and 2000

Type of registrant	NSW	Vic	Qld	SA	WA	Tas	NT	ACT	Australia
New registrant	77.9	63.0	73.8	77.1	48.4	54.0	77.4	53.8	68.7
Existing registrant	5.0	23.2	12.9	2.9	37.2	32.0	77.9	30.2	16.0
Not classified	17.1	13.8	13.3	19.9	14.4	14.0	19.4	16.1	15.3
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

These estimates vary by State and Territory, reflecting the different processing procedures adopted in each office. Western Australia, Tasmania and the Australian Capital Territory have the highest proportions of records for existing (change of status) registrants, whereas New South Wales, Queensland, South Australia and the Northern Territory achieve lower capture rates.

APEG consent

The proportion of registrations with APEG that participate in the Register is close to 100%. This is because the consent section of the APEG registration form refers to registration with both APEG and the Register. Therefore, when a carer of a child consents to inclusion on the APEG register, these details are automatically transferred to the NDR. As with the NDSS form, a new APEG form, which included information about the Register and a consent section, was introduced to coincide with the commencement of the Register.

The coverage of APEG holdings on the Register is shown in Table 3.3. Data from APEG contains records for all of 1999 and 2000 for all States with the exception of Queensland which has only provided data up to September 2000.

Table 3.3: APEG data held on the NDR

APEG State office	Months available on Register
NSW ^(a)	January 1999 – April 2001
Vic	January 1999 – May 2001
Qld ^(b)	January 1999 – September 2000
SA ^(c)	January 1999 – April 2001
WA	January 1999 – April 2001
Tas	January 1999 – March 2001

(a) The New South Wales State APEG register is responsible for collection information for the Australian Capital Territory, and may collect some data for the south-east corner of the Northern Territory.

(b) The Queensland State APEG Register is responsible for collection of information collected by paediatric endocrinologists from Darwin.

(c) The South Australian APEG Register is responsible for collection of information collected by paediatric endocrinologists from Alice Springs.

3.2 Alternative data sources

The analysis of the records currently held on the Register indicates that NDSS and APEG obtain poor coverage of people who use insulin to treat their diabetes in remote areas. In these areas, Indigenous communities may use services and products provided by Health Service Centres and Aboriginal Community Councils, rather than NDSS. People living in isolated rural and remote areas are also able to obtain diabetes treatment products free of charge from selected pharmacists under Section 100 of the Pharmacies Act.

It is planned to investigate the feasibility of capturing these data before the next report is produced. If successful, this will improve the overall coverage of the Register, and will provide more accurate statistics on the extent of insulin-treated diabetes among the Indigenous population.

4 Quality control

Considerable effort has been devoted to ensuring that data received by the Register are of high quality. For the Register to meet its objectives, it is essential that Register data be accurate and that all data items requested be provided. Also of great importance is the ability of the Register to accurately report on the incidence of insulin-treated diabetes in the population. Attaining sufficient levels of coverage is therefore a priority for the Register. The various actions undertaken to maximise the quality of data held on the Register are discussed in the following paragraphs.

4.1 Actions to improve data quality

Liaison with data managers

The Institute regularly liaises with data managers from both Diabetes Australia and APEG. During visits to State and Territory offices of both organisations in 2000, discussions were held with staff about the processing of the NDSS forms, in particular the section of the forms relating to the Register. These discussions proved valuable in highlighting a number of areas where data quality and consent rates could be improved. The Institute also provides an ongoing role in assisting data providers with data collection and provision issues. Regular statistical reports are also provided to State and Territory offices of Diabetes Australia in which progress on data quality can be monitored.

Training at Diabetes Australia

The Institute has been involved in several training sessions with Diabetes Australia, either at specific training courses for data operators, conferences for Diabetes Australia, or at individual meetings at State and Territory offices. As well as providing a forum for the promotion of the Register and its importance to Diabetes Australia staff, these sessions also enabled discussion to take place between Institute and State and Territory staff regarding specific data quality issues. These discussions proved invaluable in the first year of the Register, when it was necessary to ensure that the introduction of the new processing procedures required for the Register's component of the NDSS input processing was successful.

During the initial stages of the Register's development, a number of changes were made to the processing and transfer to the Institute of NDSS records as new problems were identified. These have included changes to the NDSS software to resolve operational issues, and the inclusion of additional items in the monthly transfer of data to the Institute. These initial problems were addressed at regular meetings with staff members from the NDSS National Office, and in discussions with State and Territory officers of Diabetes Australia.

