Australian Government
Australian Institute of Health and Welfare

Incidence of type 1 diabetes in Australia

2000–2013

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Summary

Type 1 diabetes is a lifelong autoimmune disease requiring management with insulin to ensure blood glucose levels remain within a safe range. If left untreated, or improperly managed, type 1 diabetes can lead to many health complications.

This report uses the latest available data from the National (insulin-treated) Diabetes Register to examine the incidence—that is, the number of new cases—of type 1 diabetes in Australia.

- From 2000 to 2013 there were 31,895 new cases of type 1 diabetes in Australia, with 2,323 of these in 2013.
- The rate of type 1 diabetes has remained stable for more than a decade, at around 10 to 13 cases per 100,000 population each year.
- The incidence of type 1 diabetes was higher for males than for females—12 per 100,000 compared with 9 per 100,000, respectively, in 2013.
- More than half of all new cases of type 1 diabetes were in people aged under 18 years.
  - Rates were 3 times as high among 0–14 years olds (24 per 100,000 population) compared with those aged 15 and over (8 per 100,000 population).
- The rate of type 1 diabetes was lowest in the Northern Territory, at 6 per 100,000 population, compared with other states and territories, which ranged from 11 to 13 per 100,000 population between 2000 and 2013.
- From 2001–2013, the rate of type 1 diabetes was lower in remote and very remote areas compared with other areas of Australia—7 cases per 100,000 population compared with 11–13 per 100,000, respectively.
- Aboriginal and Torres Strait Islander people had a lower incidence of type 1 diabetes than non-Indigenous Australians: 7 per 100,000 population and 10 per 100,000, respectively, in 2005–2013.

Type 1 diabetes has an enormous burden on both individuals and the community. For those with the condition, it impacts on a range of health problems, disability, quality of life and premature death, particularly when it is not well managed. For the community, the financial burden of type 1 diabetes is estimated to be $570 million annually in Australia (Colagiuri et al. 2009).

Australia's incidence of type 1 diabetes among children and young people is relatively high compared with other countries; this rate places it among the top 10 countries in the world for type 1 diabetes (Baker IDI Heart and Diabetes Institute 2012). However, unlike other countries, where the estimated rate of type 1 diabetes among those aged under 15 years increased around 3% per annum from 1999 to 2008 (Patterson et al. 2012), the rate in Australia remained stable over this period.

Given the high incidence in Australia and increases around the world, continued monitoring and reporting of type 1 diabetes is essential.

This report

This report provides a summary of the latest available information on incidence (new cases) of type 1 diabetes in Australia. The information is based on data from the 2013 National (insulin-treated) Diabetes Register, which holds data about people who use insulin to treat and manage their diabetes. Note that the results presented in this report cannot be compared with previous publications, due to changes in data collection and the methodology used to derive the National (insulin-treated) Diabetes Register (see 'Data collection').

What is type 1 diabetes?

Type 1 diabetes is an autoimmune disease that develops when the immune system destroys the insulin-producing cells of the pancreas. The absence of insulin means glucose cannot be transported into the cells (where it would usually be stored for future energy use) and consequently blood glucose levels rise. Unlike type 2 diabetes, where maintaining a healthy lifestyle has been associated with reducing or delaying disease onset, the exact cause of type 1 diabetes is unknown, although it is believed to be an interaction of genetic predisposition and environmental factors.

Type 1 diabetes can occur at any age, but it mainly develops during childhood and adolescence (Craig et al. 2011). It is a permanent condition requiring lifelong management to keep blood glucose levels within a safe range. Management is through maintaining a healthy lifestyle, regular blood glucose testing and administering insulin, which is delivered through multiple daily injections or through continuous infusion via an insulin pump. Insulin replacement is essential for survival and, except in cases where a pancreatic transplant occurs, insulin will be required every day throughout a person's life.

Optimal management of type 1 diabetes is essential to reduce the risk of short-term complications associated with low and/or high blood glucose levels. If not well managed, type 1 diabetes may also progress to a range of health complications, including kidney failure, blindness, nerve damage affecting the feet, and/or coronary heart disease and stroke.

