

Appendix 1: Data collected by the Register

Data for the Register are provided by Diabetes Australia (DA) which operates and maintains the National Diabetes Services Scheme (NDSS), the Australasian Paediatric Endocrine Group (APEG) state-based registers, and the Menzies Centre for Population Health in Tasmania which operates the Tasmanian Insulin Treated Diabetes Register (TITDR).

The NDSS database contains information about people with diabetes in all age groups and with different types of diabetes. The NDSS registration form contains a NDR consent section which was introduced to coincide with the introduction of the Register on 1 January 1999.

Signed consent by the NDSS registrant means agreement to Diabetes Australia providing his/her NDSS information to the NDR.

The APEG registers focus on children with insulin-treated diabetes who are aged under 15 years at time of diagnosis. Each APEG state office established its register independently at varying times since 1983; all collect the same minimum data set. The APEG registration form also contains a consent section for registration with both APEG and the Register.

Table A1 lists the data items held on the Register, the source of the data item, and a description of output categories available for each item. Identifiable information (e.g. name and address details) about the registrant, their medical practitioner and their carers (if applicable) are only used for AIHW's management of the Register and are not available as output from the Register. These are marked accordingly.

Table A1: Data collected by the Register: field by source and output categories

Field	Collected by DA	Collected by APEG	Derived Item	Output categories	Comments
Registrant information					
Source			X	N—NDSS A—APEG B—Both O—Other	
Registration number	X	X		Not available	Unique registration for NDSS or APEG
state/territory of registration	X	X	X	1—NSW 2—VIC 3—QLD 4—SA 5—WA 6—TAS 7—NT 8—ACT	
Register consent	X	X			Must consent to be included on Register
Research consent		X		Yes No	

(continued)

Table A1 (continued): Data collected by the Register: field, by source and output categories

Field	Collected by DA	Collected by APEG	Derived Item	Output categories	Comments
Registrant type			X	New Existing	Only for NDSS registrants
Title (Mr, Mrs, Dr etc)	X			Not available	
Surname	X	X		Not available	
First name	X	X		Not available	
Second name	X	X		Not available	
Other name(s)	X			Not available	
Sex	X	X		Male Female	
Address 1	X	X		Not available	
Address 2	X	X		Not available	
Address 3	X	X		Not available	
state/territory of usual residence			X	1—NSW 2—VIC 3—QLD 4—SA 5—WA 6—TAS 7—NT 8—ACT	Derived from postcode of usual residence
Postcode of usual residence	X	X			
Phone	X			Not available	
Date of birth	X	X		Not available	
Age			X	5-year age groups	Expressed as age at a particular point in time
Indigenous status	X	X		Indigenous Non-Indigenous Not stated	
Country of birth	X	X		Australian Standard Classification of Countries for Social Statistics, ABS Cat. No. 1269.0	
Postcode at diagnosis	X	X			
Diabetes type—reported	X	X		1 – Type 1 2 – Type 2 3 – Gestational 4 – Other types of diabetes	
Diabetes type—derived			X	1 – Type 1 2 – Type 2 3 – Gestational 4 – Other types of diabetes 9 – Not derived	

(continued)

Table A1 (continued): Data collected by the Register: field, by source and output categories

Field	Collected by DA	Collected by APEG	Derived Item	Output categories	Comments
Diagnosis date	X			Year of diagnosis	For APEG diagnosis date is assumed to be the same date as date of first insulin use
Age at diagnosis			X	5-year age groups	Derived from date of birth and date of diagnosis
Age at first insulin use			X	5-year age groups	Derived from date of birth and date of first insulin injection
Date of first insulin injection	X	X		Year of first insulin use	
Vital status			X	1—Alive 2—Deceased	
Year of death			X	Year of death	
Cause of death			X	ICD-10 coding	
Medicare number				Not available	
Registration date	X	X		Year of registration	Year of registration with NDSS or APEG
Doctor's details					
Certifying doctor's name	X	X		Not available	
Doctor's address 1	X	X		Not available	
Doctor's address 2	X	X		Not available	
Doctor's address 3	X	X		Not available	
Doctor type	X	X		G—General practitioner E—Endocrinologist S—Specialist O—Other medical practitioner D—Diabetes educator	
Doctor's provider number	X	X		Not available	
Doctor's research involvement		X		Not available	
Carer details					
Carer title	X			Not available	
Carer surname	X	X		Not available	
Carer first name	X	X		Not available	
Carer second name	X			Not available	
Carer address 1	X			Not available	
Carer address 2	X			Not available	
Carer address 3	X			Not available	
Carer state/territory of usual residence	X			Not available	
Carer phone number	X	X		Not available	
Carer postcode	X			Not available	
Carer relationship	X			Not available	

