Prevalence of type 1 diabetes among children aged 0–14 in Australia

2013

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Acknowledgments

Summary

This report presents information about the prevalence and characteristics of children aged 0–14 with type 1 diabetes in Australia, based on data from the 2013 National (insulin-treated) Diabetes Register (NDR). This is the first time national statistics on the prevalence of type 1 diabetes among children aged 0–14 have been reported by the NDR.

Type 1 diabetes is a non-preventable lifelong autoimmune disease, which is most commonly diagnosed in children. It is a difficult condition to manage, and if left untreated or improperly managed, can lead to many health complications or death.

Ongoing, regular monitoring of type 1 diabetes is essential to improve Australia's ability to respond to this important health problem.

	In 2013, 6,091 children aged 0–14 had type 1 diabetes in Australia—representing 139 cases per 100,000 population, or about 1 in every 720 children in that age group.
	Rates of type 1 diabetes were similar for both boys and girls. Rates for children aged 10–14 were twice as high (278 cases per 100,000 population) as for children aged 5–9 (123 per 100,000), and more than 10 times as high as for children aged 0–4 (27 per 100,000).
	The Northern Territory had the lowest prevalence of type 1 diabetes in children (50 cases per 100,000 population), while Tasmania had the highest (166 per 100,000).
	Children living in *Remote and very remote* areas had the lowest prevalence of type 1 diabetes (82 cases per 100,000 population) compared with all other areas in Australia (where rates varied between 133 and 169 cases per 100,000 population).
	The prevalence of type 1 diabetes among children was relatively similar across socioeconomic groups.
	There were 167 Aboriginal and Torres Strait Islander children with type 1 diabetes—equating to 69 cases per 100,000 Indigenous children, or 1 in almost 1,500.
	Just over 2 in 5 children (43%) with type 1 diabetes used a pump to administer insulin.

Introduction

This report examines the number (prevalence) of children aged 0–14 with type 1 diabetes in Australia in 2013. It is the first national report to present this information, and builds on a previous AIHW report, which presented a combination of existing data for children aged 0–9 and projected data for children aged 10–14 (AIHW 2011).

The results are part of ongoing national reporting from the National (insulin-treated) Diabetes Register (NDR), which was established in 1999 and captures data about people who use insulin to treat and manage their diabetes. See Appendix B for further information about the NDR. For those aged under 15, the NDR is ascertained from 2 data sources—the National Diabetes Services Scheme (NDSS) and the Australasian Paediatric Endocrine Group (APEG). As a result, it captures almost all children with type 1 diabetes in Australia (AIHW 2015b).

What is type 1 diabetes?

Type 1 diabetes is a chronic autoimmune disease that develops when the immune system destroys the insulin-producing cells of the pancreas (see Box 1 for further details). While type 1 diabetes can occur at any age, it mainly develops during childhood and adolescence (Craig et al. 2011). For example, in 2013, 44% of all newly diagnosed cases of type 1 diabetes were in children aged 0–14 (AIHW 2015a), despite children in this age group accounting for only 19% of the total population.

The cause of type 1 diabetes is unknown, but it is believed to be an interaction of genetic predisposition and environmental factors. Currently there is no way to prevent or cure type 1 diabetes. Without adequate ongoing management, the condition results in various short- and long-term health complications, and in some cases, unconsciousness or death.

Burden of type 1 diabetes

Diagnosis with type 1 diabetes early in life has implications for the individual, their families and society as a whole. For those living with type 1 diabetes, the condition can result in substantial morbidity, premature death and disability, and has an impact on emotional wellbeing and quality of life. It also places a heavy burden on those who support them.

At a health system level, the cost of type 1 diabetes is around $570 million annually, with per person costs increasing significantly for people with health complications as a result of their type 1 diabetes (Baker IDI Heart and Diabetes Institute 2012).

Type 1 diabetes is difficult to manage, particularly in children, requiring a careful balance of diet, exercise and insulin intake. As a result, many children have suboptimal glycaemic control (Craig et al. 2002), which increases the risk of complications. Prolonged duration of type 1 diabetes, especially where blood glucose levels have fluctuated, results in diabetes-related complications becoming increasingly common over time (Craig et al. 2011). Therefore children diagnosed at a young age are at a greater risk of developing complications compared with those diagnosed later in life (Craig et al. 2002).

Given the considerable burden of type 1 diabetes among children, monitoring is essential to improve Australia's ability to respond to this important health problem. The information in this report may inform the effective planning of treatment and support services, and the cost-effective allocation of resources to improve outcomes for those with type 1 diabetes.