Data transfer from NDSS and APEG

The time taken between registration with the data provider and the capture of a valid and complete record on the Register was monitored during the first six months of operations. This measure is an important indicator of the timeliness of data on the Register and the efficiency of data collection. Monthly data from Diabetes Australia are required to be sent to

the Institute within two weeks of the end of a processing month. Data from APEG are required to be sent on a quarterly basis, although some State offices have found it easier to send data at more regular intervals.

Computer edit checks as part of Register operations

Checking and validation of data received is a routine part of Register operations. In summary, the following tasks are undertaken:

- Routine checks are made for any missing data for mandatory fields at the time of data load. When missing data are identified the record is still loaded onto the database, but identification variables and details about missing fields are included in an error report which is returned to the data provider for correction.
- Many validity checks are undertaken once the data are loaded onto the database e.g. check that the registration date is not after or the same as the diagnosis date, that males do not have gestational diabetes, and that there are no invalid dates of birth. Any records containing invalid data items are followed up with the data provider.
- De-duplication is regularly undertaken on the entire database (i.e. the database is matched to itself). This enables duplicate records from the one source to be identified as well as duplicate records from multiple sources. Where there is a discrepancy between the information on either record, the record is checked with the data providers.

Identification of deaths

The NDI, housed at the Institute, is a record of all deaths in Australia from the early 1980s onwards. The NDI records identifying information about the deceased, including name and address at time of death and cause of death. There is generally only a 2–3 month lag period between registration of a death and its inclusion on the NDI, although there may be some variation in this period among the States.

The NDI is commonly used as a means of identifying deaths in a cohort of data. In the case of the Register, the entire database is matched to the NDI on a regular basis. Matching against the NDI will also be undertaken before data for research purposes is made available, to ensure that a person who may have recently died is not included as part of the project and therefore ensuring that the deceased's family is not contacted in relation to the research project. All identified deaths are recorded on the Register and data providers informed of their occurrence so that they can update their databases. Records of deceased registrants are still contained on the Register but are only used to report on incidence.

Approval to routinely undertake record linkage between the NDI and the Register was obtained as part of the AIHW application to the AIHW Ethics Committee to establish and maintain the Register at the Institute. The application was approved on 29th October 1998.

Reported type of diabetes

A major data quality issue of the Register is the quality of the reported type of diabetes. This is provided on the NDSS registration form, usually by the patient's medical practitioner at time of initial registration with NDSS or when a change of status form is completed, indicating a change to insulin requirement. More than half of all records on the Register are recorded as Type 1, although for 30% of these the date of initial diagnosis of diabetes is before 1999. Since all persons on the register must have commenced using insulin on or after 1 January 1999, it is suspected that many people recorded as having Type 1 diabetes actually have Type 2. It should be noted that on the current NDSS registration form, a category for

Type 2 requiring insulin is not available; it is envisaged that this category may be included in the next edition of the form.

In June 2000, AIHW conducted a small survey of 80 doctors. The aims of this survey were:

- to obtain an indication of how many Type 1 registrants on the Register have their diabetes type recorded correctly;
- to ascertain the feasibility of conducting a similar survey on a much larger sample as part of the quality control process for the Register; and
- to assess whether the recording of diabetes type differs by the type of doctor completing the form.

In 44% of replies, the doctor indicated that the type of diabetes on the NDR file was incorrect, and should be Type 2. This indicates that there may be a misconception in the medical community about types of diabetes, with some doctors changing a person's diabetes type from Type 2 to Type 1 once insulin use is commenced.

The NDR Management Committee recommended the use of a derived type of diabetes. This item is based on age at diagnosis, and the period between date of diagnosis and the time when insulin use commenced. The new variable was calculated for and is used as a validation check for records of persons aged over 35 years whose diabetes type is 1. A discussion of the change in diabetes type once the new variable is used is in Section 2.4 of this publication.

Audits of registration forms

The AIHW are contractually obliged to undertake audits of NDSS and APEG registration forms. These entail a manual check of all forms from each State and Territory office for a designated period of time, and allow comparison between registration forms and corresponding Register data for registrants. An audit of a registration form also allows the accuracy of data entry to be established, and differences in accuracy between State and Territory offices measured. In the initial stages of collection from NDSS, the audits allowed the measurement of use of redundant registration forms. These audits have also identified many problems in the data transfer process, which have since been rectified.

To date, audits of NDSS registrations have occurred on a regular basis. No audits of APEG registration forms have been undertaken as yet.