Appendix 2: Data concordance

Many records for those who were aged less than 15 years at diagnosis are common to both NDSS and APEG. The level of concordance between the two data providers for children's records varies among states and territories. This is largely due to levels of consent from both data sources, with consent levels from APEG much lower than for the NDSS (this is being addressed by APEG). However, the period between registration with a data source and arrival of the record at the AIHW can also vary. For NDSS records, the majority of records for the Register arrive within the first 3 months after registration with Diabetes Australia. For some APEG state offices, the process of certification of diabetes type by a medical specialist takes additional time, particularly when travel by endocrinologists to rural areas is required. The level of concordance between the two data sources is shown in Table A2.

Table A2: Concordance between NDSS and APEG records: registrants first diagnosed in 1999–2001 and aged under 15 years at time of diagnosis

state	Both APEG and NDSS	NDSS only	APEG only	Total
		Number		
NSW	399	276	97	772
Vic	263	229	76	568
Qld	209	201	39	449
SA	118	38	35	191
WA	213	9	27	249
Tas	43	17	1	61
NT ^(a)	7	7	1	15
ACT ^(b)	22	11	7	40
Australia	1,274	788	283	2,345
		Per cent		
NSW	51.7	35.8	12.6	100.0
Vic	46.3	40.3	13.4	100.0
Qld	46.5	44.8	8.7	100.0
SA	61.8	19.9	18.3	100.0
WA	85.5	3.6	10.8	100.0
Tas	70.5	27.9	1.6	100.0
NT ^(a)	46.7	46.7	6.7	100.0
ACT ^(b)	55.0	27.5	17.5	100.0
Australia	54.3	33.6	12.1	100.0

(a) APEG records for the Northern Territory are collected by the Queensland and South Australian APEG registers.

(b) APEG records for the Australian Capital Territory are collected by the New South Wales APEG register.

Data provided by the Menzies Centre in Tasmania showed 100 per cent concordance to existing data on the Register.

Appendix 3: Register holdings

Ascertainment for the Register is based on the number of NDSS registrants who consent to join the Register compared with the number of NDSS registrants who are eligible to join. 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; however, there were still fluctuations in the consent rates in 2000 and 2001. This will be examined in detail when the full data of the NDSS become available to the AIHW with the introduction of the new NDSS system (expected late 2003)—including improved privacy arrangements. The new system will allow all NDSS insulin-treated registrants to be included in the Register. Thus, ascertainment rates will then not be relevant and need not be calculated.

Table A3: Proportion of new NDSS registrations on the NDR, by quarter, 1999–2001

Quarter	Australia
Jan 99–Mar 99	31.9
Apr 99–Jun 99	60.2
Jul 99–Sep 99	70.6
Oct 99–Dec 99	72.8
Jan 00–Mar 00	73.0
Apr 00–Jun 00	72.8
Jul 00–Sep 00	72.0
Oct 00–Dec 00	71.0
Jan 00–Mar 01	64.0
Apr 01–Jun 01	67.1
Jul 01–Sep 01	67.0
Oct 01–Dec 01	68.5

- Ascertainment from APEG has been estimated at 100% from most state registers. At time of writing, the Institute had received data for the first half of 2002.

Table A4: APEG data held on the NDR

APEG state office	Months available on Register at September 2002
NSW ^(a)	January 1999–July 2002
Vic	January 1999–August 2002
Qld ^(b)	January 1999–August 2002
SA ^(c)	January 1999–July 2002
WA	January 1999–September 2002
Tas	January 1999–June 2002

- (a) The New South Wales state APEG register is responsible for collection of information in 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 by paediatric endocrinologists from Alice Springs.