Box 1: Type 1 diabetes

What is it?

Type 1 diabetes is a chronic autoimmune disease that develops when the immune system destroys the insulin-producing cells of the pancreas. Without insulin, glucose cannot be transported into the cells (where it would usually be stored for future energy use), so blood glucose levels rise. The cause of type 1 diabetes is unknown, although it is believed to be an interaction of genetic predisposition and environmental factors.

What are the complications?

The objective of type 1 diabetes management is to keep blood glucose levels within a normal range. Poor glycaemic control—where blood glucose levels fluctuate beyond a recommended range—is associated with both short- and long-term health complications.

Short-term complications of type 1 diabetes include: hypoglycaemia (low blood sugar); hyperglycaemia (high blood sugar); ketoacidosis (a life-threatening condition due to inadequate administration of insulin, leading to profound disturbance of the metabolism, and a build-up of acids in the blood); increased susceptibility to infections; and a reduced ability to heal. Over the longer term, diabetes may cause other health complications including diseases of the large blood vessels (macrovascular disease) such as heart attack and stroke, and diseases of the small blood vessels (microvascular disease) such as retinopathy, kidney diseases and neuropathy.

How is it managed?

Effective management of type 1 diabetes is crucial to reduce the short- and long-term complications associated with the condition. Type 1 diabetes is managed through administering insulin, a careful balance of diet and exercise, and regular blood glucose testing to keep blood glucose levels within a safe range. Maintaining this balance requires extensive education and ongoing support from health professionals.

Insulin is delivered through multiple daily injections or continuous infusion via an insulin pump. This insulin replacement is essential for survival and, except in cases where a pancreatic transplant occurs, insulin is needed every day throughout a person's life. Continuous glucose monitoring devices are available to automatically measure blood glucose levels.

What is an insulin pump?

Insulin pumps are small computerised devices that deliver insulin under the skin. They are worn 24 hours a day, and are increasingly being used as an alternative to injecting insulin with a pen or needle. There are both clinical and lifestyle benefits to using an insulin pump, but they are expensive (also incurring ongoing costs), and often require users to maintain more frequent contact with health professionals than is required for insulin injections (AIHW 2012).

About this report

The report presents the prevalence of type 1 diabetes among children aged 0–14, as of 31 December 2013, and characteristics such as: sex, age, diagnosis age, duration (time in years since diagnosis) of type 1 diabetes, state/territory of residence, residential remoteness area, socioeconomic group, and Indigenous status. Additionally, the report looks at the characteristics of insulin pump users aged 0–14, and factors that might influence insulin pump use.

More than 6,000 children had type 1 diabetes

As of 31 December 2013, 6,091 children aged 0–14 had type 1 diabetes in Australia. This represents 139 cases per 100,000 population, or 1 in 720 children aged 0–14.

Prevalence rates similar for boys and girls

Slightly more boys (3,143) than girls (2,947) had type 1 diabetes, reflecting the higher number of boys aged 0–14 in the overall population.

The prevalence rates of type 1 diabetes were very similar among boys and girls, with 140 and 139 cases per 100,000 population, respectively.

Almost 2 in 3 were aged 10–14

Almost 2 in 3 children with type 1 diabetes were aged 10–14 (3,891 children), 1,794 were aged 5–9, and 406 were aged 0–4.

The prevalence rates were more than twice as high for children aged 10–14 (278 per 100,000 population) as for those aged 5–9 (123 per 100,000), and more than 10 times as high as for those aged 0–4 (27 per 100,000) (Figure 1). The rates for girls and boys were relatively similar for all age groups.

Note: Sex was unknown for 1 child.

Source: AIHW analysis of the NDR 2013 as of 31 December 2013 (Table A1).