Over 2,000 new cases of type 1 diabetes in 2013

In 2013, there were 2,323 new cases of people with type 1 diabetes in Australia, equating to 11 cases per 100,000 population.

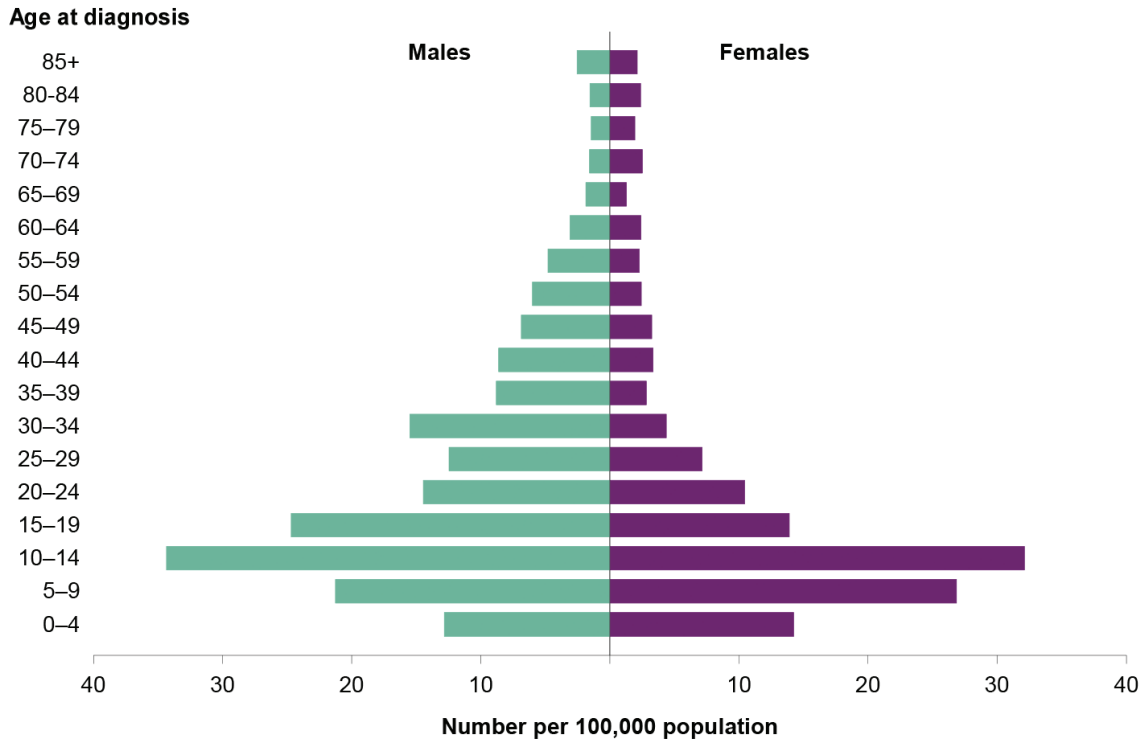
Of these, 59% were males (1,366) and 41% were females (954). Note that the total for males and females does not add to the Australian total due to missing information on sex.

Incidence—the number of new cases—was higher in males than females: the age-standardised rate was 12 cases per 100,000 for males and 9 per 100,000 for females.

More than half (52%) of all new cases were in young people under 18 years, with the peak age of diagnosis at age 10–14, at a rate of 33 per 100,000 population. This was more than 3 times the rate at age 30–34 (10 per 100,000) and 6 times the rate at 45–49 (5 per 100,000).

The incidence of type 1 diabetes was similar for males and females up to 15 years, but after this, males had higher rates than females in most age groups (Figure 1).

- For those aged 0–14 at diagnosis, the rate was 23 cases per 100,000 for males and 25 per 100,000 for females.
- For those aged 15 and over at diagnosis, the rates for males and females were 10 per 100,000 and 5, respectively.