Glossary

Derived diabetes type: In some instances the diabetes type entered on the registration form is considered to be incorrect. This largely reflects the misconception among some people and health professionals that only people with Type 1 diabetes use insulin injections regularly to manage their condition. In an effort to describe the distribution of registrants by type of diabetes more accurately, the NDR Management Committee recommended use of another data item based on age of diagnosis, and the period of time between the date of diagnosis and commencement of insulin use. The formula used for this derivation is shown in Chapter 6, Statistical Notes.

Diabetes (diabetes mellitus): The term 'diabetes mellitus' describes a metabolic disorder of multiple aetiology characterised by chronic hyperglycaemia with disturbances of carbohydrate, fat and protein metabolism resulting from defects in insulin secretion, insulin action, or both (WHO 1999).

Although diabetes is often mistaken as a single disease, there are several different forms of this condition with the common feature of abnormal blood glucose levels. The most common forms of diabetes are Type 1, Type 2 and gestational (GDM).

Gestational diabetes mellitus (GDM): Gestational diabetes is carbohydrate intolerance resulting in hyperglycaemia of variable severity, with onset or first recognition during pregnancy (WHO 1999).

Women who have had diabetes diagnosed prior to a pregnancy do not fall into this category. GDM increases the risk of perinatal morbidity and mortality and substantially increases the mother's risk of developing diabetes later in life (AIHW 2002a).

Impaired glucose tolerance: Impaired glucose regulation refers to a metabolic state intermediate between normal glucose homeostasis and diabetes (WHO 1999).

People with IGT have a 1 in 3 chance of developing Type 2 diabetes within 10 years (AIHW 2002a).

Insulin-treated diabetes mellitus (ITDM): A classification of diabetes which includes all those who use insulin to treat their diabetes, which includes those with Type 1, Type 2, gestational and other types of diabetes.

Multiple causes of death: These may include those conditions involved in the morbid train of events leading to death which were classified as either the underlying cause, the immediate cause, or any intervening causes and those conditions which contributed to death, but were not related to the disease or condition causing death (ABS 2002a).

National Death Index (NDI): The NDI is a data set, housed at the AIHW, which contains records of all deaths occurring in Australia since 1980, provided by the Registrars of Births, Deaths and Marriages in all states and territories.

Other types of diabetes: Other types of diabetes include certain conditions or syndromes, such as:

- genetic defects of beta-cell function;
- genetic defects in insulin action;
- diseases of the exocrine pancreas;
- endocrinopathies;

- drug- or chemical-induced diabetes;
- uncommon but specific forms of immuni-mediated diabetes mellitus; and
- other genetic syndromes sometimes associated with diabetes (WHO 1999).

These types of diabetes are relatively uncommon. Only persons being treated with insulin for these types of diabetes are included in the National Diabetes Register.

Reported diabetes type: In order to receive syringes at a subsidized cost, a NDSS registrant must have his or her requirement for insulin verified by a medical practitioner, or since 2001, a registered diabetes educator. As part of that process, the type of diabetes is also noted on the form. This is the reported diabetes type.

For APEG registrants, the diabetes type is verified by the child's doctor; in most cases the doctor is an endocrinologist or paediatrician.

Type 1 diabetes: This form of diabetes, previously encompassed by the terms 'insulin-dependent diabetes' or 'juvenile-onset diabetes', results from autoimmune mediated destruction of the beta cells of the pancreas (WHO 1999).

People with Type 1 diabetes require daily insulin therapy to survive. Type 1 diabetes is most commonly diagnosed before the age of 30 years.

Type 2 diabetes: Type 2 diabetes is the most common form of diabetes. It is often associated with lifestyle—obesity, inactivity and poor diet are considered major contributing factors. Often this type of diabetes can be managed with changes to diet and exercise. However, in some cases insulin is required and only insulin-treated persons with Type 2 diabetes are included in the National Diabetes Register. Type 2 diabetes is most commonly diagnosed after the age of 40 years; however, recent trends have indicated an increase in diagnosis in younger years.

Underlying cause of death: The disease or injury which initiated the train of morbid events leading directly to death.

