Appendix

Data held on the NDR

As described in Chapter 1, the NDR has two main data sources: the National Diabetes Services Scheme database (NDSS), and the Australasian Paediatric Endocrine Group's (APEG) state and territory databases. For details about NDSS and APEG, see the Data Sources section below.

Table A1 lists the data items held on the NDR, the source of each data item, and a description of output categories available for each item. Identifiable information is used only for AIHW's management of the NDR and is not available as output. These items are marked accordingly.

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

Field	Collected by NDSS	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	
NDR consent	X	X	X		Must consent to be included on NDR
Research consent	X	X		Yes No	
Title (Mr, Mrs, Dr etc.)	X			Not available	
Family name	X	X		Not available	
Given names	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	

(continued)

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

Field	Collected by NDSS	Collected by APEG	Derived Item	Output categories	Comments
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	
Main language spoken at home	X			DA language code	
Postcode at diagnosis	X	X			
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
Time since diagnosis	X			Not recorded Last year 1–2 years ago 3–5 years ago More than 5 years	
Registration date	X	X		Year of registration	Year of registration with NDSS or APEG
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	
Date of first insulin injection	X	X		Year of first insulin use	

(continued)

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

Field	Collected by NDSS	Collected by APEG	Derived Item	Output categories	Comments
Time since first insulin injection	X			Not recorded Last year 1–2 years ago 3–5 years ago More than 5 years	
Age at first insulin use			X	5-year age groups	Derived from date of birth and date of first insulin injection
Insulin Type—Injection	X			No Yes	
Insulin Type—Inhalent	X			No Yes	
Insulin Type—Pump	X			No Yes	
Insulin Type—Other therapy	X			No Yes	
Date of first syringe purchase	X			Year of first syringe purchase	
Vital status			X	1—Alive 2—Deceased	
Year of death			X	Year of death	
Underlying cause of death			X	ICD-10 coding	
Associated cause(s) of death			X	ICD-10 coding	
Form ID	X			Old—pre 2003 form change New—post 2003 form change	
Date last modified	X			Not available	No information on what was modified
Doctor's details					
Certifying doctor's name		X		Not available	
Doctor's address 1		X		Not available	
Doctor's address 2		X		Not available	
Doctor's address 3		X		Not available	
Doctor type		X		G—General practitioner E—Endocrinologist S—Specialist O—Other medical practitioner D—Diabetes educator	
Doctor's provider number		X		Not available	
Doctor's research involvement		X		Not available	
Certified by a doctor	X			No Yes (GP, specialist, endocrinologist)	

(continued)

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

Field	Collected by NDSS	Collected by APEG	Derived Item	Output categories	Comments
Certified by a CDE-RN	X			No Yes	
Carer details					
Carer family name		X		Not available	
Carer given name		X		Not available	
Carer phone number		X		Not available	
Carer flag (carer details are present)	X			No Yes	
Flag—use carer's mailing address)	X			No Yes	

Concordance between NDSS and APEG

The overlap between the APEG and NDSS records on the NDR is summarised in Tables A2 and A3, by year of first insulin use and state, respectively. The tables show that APEG records as a proportion of NDSS records ranged between 76% and 84% for the first 5 years. One possible reason for the drop off in the proportion in 2004 could be the introduction of the new NDSS registration form in late 2003 which changed the consent arrangement to an opt-out system, meaning the NDR now receives a higher proportion of total NDSS records than in the past. The lower coverage for the final year is likely to improve as more APEG records for that period are received. Over 80% of APEG records are received within 12 months of diagnosis.

The concordance varies greatly by state, from 61% in Queensland to 105% in Western Australia (Table A3).

Table A2: Concordance between NDSS and APEG records for registrants first diagnosed in 1999–2005 and aged under 15 years at time of diagnosis, by year

Year	Both APEG and NDSS	NDSS only	APEG only	Total	APEG as proportion of NDSS (%)
1999	389	221	121	731	83.6
2000	500	215	61	776	78.5
2001	571	213	87	871	83.9
2002	599	258	67	924	77.7
2003	646	287	70	1,003	76.7
2004	610	367	43	1,020	66.8
2005	513	390	56	959	63.0

Source: National Diabetes Register (data extracted April 2007).