4.2 Actions to improve case ascertainment

Marketing strategy

A marketing strategy for the Register was developed and implemented, with its major aim being to maximise the level of case ascertainment on the Register. This has been achieved by targeting people with diabetes, in particular those newly diagnosed with insulin-treated diabetes mellitus, and health practitioners who form part of the diabetes management team caring for the diabetes population. Among health practitioners, the main target group is diabetes educators. Although the entire management team needs to know about the Register, diabetes educators are often seen as the link between people with diabetes and more specialised treatment and management. As a result, they have more regular contact with people with diabetes compared with other health practitioners and are the ones most

likely to provide advice to people filling in NDSS registration forms, the primary mechanism for participation in the Register.

Other members of the diabetes management team, including general practitioners and endocrinologists, have been targeted by this strategy.

The primary outputs from the marketing strategy have been the development of an information brochure and poster and the publication of articles describing the scope, purpose and eligibility criteria for the Register in a range of magazines and newsletters.

Information brochure and poster

The National Diabetes Register information brochure explains the purpose of the Register, the details being collected by the Register, confidentiality and access issues, the role of research using the Register, and how to join the Register. Brochures were initially produced in Italian, Greek, Croatian, Vietnamese, Chinese and Spanish as well as English. The foreign language brochures were in response to a need identified in the pilot test of the NDSS registration form conducted in October 1998, and past studies which show that diabetes occurs more frequently in some non-English speaking groups. During 2000, feedback from health professionals in the diabetes community identified a need to have brochures available in Arabic. Subsequently these were produced and distributed.

The posters and brochures were distributed to diabetes centres, endocrinologists and general practitioners throughout Australia, as well as to the National Association of Diabetes Centres (NADC) and members of the Australian Diabetes Educators Association (ADEA) members.

Publications

To increase awareness of the Register among the diabetes community, several articles were published in professional and diabetes-related magazines and newsletters. These include the publications of diabetes organisations (such as Diabetes Australia, Australian Diabetes Educators Association (ADEA), International Diabetes Institute (IDI)) and publications targeting specific professions relevant to diabetes care (*GP Review*, *Pharmacy Review* etc.). These articles provided information about the Register, including its long-term purposes and how people could participate in the Register. They also sought the assistance of health practitioners, where practicable, in encouraging their patients to participate in the Register. Information about the Register has also been placed on the Diabetes Australia website: www.diabetesaustralia.com.au.

National Diabetes Register Helpline

The Helpline was organised at the Institute to provide an information service for those in the diabetes community. The freecall 1800 number has been placed on both the NDSS and APEG registration forms, and has featured in all aspects of the marketing strategy.

Information was recorded on the first two months of operation of the Helpline. An analysis of these calls for the period 1 January 1999 to 28 February 1999 showed that most inquiries (82%) were for NDSS registrations and products. The Institute's response to these requests for information about NDSS was to provide the caller with the Diabetes Australia Helpline number. Of the remaining calls, 55% were diabetes educators or other health professionals, and 36% were persons with diabetes.

At time of writing (July 2001), the majority of calls on the Helpline (98%) were for NDSS. The remainder were from researchers interested in the Register and persons requesting further brochures.

It is envisaged that the Helpline may be used to initially record contact details of registrants who are not registered with NDSS or APEG, so that further information about the Register and consent forms can be forwarded to them.

5 Epidemiological research

The Register is now available for epidemiological research. A package 'Access to the National Diabetes Register' has been developed for those wishing to obtain data from the Register for epidemiological studies. This package can be obtained by contacting:

**The Project Officer, National Diabetes Register
Health Registers and Cancer Monitoring Unit
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601**

Phone: (02) 6244 1097 Fax: (02) 6244 1299

Email: phil.trickett@aihw.gov.au

Applications to access the Register for research will be considered only if the applicant provides assurance of scientific quality, evidenced either by the project having been funded through a competitive peer-reviewed grant process or by review by independent peers acceptable to the Institute.

Before a project can proceed, approval must be sought from the investigator's host ethics committee and the AIHW Ethics Committee.