Notes

1. Year of first insulin use is used as a proxy for year of diagnosis.
2. Some of those diagnosed in older age groups may have had late-onset autoimmune diabetes of adults: a condition that requires insulin relatively soon after diagnosis, but not necessarily immediately (Diabetes Australia 2012). If these people were registered as having type 1 diabetes and began using insulin within the first year of diagnosis, their diabetes type remained for this analysis as type 1.

Source: AIHW analysis of the NDR 2013 (Table 3, *Incidence of type 1 diabetes in Australia, 2000–2013: detailed tables*).

Figure 1: Incidence of type 1 diabetes by age at diagnosis and sex, 2013

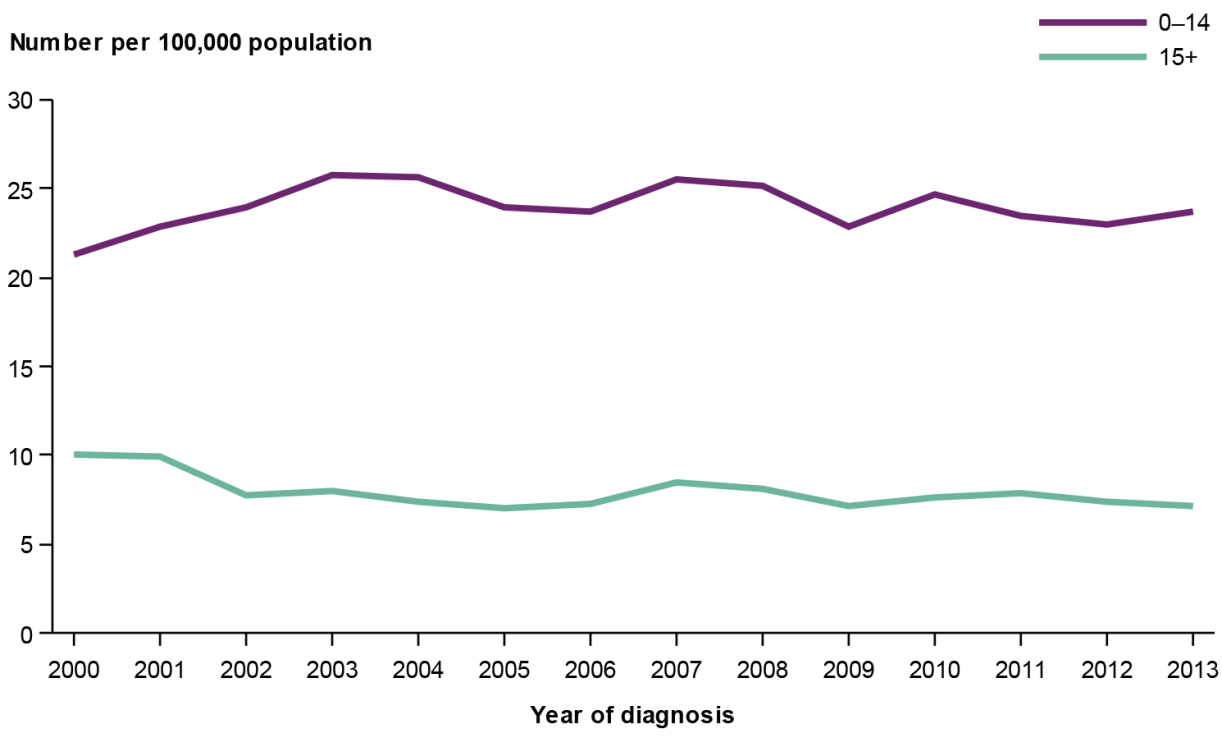
Incidence of type 1 diabetes remained relatively stable between 2000 and 2013

From 2000 to 2013, there were 31,895 cases of type 1 diabetes diagnosed.

This was an average of around 2,300 new cases each year, or 6 cases per day.

Incidence of type 1 diabetes remained relatively stable between 2000 and 2013, fluctuating between 10 and 13 cases per 100,000 population each year. This pattern remained consistent for males and females—the rate of new cases for females fluctuated between 9 and 11 cases per 100,000 each year and for males between 12 and 15 cases.