Figure 1: Prevalence of type 1 diabetes among children aged 0–14, by age and sex, 2013
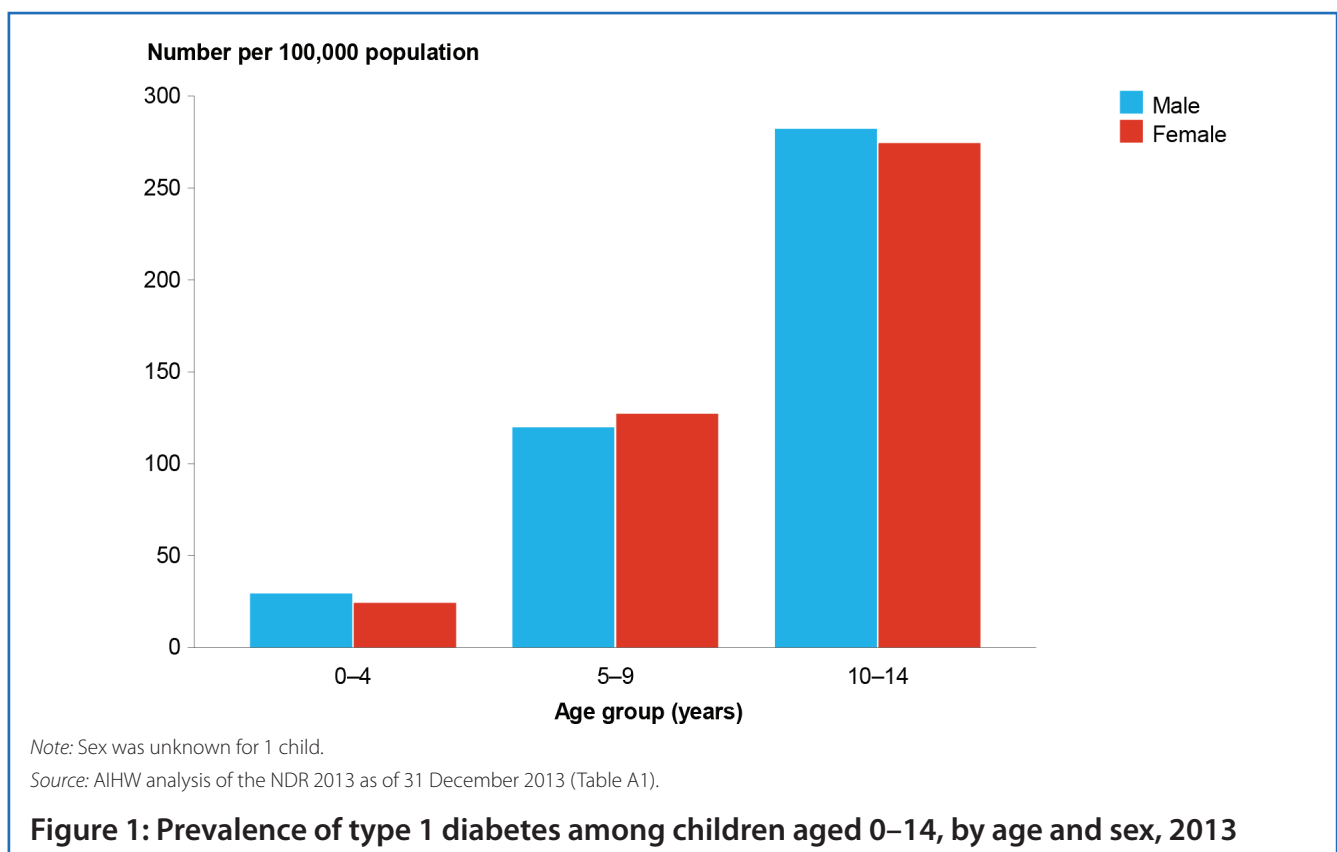
Almost 3 in 4 were diagnosed by the age of 9

About 1 in 5 (21%) children with type 1 diabetes were diagnosed by the age of 3, and almost half (48%) by the age of 6. Almost 3 in 4 children (74%) were diagnosed with type 1 diabetes by the age of 9. The remaining 1 in 4 children were diagnosed at 9–14, with fewer diagnoses as age increased—less than 1% of children with type 1 diabetes were aged 14 when diagnosed (Table A2).

Average time since diagnosis was 4 years

Longer duration of type 1 diabetes has been associated with an increased risk of long-term complications (see Box 1).

In 2013, the mean length of time (duration) with type 1 diabetes was about 4 years.

Almost 2 in 3 children (63%, or 3,851) had been diagnosed with type 1 diabetes for 4 years or fewer, and of these, 1 in 4 had the condition for less than 1 year (984 children). Only a small proportion of children aged 0–14 had been diagnosed with type 1 diabetes for 10 years or more (7%, or 421 children) (Figure 2).

Source: AIHW analysis of the NDR 2013 as of 31 December 2013.