6 Statistical notes

6.1 Calculation of age at diagnosis

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

APEG records

Age at diagnosis = 1st injection date - date of birth
(diagnosis date is not available for most APEG records, but 1st injection date for children diagnosed with Type 1 diabetes is considered to be the same as diagnosis date)

NDSS records

Age at diagnosis = date of diagnosis - date of birth

If date of diagnosis is missing,

Age at diagnosis = date of 1st insulin injection - date of birth

If date of diagnosis and date of 1st insulin injection are missing,

Age at diagnosis = date of 1st syringe purchase - date of birth

6.2 Derivation of diabetes type

The following formula is used to assist in obtaining a more accurate measure of the type of diabetes. The purpose of this formula is to re-classify registrants believed to be incorrectly recorded as having Type 1 diabetes rather than Type 2. Records of registrants reporting Type 1 diabetes, gestational diabetes or other types of diabetes were excluded from this derivation.

For persons reporting Type 1 only:

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

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

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

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

6.3 Age-standardised rates

To control for any effects of varying age structures of populations, direct age standardisation was used to calculate all rates, apart from Table 2.7 which compares registration rates between Indigenous and non-Indigenous registrants, and Table 2.11 which describes death rates for registrants. The rates in those tables use indirect standardisation, which is recommended when calculating rates for small populations such as the Indigenous population.

The 1991 Australian population was used as the standard population in calculating age-standardised rates.

Direct standardised rates were calculated using the following formula. The usual convention of using age-specific rates for five-year age groups was followed.

$$SR = \frac{\sum\{R_i \times P_i\}}{\sum P_i}$$

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

Indirect standardised rates were calculated using the following formula.

$$SR = \frac{C}{\sum\{R_i \times P_i\}} \times \text{Crude rate of the standard population}$$

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

6.4 Mortality rates

Mortality rates for both the Register population and total Australia (Table 2.11) were calculated using the indirect standardised formula (see Section 6.3). However, an adjustment was made to the annual standardised rates for the Register population, for the average period that the population was on the Register and therefore exposed to the risk of death as a registrant. For example, for registrants who joined the Register in 1999, the average period that each registrant was on the Register and therefore exposed to the risk of death in 1999 was only 0.37 of a year, reflecting the relatively lower registrations in the first half of 1999. If registrants had joined the Register evenly throughout 1999, the average time spent on the Register in that year would have been 0.5 of a year.

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

APPENDIX 1: Data collected by the Register

Field	Collected by DA	Mandatory for DA	Format provided by DA	Collected by APEG	Mandatory for APEG	Format provided by APEG
Source	✓	X	N – NDSS A – APEG O – Other	✓		N – NDSS A – APEG O – Other
BatchNo	✓	X	Batch or sequential Number	X		
Num_Recs	✓	X	Number of records in batch incl header	X		
Load_time	✓	X	HHMMSS	✓		
Load_date	✓	X	DDMMCCYY	✓		
Title	✓		Mr, Mrs, Ms, Dr, Sr, Prof, ...	X		
Surname	✓	X	50 char	✓	X	50 char
First Name	✓	X	50 char	✓	X	50 char
Second Name	✓		50 char	✓		50 char
Other Name(s)	✓		30 char	X		Not collected
Sex ¹	✓	X	1 – Male 2 – Female 3 – Indeterminate 4 – Not stated	✓	X	1 – Male 2 – Female 3 – Indeterminate 4 – Not stated
Address 1	✓	X	Number + street	✓	X	Number + street
Address 2	✓		Other address information	✓		Other address information
Address 3	✓		Suburb	✓	X	Suburb

(continued)

Appendix 1 (continued): Data collected by the Register

Field	Collected by		Mandatory for		Format provided by DA	Collected by APEG	Mandatory for APEG		Format provided by APEG
	DA	DA	DA	DA			APEG	APEG	
State/Territory ¹ of usual residence	✓	X	X	X	1 – NSW 2 – VIC 3 – QLD 4 – SA 5 – WA 6 – TAS 7 – NT 8 – ACT 9 – Other Territories (Cocos Islands, Christmas Island and Jervis Bay Territory)	✓	X	1 – NSW 2 – VIC 3 – QLD 4 – SA 5 – WA 6 – TAS 7 – NT 8 – ACT 9 – Other Territories (Cocos Islands, Christmas Island and Jervis Bay Territory)	
Phone	✓				Area code + phone	X		Not collected	
Postcode	✓	X	X	X	NNNN	✓	X	NNNN	
Postcode at Diagnosis	✓	X	X	X	NNNN	✓	X	NNNN	
Date of Birth ¹	✓	X	X	X	DDMMCCYY	✓	X	DDMMCCYY	
Indigenous Status ¹	✓	X	X	X	1 – Aboriginal but not TS Islander 2 – TS Islander but not Aboriginal 3 – Aboriginal and TS Islander 4 – Not Aboriginal or Torres Strait Islander 9 – Not stated	✓	X	1 – Aboriginal but not TS Islander 2 – TS Islander but not Aboriginal 3 – Aboriginal and TS Islander 4 – Not Aboriginal or Torres Strait Islander 9 – Not stated	
Country of Birth ¹	✓				Australian Standard Classification of Countries for Social Statistics, ABS Cat. No. 1269.0	✓		Australian Standard Classification of Countries for Social Statistics, ABS Cat. No. 1269.0	
Diagnosis Date	✓	X	X	X	DDMMCCYY (Day to default to 01)	X		Not collected (assumed to be the same as date of first insulin injection)	
Diabetes Type	✓	X	X	X	1 – Type 1 2 – Type 2 3 – Gestational 4 – Other	✓	X	1 – Type 1 2 – Type 2 3 – Gestational 4 – Other	