Similarly there were no differences in trends across age groups, with the incidence rate for 0–14 year olds remaining 2–3 times as high as for those aged 15 and over during this period—on average, a rate of 24 per 100,000 population compared with 8 per 100,000, respectively (Figure 2).



Notes

1. Year of first insulin use is used as a proxy for year of diagnosis.
2. Age-standardised to the 2001 Australian population.

Source: AIHW analysis of the NDR 2013 (Table 3, *Incidence of type 1 diabetes in Australia, 2000–2013: detailed tables*).

Figure 2: Trend in the incidence of type 1 diabetes by year of diagnosis and age at diagnosis, 2000–2013

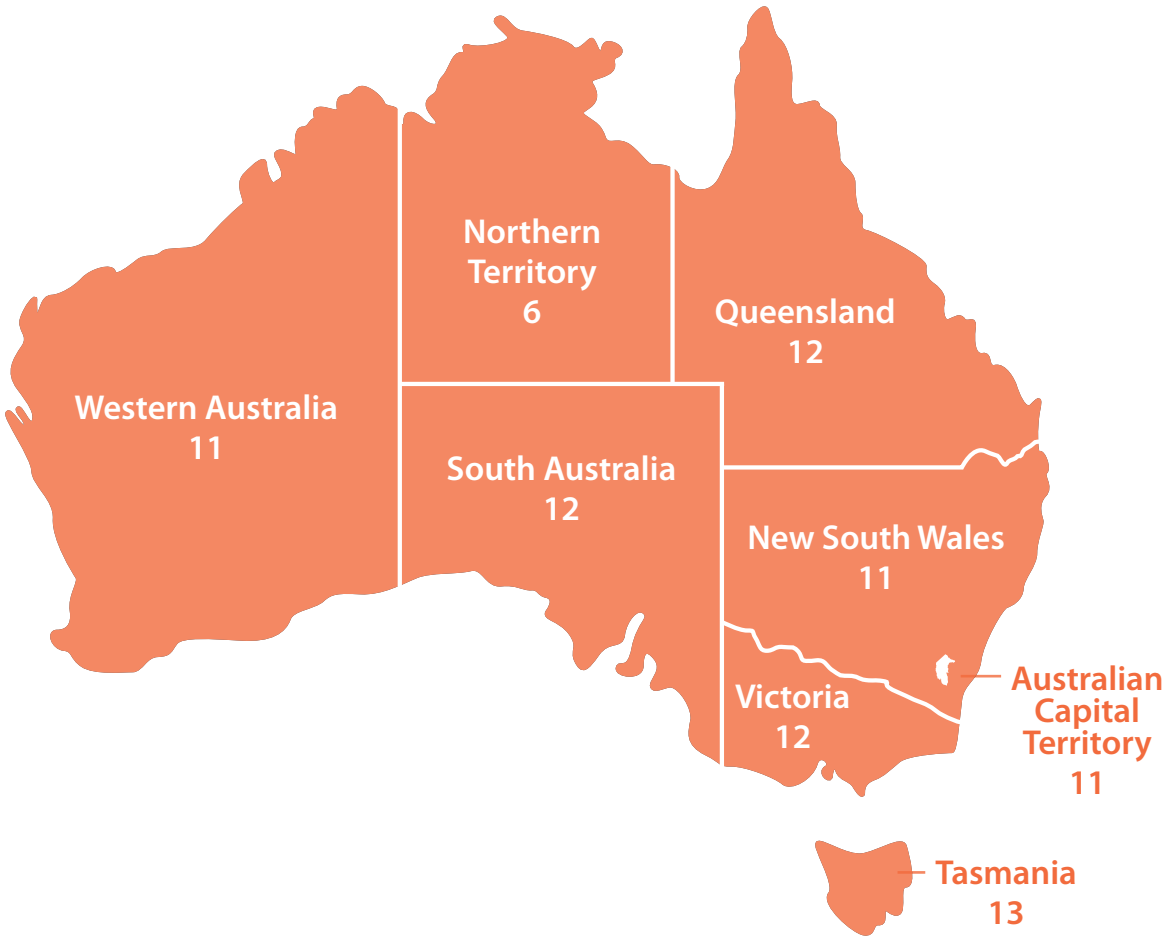
Rate of type 1 diabetes lowest in the Northern Territory