Table A3: Concordance between NDSS and APEG records for registrants first diagnosed in 1999–2005 and aged under 15 years at time of diagnosis, by state/territory of residence

State/territory of residence	Both APEG and NDSS	NDSS only	APEG only	Total	APEG as proportion of NDSS (%)
NSW	1,172	645	171	1,988	73.9
Vic	902	564	106	1,572	68.8
Qld	641	527	75	1,243	61.3
WA	561	24	54	639	105.1
SA	339	108	60	507	89.3
Tas	133	31	26	190	97.0
ACT [(a)]	63	35	9	107	73.5
NT [(b)]	17	16	4	37	63.6
Australia	**3,828**	**1,951**	**505**	**6,284**	**75.0**

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

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

Note: Columns may not add to the Australian totals as these include records were state/territory of residence was unknown.

Source: National Diabetes Register (data extracted April 2007).

Data sources

AIHW population database

Population data held by the AIHW are sourced from the ABS Demography section and are updated as revised/new estimates become available. All population estimates currently produced by ABS are based on a usual residence concept, that is, where people usually reside, and are referred to as Estimated Resident Populations (ERPs).

De-identified NDSS dataset

The de-identified NDSS dataset is a file provided by Diabetes Australia Ltd which contains de-identified information on all NDSS registrations since 1987. This report analyses data on registrants in the scope of the NDR, that is, they use insulin to treat their diabetes and their insulin use started on or after 1 January 1999.

National Death Index

The National Death Index is a database housed at the Australian Institute of Health and Welfare that contains records of all deaths occurring in Australia since 1980. The data are obtained from the Registrars of Births, Deaths and Marriages in each state and territory. The Index is designed to facilitate the conduct of epidemiological studies and its use is strictly confined to medical research.

National Diabetes Register

The NDR has two sources of ascertainment: the National Diabetes Services Scheme database; and the Australasian Paediatric Endocrine Group's state and territory databases for 0–14 year olds.

National Diabetes Services Scheme (NDSS)

The NDSS is an initiative of the Australian Government that subsidises the supply of insulin syringes, insulin infusion pump consumables and diagnostic reagents (blood and urine testing strips) to registered persons with diabetes. The Scheme was established in 1987 and is administered by Diabetes Australia Ltd, which coordinates the supply of products in all states and territories. The NDSS aims at enhancing the capacity of people with diabetes to understand and manage their life with diabetes and to ensure they have timely, reliable and affordable access to the supplies and services they require to effectively self-manage their condition. (See Table A1 for a list of the data items that the NDSS contributes to the NDR.)

Australasian Paediatric Endocrine Group (APEG)

The Australasian Paediatric Endocrine Group (APEG) is the professional body in Australia and New Zealand which represents those involved in management and research of children with disorders of the endocrine system including diabetes mellitus.

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 and adolescents with Type 1 diabetes. Each state has established its database independently, and at varying times since 1985, but all collect the same minimum dataset. (See Table A1 for a list of the data items that APEG contributes to the NDR.)

Glossary

Associated cause(s) of death

Any condition(s), diseases and injuries—other than the underlying cause—considered to contribute to a death. Compare with *Underlying cause of death.* See also C*ause of death.*

Cause of death

From information reported on the medical certificate of cause of death, each death is classified by the underlying cause of death according to rules and conventions of the 10th revision of the *International classification of diseases.* See also U*nderlying cause of death* and *Associated cause(s) of death.*

Derived diabetes type

Refers to how a classification of individuals on the NDR as Type 1, Type 2 and so on is derived from data in the NDR. The method of calculation (algorithm) is based on age of diagnosis and the period of time between the date of diagnosis and start of insulin use. For more information on this, see Section 6.3.

Diabetes (diabetes mellitus)

A chronic condition in which the body cannot properly use its main energy source, the sugar glucose. This is due to either the pancreas not producing enough of the hormone insulin or the body being unable to effectively use the insulin produced. Insulin helps glucose enter the body's cells from the bloodstream and then be processed by them. Diabetes is marked by an abnormal build-up of glucose in the blood and it can have serious short- and long-term effects on many of the body's systems, especially the blood vessels and nerves.

For the different types of diabetes, see *Type 1 diabetes, Type 2 diabetes, Gestational diabetes mellitus (GDM)* and *Other types of diabetes.*

Gestational diabetes mellitus (GDM)

Develops during pregnancy in some women but usually disappears when the pregnancy is over. However, women who have had GDM are at greater risk of developing *Type 2 diabetes* later in life. GDM increases the risk of perinatal morbidity and mortality. See Box 2.1.