(continued)

Appendix 1 (continued): Data collected by the Register

Field	Collected by DA	Mandatory for DA	Format provided by DA	Collected by APEG	Mandatory for APEG	Format provided by APEG
Certifying Doctors name	✓		May include first name and surname	✓		May include first name and surname
Doctor's Address 1	✓		Number + street	✓		Number + street
Doctor's Address 2	✓		Other address information	✓		Other address information
Doctor's Address 3	✓		Suburb	✓		Suburb
Doctor's Type	✓	X	G – General practitioner E – Endocrinologist S – Specialist physician O – Other medical practitioner	✓	X	G – General practitioner E – Endocrinologist S – Specialist physician O – Other medical practitioner
Doctor – Insulin Required ?	✓	X	1 – Yes 2 – No	X		Not collected (assumed to be Yes)
Provider Number	✓	X	NNNNNNNNN (Health Insurance Commission allocated Provider Number)	✓		NNNNNNNNN (Health Insurance Commission allocated Provider Number)
Date of first insulin injection	✓	X	DDMMCCYY (Day to default to 01)	✓	X	DDMMCCYY (Day to default to 01)
Doctor's research involvement.	X			✓	X	1 – Yes 2 – No
Unique Registration No.	✓	X	Unique DA State registration number	✓	X	Unique State APEG registration number
Register Consent	✓	X	1 – Yes 2 – No	✓	X	1 – Yes 2 – No
Research Consent	X		Not collected	✓	X	1 – Yes 2 – No
Medicare Number ¹	✓	X	NNNNNNNNNN	X		Not collected
Registration Date	✓		DDMMCCYY	✓		DDMMCCYY
Carer Title	✓		Mr, Mrs, Ms, Dr, Sr, Prof...	X		Not Collected
Carer Surname	✓			✓		50 Char
Carer First Name	✓			✓		50 Char

(continued)

Appendix 1 (continued): Data collected by the Register

Field	Collected by DA	Mandatory for DA	Format provided by DA	Collected by APEG	Mandatory for APEG	Format provided by APEG
Carer Second Name	✓			X		Not Collected
Carer Address 1	✓		Number + street	X		Not collected
Carer Address 2	✓		Other address information	X		Not collected
Carer Address 3	✓		Suburb	X		Not collected
Carer State/Territory ¹ of Usual Residence	✓		1 – NSW 2 – VIC 3 – QLD 4 – SA 5 – WA 6 – TAS 7 – NT 8 – ACT 9 – Other Territories (Cocos Islands, Christmas Island and Jervis Bay Territory)	X		Not collected
Carer Phone	✓		Area code + phone	✓		Area code + phone
Carer Postcode	✓		NNNN	X		Not collected
Carer Relationship	✓		Relationship to person with diabetes	X		Not collected
Person Status	✓	X	M – Moved T – Transferred V – Visitor D – Dead	X		Not collected
Status	✓	X	N – New (new addition to the database) U – Update (the record details have changed) D – Deletion (the record is no longer active on the database)	X		Not collected

¹ These data fields appear in the *National Health Data Dictionary Version 10.0* (1998).

APPENDIX 2: Telephone Survey of non-consenting NDSS registrants — September 2000

Introduction

In an effort to establish why consent rates for the Register were not as high as expected, AIHW developed a telephone survey in mid-2000 to obtain a measure of awareness of the Register among NDSS registrants who had not consented to join the Register. The survey also aimed to measure their willingness to participate in the Register.