In 2013, the numbers of newly diagnosed cases of type 1 diabetes were:

- 677 in New South Wales
- 620 in Victoria
- 494 in Queensland
- 253 in Western Australia
- 176 in South Australia
- 52 in Tasmania
- 35 in the Australian Capital Territory
- 13 in the Northern Territory

Over the period 2000–2013, incidence was lowest in the Northern Territory at 6 per 100,000 (Figure 3). This may be due to the high proportion of Aboriginal and Torres Strait Islander people living in the Northern Territory (30%) (ABS 2014), who experience lower rates of type 1 diabetes than other Australians.

Other states and the Australian Capital Territory had rates ranging from 11 to 13 per 100,000.



Note: Age-standardised to the 2001 Australian population.

Source: AIHW analysis of the NDR 2013 (Table 7, *Incidence of type 1 diabetes in Australia, 2000–2013: detailed tables*).

Figure 3: Incidence of type 1 diabetes per 100, 000 population by state or territory of usual residence, 2000–2013

Health inequalities—type 1 diabetes does not discriminate

Social, economic and environmental conditions strongly influence health. Typically, health varies among different population groups depending on factors such as geographical region, area of socioeconomic disadvantage and Indigenous status.

Type 1 diabetes does not appear to be related to circumstances that would ordinarily increase risk of ill health.

Remoteness

In 2013, the majority of new cases of type 1 diabetes were among people living in major cities—68%. Thirty per cent were in regional areas and 2% were in remote or very remote areas. This distribution reflected the overall population distribution across these regions in Australia.

However, the age-adjusted incidence rates (2001–2013) were lower in remote and very remote areas (7 cases per 100,000) than other areas of Australia where rates were similar (13, 11 and 11 cases per 100,000 in inner regional areas, outer regional areas and major cities, respectively) (Figure 4).

Socioeconomic disadvantage

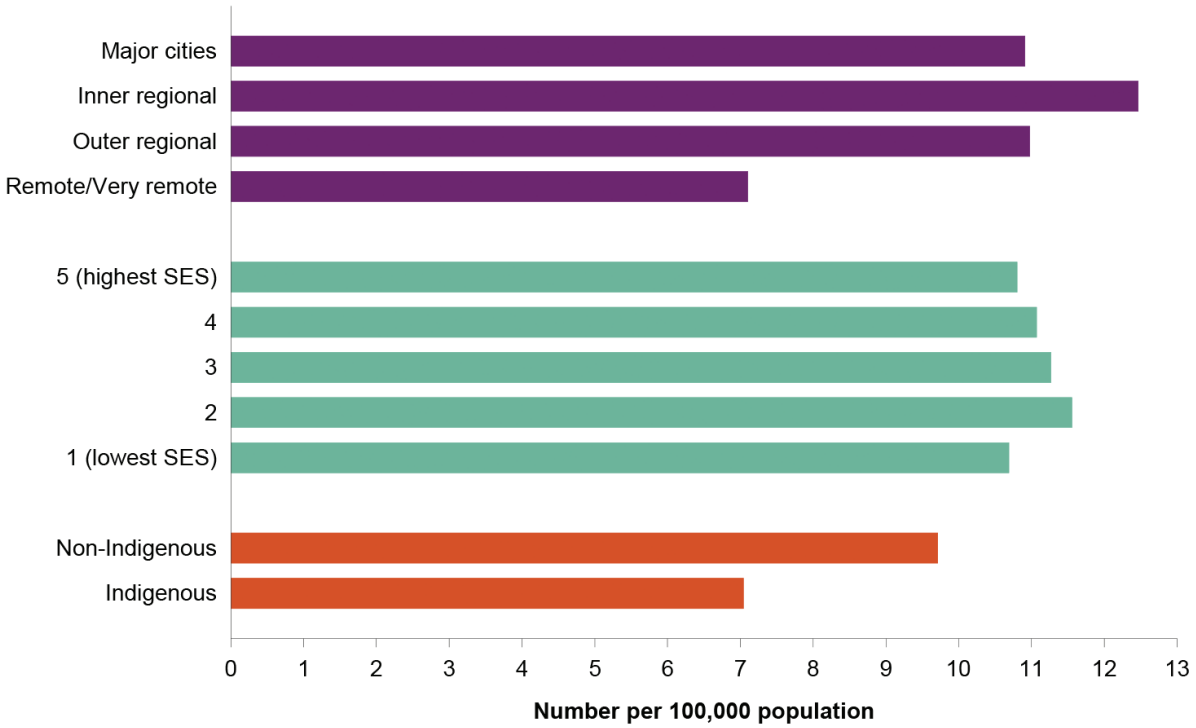
For all years, the rate of type 1 diabetes was similar across all socioeconomic status groups (Figure 4).