Women who had their diabetes diagnosed before a pregnancy do not fall into this category.

Glucose

A simple sugar that is the major source of energy for the body and the sole source of energy for the brain. It is supplied through food and is also produced and released by the liver. Its proper use requires the hormone insulin.

Incidence

The number of new cases (of an illness or event) occurring during a given period. Compare with *Prevalence.*

Insulin

A hormone produced by the pancreas, its main action is to enable body cells to absorb glucose from the blood and use it for energy.

Insulin-treated diabetes

All types of diabetes treated with insulin, includes Type 1, Type 2, gestational and other types of diabetes. It is a term used to describe those on the NDR and is not a standard classification used in clinical practice.

Latent autoimmune diabetes in adults (LADA)

Adult patients with a slowly progressive form of autoimmune or Type 1 diabetes who could be treated initially without insulin injections.

Other types of diabetes

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

- genetic defects of beta-cell function (formerly referred to as maturity-onset diabetes of the young (MODY)
- genetic defects in insulin action
- diseases of the exocrine pancreas (including cystic fibrosis and cancer of the pancreas)
- endocrinopathies (for example, acromegaly and Cushing's Syndrome)
- drug- or chemical-induced diabetes (for example, steroid-induced diabetes)
- infections (for example, congenital rubella)
- uncommon but specific forms of immune-mediated diabetes mellitus
- 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 on the National Diabetes Register. See Box 2.1.

Pancreas

The organ that lies behind the lower part of the stomach and produces insulin.

Prevalence

The number or proportion (of cases or instances) present in a population at a given time. Compare with *Incidence.*

Reported diabetes type

The type of diabetes recorded on the NDSS or APEG registration forms. Diabetes type is known to be misreported in many instances; for details see Section 6.3.

Type 1 diabetes

Mostly arises in childhood or young adults, though can occur at any age. It is marked by the inability to produce insulin. People with Type 1 diabetes need insulin replacement for survival. Most cases are caused by an autoimmune condition that destroys the pancreatic cells that produce insulin. See Box 2.1.

Type 2 diabetes

The most common form of diabetes, and occurs mostly in people aged 40 years and over. People with Type 2 diabetes produce insulin but may not produce enough or cannot use it effectively. Some cases may be managed with changes to diet along with increased exercise

and weight loss. Many require drugs as well, namely oral glucose-lowering drugs that work on the pancreas. Many others require insulin in addition to other treatments. See Box 2.1.

Underlying cause of death

The condition, disease or injury initiating the sequence of events leading directly to death, that is, the main or principal cause. Compare with *Associated cause(s) of death.*

References

ABS (Australian Bureau of Statistics) 1998. Standard Australian classification of countries (SACC). ABS cat. no. 1269.0. Canberra: ABS

ABS 2001. Australian standard geographical classification (ASGC) 2001. ABS cat. no. 1216.0. Canberra: ABS.

ABS 2006a. National health survey 2004–05: summary of results. ABS cat. no. 4820.0.55.001. Canberra: ABS.

ABS 2006b. Migration Australia 2004–05. ABS cat. no. 3412.0. Canberra: ABS.

ABS 2006c. Diabetes in Australia: a snapshot, 2004–05. ABS cat. no. 3412.0. Canberra: ABS.

ABS & AIHW (Australian Institute of Health and Welfare) 2005. The heath and welfare of Australia's Aboriginal and Torres Strait Islander peoples. ABS cat. no. 4704.0. Canberra: ABS.

AIHW 2001. National Diabetes Register statistical profile, December 2000. AIHW cat. no. CVD 18. Diabetes Series no. 2. Canberra: AIHW.

AIHW 2002. Diabetes: Australian facts 2002. AIHW cat. no. CVD 20. Diabetes Series no. 3. Canberra: AIHW.

AIHW 2004. Rural, regional and remote health: a guide to remoteness classifications. AIHW cat. no. PHE 53. Canberra: AIHW.

AIHW 2006. National Diabetes Register: impact of changed consent arrangements on ascertainment from the National Diabetes Services Scheme. AIHW cat. no. CVD 35. Diabetes Series no. 5. Canberra: AIHW.

AIHW: Dixon T & Webbie K 2005. Diabetes-related deaths 2001–2003. Bulletin no. 32. AIHW cat. no. AUS 69. Canberra: AIHW.