Methodology

AIHW commissioned Diabetes Australia, as data custodians of the NDSS database, to conduct a survey from a sample of approximately 300 NDSS registrants who were eligible for the Register, but had not consented to have their information transferred to the AIHW. Eligibility for the NDR is defined as having been diagnosed with insulin treated diabetes mellitus or having commenced treatment with insulin injections since 1 January 1999. Diabetes Australia used Stollznow Research to undertake the survey.

Stollznow Research developed a brief questionnaire to be used during a telephone interview. Provision was made for recording additional comments made by NDSS registrants, including reasons for not choosing to participate in the interview. Time to complete the interview was estimated at less than five minutes per registrant once contact had been made.

An initial test of 10 respondents was requested by the Privacy Commissioner to ensure that there was no strongly negative reaction to respondents being contacted. Results from this test indicated that there were no negative reactions to interviewers calling; the majority of those called were happy to answer the questions.

The telephone survey was conducted in September 2000.

Findings

Interviews were conducted with 278 respondents out of a sample of 313 persons, a response rate of almost 90% (Table A1). Only 7 respondents (2%) were unwilling to participate in an interview.

Table A1: Response status

Survey response	Number
<i>Declined interview/interview not conducted</i>	
Language problems	7
Deceased	15
No time to do interview	3
Unable to contact respondent	3
Not interested	4
Other responses	3
Total interviews not conducted	35
Total interviews conducted	278
Total sample	313

Table A2 shows eligibility for the Register by those who were able to respond to the survey by reported type of diabetes. As noted previously, to be eligible for the Register a person must be using insulin. However, there were 62 non-insulin-using persons incorrectly included in the sample. In the case of gestational diabetes, registrants may have been eligible for the Register at a time before interview, but the condition may not have existed at the time of the interview. A large proportion of these is included in the 'not stated' insulin usage cell.

Table A2: Reported insulin usage and diabetes type

Use of insulin	Diabetes type							Total
	Type 1	Type 2 non-insulin-using	Type 2 insulin-using	Gestational	Other ^(a)	Don't know diabetes type	Not stated	
Insulin using	47	1	91	4	2	47	3	195
Non-insulin using	1	28		19	2	11	1	62
Not stated				17	3		1	21
Total	48	29	91	40	7	58	5	278

(a) Includes diabetes related to liver and bone marrow transplants and chemotherapy.

As the survey was designed for NDSS registrants eligible for the Register, only the 195 respondents (62% of total sample) who were eligible for the Register at time of interview are discussed in the following paragraphs.

More respondents were unaware of the Register than were aware of the Register, 58.5% compared to 38.9% (Table A3). Only 27.6% of females were aware of the Register, compared with 50.5% of males.

Table A3: Awareness of the NDR by sex

	Aware	Not aware	Not stated	Total
Males	49	46	2	97
Females	27	68	3	98
Total (number)	76	114	5	195
Total (per cent)	38.9	58.5	2.5	100.0

Eighty per cent of respondents who were aware of the Register either thought they were already on the Register, or considered they had not been asked to participate in the Register, or didn't know if they had been asked to participate (Table A4). A large proportion (57%) of respondents who believed that they had been asked to participate in the register thought that they were already signed up. Diabetes Australia considers that most of these have probably confused membership of the NDSS with NDR registration. Only two records (7%) gave privacy-related reasons as to why they had chosen not to take part.

Table A4: NDSS registrants aware of the NDR by whether asked to participate on the NDR and reasons for not participating

Whether asked to participate and reason for not providing consent	Number	Per cent of those asked	Per cent of all aware of NDR
Yes			
Already on it	16	57.1	
Too busy	1	3.6	
Privacy issue	1	3.6	
Worries about Government/National organisations	1	3.6	
Other reasons	8 ^(a)	28.6	
Not stated	1	3.6	
<i>Total asked to participate</i>	28	100.0	36.8
No	28		36.8
Don't know	17		22.4
Not stated	3		4.0
Total	76		100.0

(a) Reasons in this category were: 'because of his age', 'doctor advised not much benefit to me', 'has enough problems as it is', 'has had a lot of heart surgery', 'no, just didn't think about it', 'only recently on insulin', 'oversight, is already part of study in WA' and 'it was some study about diabetes and alcohol which did not relate to me'.

Each of the 195 eligible Register respondents were asked if they would be interested in taking part in the Register, and if they would like to have a brochure and new registration form sent to them. Almost three quarters (74%) reported 'yes' to this question, 24% said 'no', and the remaining respondents did not know or did not provide a response. Almost half of those who responded 'no' gave the following reasons for not wishing to be sent information about the Register:

- thought they were already on the register;
- thought they were too old;
- not being at home (going to hospital or on holidays);
- language difficulties;
- too busy, not wanting to be involved or having enough worries already; and
- thought that a joining fee was involved.