References

- Armitage P, Berry G & Matthews JNS 2002. *Statistical methods in medical research*. 4th edn. Melbourne: Blackwell Scientific Publications.
- ABS (Australian Bureau of Statistics) 1998a. *National Nutrition Survey: nutrient intakes and physical measurements, Australia, 1995*. ABS Cat. No. 4805.0. Canberra: ABS.
- ABS (Australian Bureau of Statistics) 1998b. *Standard Australian Classification of Countries (SACC)*. ABS Cat. No. 1269.0. Canberra: ABS.
- ABS (Australian Bureau of Statistics) 2001a. *Population by age and sex, New South Wales, 2000*. ABS Cat. No. 3235.1. Canberra: ABS.
- ABS (Australian Bureau of Statistics) 2001b. *Population by age and sex, Victoria, 2000*. ABS Cat. No. 3235.2. Canberra: ABS.
- ABS (Australian Bureau of Statistics) 2001c. *Population by age and sex, Queensland, 2000*. ABS Cat. No. 3235.3. Canberra: ABS.
- ABS (Australian Bureau of Statistics) 2001d. *Population by age and sex, South Australia, 2000*. ABS Cat. No. 3235.4. Canberra: ABS.
- ABS (Australian Bureau of Statistics) 2001e. *Population by age and sex, Western Australia, 2000*. ABS Cat. No. 3235.5. Canberra: ABS.
- ABS (Australian Bureau of Statistics) 2001f. *Population by age and sex, Tasmania, 2000*. ABS Cat. No. 3235.6. Canberra: ABS.
- ABS (Australian Bureau of Statistics) 2001g. *Population by age and sex, Northern Territory, 2000*. ABS Cat. No. 3235.7. Canberra: ABS.
- ABS (Australian Bureau of Statistics) 2001h. *Population by age and sex, Australian Capital Territory, 2000*. ABS Cat. No. 3235.8. Canberra: ABS.
- ABS (Australian Bureau of Statistics) 2002a. *Causes of death, Australia, 2001*. ABS Cat. No. 3303.0. Canberra: ABS.
- ABS (Australian Bureau of Statistics) 2002b. *Census of population and housing, selected social and housing characteristics, Australia, 2001*. ABS Cat. No. 2015.0. Canberra: ABS.
- AIHW (Australian Institute of Health and Welfare) 2001. *National diabetes register statistical profile December 2000*. AIHW Cat. No. CVD 18 (Diabetes Series No. 2). Canberra: AIHW.
- AIHW (Australian Institute of Health and Welfare) 2002a. *Diabetes: Australian facts 2002*. AIHW Cat. No. CVD 20 (Diabetes Series No. 3). Canberra: AIHW.
- AIHW (Australian Institute of Health and Welfare) 2002b. *National health data dictionary. Version 11*. AIHW Cat. No. HWI 36. Canberra: AIHW.
- AIHW & AACR (Australian Institute of Health and Welfare & Australasian Association of Cancer Registries) 2002. *Cancer in Australia 1999*. AIHW Cat. No. CAN 15 (Cancer Series No. 20). Canberra: AIHW.
- Colagiuri S, Colagiuri R & Ward J 1998. *National diabetes strategy and implementation plan*. Canberra: Diabetes Australia.

De Courten M, Hodge A, Dowse G, King I, Vickery J & Zimmet P 1998. Review of the epidemiology, aetiology, pathogenesis and preventability of diabetes in Aboriginal and Torres Strait Islander populations. Canberra: Commonwealth Department of Health and Family Services.

DPIE & DSHS (Department of Primary Industries and Energy & Department of Human Services and Health) 1994. Rural, remote and metropolitan areas classification. 1991 Census edition. Canberra: AGPS.

IDF (International Diabetes Federation) 2000. Diabetes atlas 2000. Belgium: IDF.

Karvonen M, Tuomilehto J, Libman I & LaPorte R 1993. A review of the recent epidemiological data on the worldwide incidence of Type 1 (insulin-dependent) diabetes mellitus. *Diabetologia* 36:883–92.

World Health Organization (WHO) 1992. International statistical classification of diseases and related health problems ICD-10. 9th revision, volume 1. Geneva: WHO.

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