## **National Diabetes Register**

Statistical profile, December 2001

The Australian Institute of Health and Welfare is Australia's national health and welfare statistics and information agency. The Institute's mission is to improve the health and well-being of Australians by informing community discussion and decision making through national leadership in developing and providing health and welfare statistics and information.

## DIABETES SERIES Number 4

# National Diabetes Register

**Statistical Profile, December 2001** 

**July 2003** 

Australian Institute of Health and Welfare Canberra

AIHW cat. no. CVD 24

#### © Australian Institute of Health and Welfare 2003

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

This publication is part of the Australian Institute of Health and Welfare's Diabetes Series. A complete list of the Institute's publications is available from the 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 285 8

## **Suggested citation**

Australian Institute of Health and Welfare 2003. National diabetes register: statistical profile, December 2001. AIHW Cat. No. CVD 24 (Diabetes Series No. 4). Canberra: AIHW.

#### Australian Institute of Health and Welfare

Board Chair Dr Sandra Hacker

Director Dr Richard Madden

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

National Diabetes Register Project Officer Australian Institute of Health and Welfare GPO Box 570 Canberra ACT 2601

Phone: (02) 6244 1000

E-mail: diabetes@aihw.gov.au

Published by Australian Institute of Health and Welfare Printed by Pirion

## **Contents**

List of tables	vii
Acknowledgments	viii
Abbreviations	ix
Symbols	ix
Executive summary	x
1. Introduction	1
2. Summary of Register data	2
2.1 Age and sex	2
2.2 Geographical location	3
2.3 Type of diabetes	4
2.4 Mortality	6
2.5 Indigenous status	6
2.6 Country of birth	7
3. Persons with Type 1 diabetes	9
3.1 New cases of Type 1 diabetes under 40 years of age	9
3.2 Incidence estimates for 0–14 year olds	11
International comparison	12
Geographical location	13
4. Persons with insulin-treated diabetes excluding Type 1	16
4.1 Age and sex	
4.2 Geographical location	17
5. Mortality	20
5.1 Mortality rates	20
5.2 Cause of death	21
6. Statistical notes	23
6.1 Calculation of age at diagnosis	23
6.2 Derivation of diabetes type	23
6.3 Age-standardised rates	24
6.4 Mortality rates	24

6.5 Confidence intervals	
7. Diabetes research	26
Appendix 1: Data collected by the Register	27
Appendix 2: Data concordance	30
Appendix 3: Register holdings	31
Glossary	33
References	35

## List of tables

<b>Table 2.1:</b>	NDR registrants: current age and sex, 1999–2001	3
Table 2.2:	NDR registrants: geographical locations, states and territories, 1999–2001	4
Table 2.3:	NDR registrants: reported and derived diabetes type, by age, 1999-2001	5
Table 2.4:	NDR registrants: derived diabetes type, by sex, 1999–2001	6
<b>Table 2.5:</b>	NDR registrants: vital status and derived type of diabetes, by states and territories, 1999–2001	6
Table 2.6:	NDR registrants: Indigenous status, by age at first insulin use, states and territories, 1999–2001	7
Table 2.7:	NDR registrants aged 15 years and over at diagnosis: country of birth, sex and median age at diagnosis, 1999–2001	8
Table 3.1:	NDR registrants aged 0–39 years with derived Type 1 diabetes, by age and sex, 1999–2001	. 10
Table 3.2:	NDR registrants aged 0–39 years with derived Type 1 diabetes: states and territories, 1999–2001	. 10
Table 3.3:	NDR registrants aged 0–39 years with derived Type 1 diabetes: geographical locations, 1999–2001	. 11
Table 3.4:	New cases of Type 1 diabetes among 0–14 year olds: sex and age, states and territories, 2000 and 2001	. 12
Table 3.5:	New cases of Type 1 diabetes among 0–14 year olds: states and territories, 1999, 2000, 2001	. 12
Table 3.6:	Incidence of Type 1 diabetes in 0–14 year olds: selected countries, 2000	. 13
Table 3.7:	New cases of Type 1 diabetes among 0–14 year olds: Statistical Divisions, 1999–2001.	. 14
Table 4.1:	NDR registrants with insulin-treated diabetes, excluding Type 1: derived type, by age at first insulin use and sex, 1999–2001	. 17
Table 4.2:	NDR registrants with derived insulin-treated diabetes (excluding Type 1): diabetes type, age at first insulin use and geographical location, 1999–2001	. 18
Table 5.1:	NDR registrants: deaths, 1999–2001	. 20
Table 5.2:	NDR registrants: average annual age-standardised death rates, 1999–2001	. 21
Table 5.3:	NDR registrants: underlying causes of death for deceased registrants, 1999–2000.	. 22
Table A1:	Data collected by the Register: field, by source and output categories	. 27
Table A2:	Concordance between NDSS and APEG records: registrants first diagnosed in 1999–2001 and aged under 15 years at time of diagnosis	. 30
Table A3:	Proportion of new NDSS registrations on the NDR, by quarter, 1999–2001	. 31
Table A4	APEC data held on the NDR	32