At the time of the survey, there were 11,046 records on the Register which had been transferred from the NDSS. Based on results from the survey, a conservative estimate of an additional 4,600 persons may consent to have their information included on the Register if provided with the opportunity through a back-capture program. An increase of this estimate would largely be dependent on the inclusion of persons such as those who did not complete an interview. These included persons with language problems or with no available time to be interviewed, and those not able to be contacted.

Respondents who reported that they were aware of the Register were also asked how they knew about it (Table A5). The responses confirm that people working in the diabetes environment play an important part in promoting the Register to their clients. Diabetes educators and doctors were reported as common sources of Register awareness (25.0% and 18.4% respectively). Awareness of the Register from the NDSS form was also frequently reported (21.1%).

Table A5: How registrants became aware of the NDR

Response	Number	Per cent
Hospitals/health centres	9	11.8
Diabetes educator	19	25.0
NDR brochure	12	15.8
Doctor/specialist	14	18.4
Nurse	6	7.9
Other health-related professional	2	2.6
Family/friends	3	3.9
NDSS form	16	21.1
Diabetes Australia	4	5.3
Article in a magazine	5	6.6
Other	5	5.3
Not stated	4	5.3
Total aware of NDR^(a)	76	100.0

(a) More than one response may have been given by registrants, therefore components do not add to total.

Conclusions

1. Only two persons in the sample of those eligible for the Register did not want to participate because of privacy reasons.
2. 74% of those eligible for the Register asked for the opportunity to join the Register through being sent information and a registration form. Some 24% said that they did not want to have information sent to them, many of those considering themselves to be already registered, too old or too busy to participate in the Register.
3. This suggests strong support from NDSS registrants who have not joined the Register to have information sent to them, providing them with another opportunity to join. The overwhelming majority of people with insulin-treated diabetes appear to wish to contribute to research into diabetes by participation in the Register.
4. Increased efforts are needed to educate doctors, diabetes educators and others assisting people with diabetes in completing the NDSS/NDR registration, so to encourage them to provide a positive response in completing the NDR section.
5. Results indicate a re-design of the NDSS registration form (incorporating a change to 'opt off' or Yes/No methodology) would contribute to a rise in registration with the Register. The complexity of the current form appears to be a significant factor in the less than optimal level of NDR registration.
6. Confounding factors, such as the complex registration form and the confusion and stress often experienced by registrants at time of diagnosis, indicate that a back-capture program should be implemented. The fact that most NDSS registrants would like to be given the opportunity to participate in the Register adds additional support to a back-capture program.

Glossary

Diabetes mellitus: A disease characterised by high blood levels of glucose, caused by deficient production of insulin (the hormone that helps metabolise glucose) and/or resistance to its action.

Type 1 diabetes mellitus: characterised by a complete deficiency of insulin. Insulin injections are required to maintain normal glucose level. Also known as insulin-dependent diabetes mellitus. Initial diagnosis is commonly during childhood.

Type 2 diabetes mellitus: characterised by a relative insufficiency of insulin and resistance to its action. Also known as non-insulin dependent diabetes mellitus and is the most common form of diabetes among over 40 year olds.

Gestational diabetes mellitus (GDM): occurs during pregnancy to women not previously known to have diabetes. It greatly increases their risk of developing diabetes later in life.

Insulin-treated diabetes mellitus (ITDM): A classification of diabetes which includes all those who use insulin to treat their diabetes. Can be Type 1, Type 2 or GDM. The Register collects information on those people with ITDM.