Indigenous people

In 2013, of the 2,323 new cases of type 1 diabetes, 70 (3%) were among Aboriginal or Torres Strait Islander people.

From 2005–2013, the 489 Indigenous people who were diagnosed with type 1 diabetes represented 7 per 100,000 population. This was lower than the non-Indigenous rate of 10 per 100,000 (Figure 4).

Refer to *Incidence of type 1 diabetes in Australia, 2000–2013: statistical notes and methods* and the *Data Quality Statement: National (insulin-treated) Diabetes Register 2013* for information on the limitations of data on Indigenous people in this report.



Notes

1. Age-standardised to the 2001 Australian population.
2. Remoteness and socioeconomic status data are for 2001–2013.
3. Remoteness is classified according to the Australian Statistical Geography Standard 2011 Remoteness Areas of current residence.
4. Socioeconomic status (SES) is classified into population-based quintiles according to the Index of Relative Socio-Economic Disadvantage based on postcode of current residence.
5. Indigenous data are for 2005–2013.
6. Analysis of Indigenous status excludes 34 National Diabetes Services Scheme registrations before 2005 due to changes in data coding.

Source: AIHW analysis of the NDR 2013 (Table 11 and Table 25, *Incidence of type 1 diabetes in Australia, 2000–2013: detailed tables*).

Figure 4: Incidence of type 1 diabetes by remoteness, socioeconomic status and Indigenous status

Data collection

The National (insulin-treated) Diabetes Register

The National (insulin-treated) Diabetes Register collects information about people who began using insulin as part of their treatment for diabetes since 1999. The register includes most people diagnosed with type 1 diabetes since 1999, as well as those who use insulin to manage type 2 diabetes, gestational diabetes and other, less common forms of diabetes (Table 1).

Table 1: The number of people with insulin-treated diabetes on the 2013 National (insulin-treated) Diabetes Register

Diabetes type	2013	2000–2013
Type 1 diabetes	2,323	31,895
Insulin-treated type 2 diabetes	20,376	260,097
Insulin-treated gestational diabetes	5,873	42,574
Other forms of diabetes[(a)]	494	3,460
All insulin-treated diabetes[(b)]	29,545	346,763

(a) There are a number of conditions or syndromes that come under this category, such as genetic defects of beta-cell function and endocrine diseases and infections.

(b) Total includes insulin-treated diabetes where diabetes type is unknown. In 2013, diabetes type was unknown for 479 insulin users; in 2000–2013, diabetes type was unknown for 8,737 insulin users.

Source: AIHW analysis of the NDR 2013.

The National (insulin-treated) Diabetes Register is maintained by the Australian Institute of Health and Welfare under contract with the Department of Health and is derived from two primary data sources:

- National Diabetes Services Scheme
- Australasian Paediatric Endocrine Group.

The **National Diabetes Services Scheme** was established in 1987 and is administered by Diabetes Australia. It is an initiative of the Australian Government to subsidise the supply of diabetes-related products—such as pens and needles to administer insulin, blood glucose test strips and insulin pump consumables—to people who are registered with the scheme. A diagnosis of diabetes, substantiated by a health professional, is required in order to register with the National Diabetes Services Scheme.