## **Acknowledgments**

This report has been prepared by John Harding, Ilona Brockway and Louise Catanzariti of the Australian Institute of Health and Welfare, with guidance from the National Diabetes Register Management Committee (see membership list below). Their assistance is much appreciated. The authors also acknowledge the input of staff from within the Australian Institute of Health and Welfare, particularly Anne-Marie Waters, Zoe Holdenson, Lynelle Moon, and staff from the Media and Publishing Unit.

Referee comments, which were very helpful in finalising the report, were gratefully received from the following people: Professor Don Chisholm, Associate Professor Stephen Colagiuri, Associate Professor Peter Colman, Dr Jeff Flack, Dr Rosemary Knight, Emma Rooney, Dr Jonathan Shaw, and Professor Paul Zimmet.

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

The National Diabetes Register and this report have been produced with financial assistance from the Commonwealth Department of Health and Ageing.

For further information on the Register and the statistics in this report, please contact Louise Catanzariti on phone: (02) 6244 1279 or e-mail: louise.catanzariti@aihw.gov.au.

## **Membership of the National Diabetes Register Management Committee**

Associate Professor Peter Colman, Royal Melbourne Hospital (Chair)

Ms Sheila Royles, Juvenile Diabetes Research Foundation

Dr Fergus Cameron, Australasian Paediatric Endocrine Group

Mr Brian Conway, Diabetes Australia

Dr Jeff Flack, Bankstown-Lidcombe Hospital

Dr Rosemary Knight, Commonwealth Department of Health and Ageing

Dr Richard Madden, Australian Institute of Health and Welfare

Dr Jonathan Shaw. International Diabetes Institute

## **Abbreviations**

ABS Australian Bureau of Statistics

AIHW Australian Institute of Health and Welfare
APEG Australasian Paediatric Endocrine Group

DA Diabetes Australia

DoHA Department of Health and Ageing

GDM Gestational diabetes mellitus

ICD-10 International Classification of Diseases, 10th revision

ITDM Insulin-treated diabetes mellitus

MACOD Ministerial Advisory Committee on Diabetes

Menzies Centre Menzies Centre for Population Health in Tasmania

NDI National Death Index

NDR National Diabetes Register

NDSS National Diabetes Services Scheme

Register National Diabetes Register

TITDR Tasmanian Insulin Treated Diabetes Register

WHO World Health Organization

## **Symbols**

... Not available

n.a. Not applicable

Rounded to zero

## **Executive summary**

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

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

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

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

#### Insulin-treated diabetes in males and females

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

## Diabetes type of persons with insulin-treated diabetes

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

## Age distributions of registrants

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

#### Commencement of insulin use

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

#### Incidence of Type 1 diabetes among children 0-14 years

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

#### **Deaths**

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

#### Geographical coverage

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

## Indigenous status

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