References

- AIHW: Mathers C & Penm R 1999. Health system costs of cardiovascular diseases and diabetes in Australia 1993–94. AIHW Cat. No. HWE 11. Canberra: Australian Institute of Health and Welfare.
- AIHW: Mathur S, Gajanayake I & Hodgson G 2000. Diabetes as a cause of death, Australia, 1997 and 1998. AIHW Cat. No. CVD 12. Canberra: Australian Institute of Health and Welfare (Diabetes Series no. 1).
- Australian Institute of Health and Welfare (AIHW) 2001. National Health Data Dictionary. Version 10. AIHW Catalogue no. HWI 30. Canberra: Australian Institute of Health and Welfare.
- Australian Bureau of Statistics (ABS) 1998. ABS Standard Australian Classification of Countries, 1998, ABS Cat. No. 1269.0. Canberra: ABS.
- Australian Bureau of Statistics (ABS) 1998. National Nutrition Survey: nutrient intakes and physical measurements, Australia, 1995. ABS Cat. No. 4805.0. Canberra: ABS.
- Australian Bureau of Statistics (ABS) 1997. National Health Survey: diabetes, Australia, 1995. ABS Cat. No. 4371.0. Canberra: ABS.
- Australian Institute of Health and Welfare (AIHW) 1998. International health – how Australia compares. AIHW Cat. No. PHE 8. Canberra: AIHW.
- Australian Institute of Health and Welfare (AIHW) 1999. Heart, stroke and vascular diseases, Australian facts. AIHW Cat. No. CVD 7. Canberra: AIHW and the Heart Foundation of Australia (Cardiovascular Disease Series No. 10).
- Britt H, Miller GC, Charles J, Knox S, Sayer GP, Valenti L, Henderson J & Kelly Z 2001. General practice activity in Australia 1999–2000. AIHW Cat. No. GEP 5. Canberra: Australian Institute of Health and Welfare (General Practice Series No. 5).
- Beischer NA, Oats JN, Henry OA, Sheedy MT & Walstab JE 1991. Incidence and severity of gestational diabetes mellitus according to country of birth in women living in Australia. *Diabetes* 40 Suppl 2:358.
- Colagiuri S, Colagiuri R & Ward J 1998. National diabetes strategy and implementation plan. Canberra: Diabetes Australia.
- Craig ME, Howard NJ, Silink M & Chan A 2000. The rising incidence of childhood Type 1 diabetes in New South Wales, Australia. *Journal of Pediatric Endocrinology & Metabolism* 13:363–372.
- Dunstan D, Zimmet P, Welborn T, Sicree R, Armstrong T, Atkins R, Cameron A, Shaw J & Chadban S 2000. Diabetes & associated disorders in Australia 2000: The accelerating epidemic. Melbourne: International Diabetes Institute.
- Glatthaar C, Whittall DE, Welborn TA, Gibson MJ, Brooks BH, Ryan MMP & Byrne GC 1988. Diabetes in Western Australian children: descriptive epidemiology. *Med J Aust* 148:117–23.
- International Diabetes Federation 2000. Diabetes Atlas 2000. Belgium: International Diabetes Federation.
- Karvonen M, Tuomilehto J, Libman I, LaPorte R 1993. A review of the recent epidemiological data on the world wide incidence of Type 1 (insulin-dependant) diabetes mellitus. *Diabetologia* 36:883–92.

- Kelly HA & Byrne GC 1992. Incidence of IDDM in Western Australia in children aged 0-14 yr from 1985-1989. *Diabetes Care* 15:515-7.
- Kelly HA, Russell MT, Jones TW & Byrne GC 1994. Dramatic increase in incidence of insulin dependent diabetes mellitus in Western Australia. *Med J Aust* 161:426-8.
- King H, Senator G, Zimmet P & Dixon J 1986. A new population-based diabetes register in Tasmania, Australia. In Serrano-Rios M & Lefebvre PJ (eds). *Diabetes 1985*. Amsterdam: Elsevier 1986:430-4.
- McCarty DJ, Greenaway TM, Kamp MC, Dwyer T & Zimmet PZ 1999. Management of insulin-treated diabetes in Tasmania. *Med J Aust* 170:312-5.
- McCarty DJ, Zimmet P, Dalton A, Segal L & Welborn TA 1996. The rise and rise of diabetes in Australia, 1996: a review of statistics, trends and costs. Canberra: Diabetes Australia.
- Moses RG & Matthews JA 1986. Prevalence of diabetes mellitus in Australia. The establishment of a register of diabetic children aged 0 to 19 years in the Illawarra area. *Med J Aust* 144:630-2.
- Silink M 1994. Childhood diabetes and hypoglycaemia. In: Roberson M and Robertson D (eds). *Practical paediatrics*, 3rd ed. Melbourne: Churchill Livingstone, pp.553-40.
- Sutton DL, Lyle DM & Pierce JP 1989. Incidence and prevalence of insulin-dependent diabetes mellitus in the zero to 19 years age-group in Sydney. *Med J Aust* 151:140-6.
- Verge CF, Silink M & Howard NJ 1994. The Incidence of childhood IDDM in New South Wales, Australia. *Diabetes Care* 17:693-6.