The **Australasian Paediatric Endocrine Group** is a professional body that represents health professionals involved in the management and research of disorders of the endocrine system, including diabetes in children and adolescents. The Australasian Paediatric Endocrine Group maintains clinic-based state and territory diabetes registers.

Coverage of type 1 diabetes on the National (insulin-treated) Diabetes Register

Almost all people with type 1 diabetes who were diagnosed from 1999 are captured on the National (insulin-treated) Diabetes Register because all people with type 1 diabetes must use insulin to treat their condition. The requirement for products such as pens/needles, or insulin pump consumables, to administer insulin is a driver for people with type 1 diabetes to register with the National Diabetes Services Scheme in order to obtain these products at subsidised prices. Additionally, the coverage rate of the National (insulin-treated) Diabetes Register is high for those diagnosed under 15 years as data are also obtained from the Australasian Paediatric Endocrine Group state-based registers.

Comparisons with previous reports

The methods to create the National (insulin-treated) Diabetes Register have recently been updated, and the derivation of the register used for these analyses applied the new processes retrospectively across all years. This means that the information in this report can be compared over time. However, results presented in this report cannot be compared with previous publications or results based on previous National (insulin-treated) Diabetes Register data.

Technical definitions

age-standardised rate: Enables comparisons to be made between populations that have different age structures.

incidence: The number of new cases (of an illness or event) occurring during a given period.

remoteness: A system which classifies geographical locations into groups (*Major cities*, *Inner regional*, *Outer regional*, *Remote*, *Very remote*) according to distance from major population centres and services. Remoteness is a geographical concept and does not take account of accessibility which is influenced by factors such as the socioeconomic status or mobility of a population.

socioeconomic status: Socioeconomic status is classified according to the Australian Bureau of Statistics' Socio-Economic Indexes for Areas (SEIFA), whereby areas are classified on the basis of social and economic information collected in the Census of Population and Housing. In this report, the SEIFA Index of Relative Socio-Economic Disadvantage was used. This is derived from social and economic characteristics of the local area, such as low income, low educational attainment, high levels of public sector housing, high unemployment and jobs in relatively unskilled occupations.

Where to find more information

- *Incidence of type 1 diabetes in Australia, 2000–2013: detailed tables*
- *Incidence of type 1 diabetes in Australia, 2000–2013: statistical notes and methods*
- *Data Quality Statement: National (insulin-treated) Diabetes Register 2013*

References

Australian Bureau of Statistics 2014. Estimates and projections, Aboriginal and Torres Strait Islander Australians, 2001 to 2026. Canberra: ABS.

Baker IDI Heart and Diabetes Institute 2012. Diabetes: the silent pandemic and its impact on Australia. Melbourne: Baker IDI Heart and Diabetes Institute. Viewed 13 June 2013, <https://www.bakeridi.edu.au/Assets/Files/14814%20Diabetes%20management%20booklet%205%20Mar_FINAL.pdf>.

Colagiuri S, Brnabic A, Gomez M, Fitzgerald B, Buckley A & Colagiuri R 2009. DiabCo$t Australia type 1: assessing the burden of type 1 diabetes in Australia. Canberra: Diabetes Australia.

Craig M, Twigg S, Donaghue K, Cheung N, Cameron F, Conn J et al. 2011. National evidence-based clinical care guidelines for type 1 diabetes in children, adolescents and adults. Canberra: Department of Health and Ageing.

Diabetes Australia 2012. Diabetes management in general practice: guidelines for type 2 diabetes. Canberra: Diabetes Australia.

Patterson CC, Gyürüs E, Rosenbauer J, Cinek O, Neu A, Schober E et al. 2012. Trends in childhood type 1 diabetes incidence in Europe during 1989-2008: evidence of non-uniformity over time in rates of increase. Diabetologia 55:2142–7.

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Incidence of type 1 diabetes in Australia, 2000–2013 presents the latest available national data on new cases of type 1 diabetes from Australia's National (insulin-treated) Diabetes Register.

In 2013, there were 2,323 new cases of type 1 diabetes in Australia, equating to 11 cases per 100,000 population. This rate has remained relatively stable between 2000 and 2013, fluctuating between 10 and 13 cases per 100,000 population each year.