AIHW: Dixon T & Webbie K 2006. The national system for monitoring diabetes in Australia. AIHW cat. no. CVD 32. Canberra: AIHW.

AIHW: Holdenson Z, Catanzariti L, Phillips G & Waters AM 2003. A picture of diabetes in overseas-born Australians. AIHW Bulletin no. 9. Canberra: AIHW.

AIHW: Mathur S, Gajanayake I & Hodgson G 2000. Diabetes as a cause of death, Australia, 1997 and 1998. AIHW cat. no. CVD 12. Diabetes Series no. 1. Canberra: AIHW.

Breslow NE & Day NE 1987. Rates and rate standardization. In: Statistical methods in cancer research. Volume II—the design and analysis of cohort studies. Lyon: International Agency for Research on Cancer.

Chong J, Craig M, Cameron F et al. 2007. Marked increase in type 1 diabetes mellitus incidence in children aged 0–14 yr in Victoria, Australia, from 1999 to 2002. Pediatric Diabetes 8:67–73.

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

Craig M, Femia G, Broyda V, Lloyd M, & Howard N 2007. Type 2 diabetes in Indigenous and non-Indigenous children and adolescents in New South Wales. Medical Journal of Australia 186:497–9.

Daneman D 2006. Type 1 diabetes. The Lancet 367:847–58.

DeCourten 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.

DIAMOND Project Group 2006. Incidence and trends of childhood Type 1 diabetes worldwide 1990–1999. Diabetic Medicine 23:857–66.

Dobson AJ, Kuulasmaa K, Eberle E & Scherer J 1991. Confidence intervals for weighted sums of Poisson parameters. Statistics in Medicine 10:457–62.

DoHA (Department of Health and Ageing) 2001. Measuring remoteness: accessibility/ remoteness index of Australia (ARIA). DoHA Occasional Papers New Series no. 14. Canberra: AusInfo.

DoHA 2007. National Diabetes Services Scheme (NDSS). Viewed 21 May 2007, <www.health.gov.au/internet/wcms/publishing.nsf/content/health-pbs-healthpro-supply-ndss.htm>.

Gale E 2001. The discovery of Type 1 diabetes. Diabetes 50:217–26.

Haynes A, Bower C, Bulsara MK et al. 2004. Continued increase in the incidence of childhood Type 1 diabetes in a population-based Australian sample (1985–2002). Diabetologia 47:866–70.

HDSC (Health Data Standards Committee) 2006. National health data dictionary. Version 13. Canberra: AIHW.

IDF (International Diabetes Federation) 2006. Diabetes atlas, 3rd edition. Belgium: IDF.

LaPorte RE, McCarty D, Bruno G, Tajima N & Baba S 1993. Counting diabetes in the next millennium: application of capture–recapture technology. Diabetes Care 16(2):528–34.

LaPorte RE, Tajima N, Akerblom HK, Berlin N, Brosseau J, Christy M et al. 1985. Geographic differences in the risk of insulin-dependent diabetes mellitus: the importance of registries. Diabetes Care 8 Suppl(1):101–7.

McMahon S, Haynes A, Ratnam N, Grant M, Carne C, Jones T & Davis E 2004. Increase in type 2 diabetes in children and adolescents in Western Australia. Medical Journal of Australia 180:459–61.

Nathan D, Buse J, Davidson M, Heine R, Holman R, Sherwin R & Zinman B 2006. Management of hyperglycemia in Type 2 diabetes: a consensus algorithm for the initiation and adjustment of therapy. *Diabetes Care* 29:1963–72.

Pinhas-Hamiel O & Zeitler P 2005. The global spread of Type 2 diabetes mellitus in children and adolescents. Journal of Pediatrics 146:693–700.

Taplin CE, Criag M, Lloyd M et al. 2005. The rising incidence of childhood Type 1 diabetes in New South Wales, 1990–2002. Medical Journal of Australia 183(5):243–6.

Turner R, Stratton I, Horton V, Manley S, Zimmet P, Mackay IR et al. 1997. UKPDS 25: autoantibodies to islet-cell cytoplasm and glutamic acid decarboxylase for prediction of insulin requirement in type 2 diabetes. UK Prospective Diabetes Study Group. Lancet 350(9087):1288–93.

Whitall D, Glatthaar C, Knuiman M & Welborn T 1990. Deaths from diabetes are under-reported in national mortality statistics. Medical Journal of Australia 152:598–600.

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

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.

List of tables