Figure 2: Number of children with type 1 diabetes, by duration of type 1 diabetes, 2013
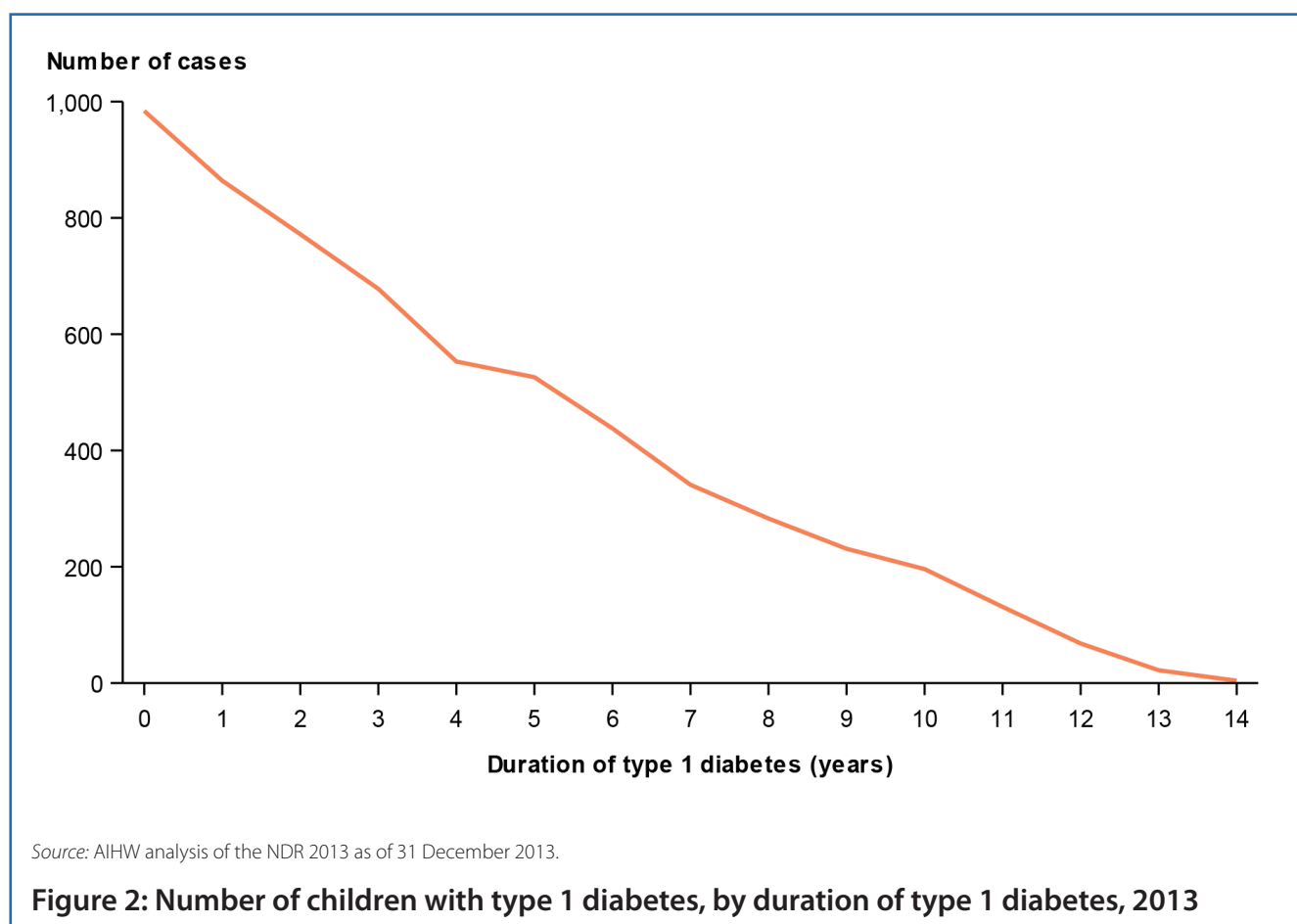
Because the long-term complications associated with type 1 diabetes develop gradually over time, children diagnosed at a very young age are potentially more vulnerable to poorer health later in life. As such, in this cohort of children with type 1 diabetes, those at greatest risk are those aged 0–4, and those aged 5–14 who were diagnosed with the condition at a young age.

Out of 406 children aged 0–4 with type 1 diabetes, 41% had been diagnosed for less than 1 year, and 59% for 1–4 years. Among children aged 5–9, the majority (57%) had been diagnosed with type 1 diabetes for 1–4 years, and almost one-quarter (24%) had been diagnosed for 5–9 years. Among the oldest age group, about 1 in 9 (11%) had been diagnosed with type 1 diabetes for 10 or more years, and 36% had been diagnosed for 5–9 years (Figure 3).

Source: AIHW analysis of the NDR 2013 as of 31 December 2013 (Table A3).

Figure 3: Duration of type 1 diabetes among children aged 0–14, by age, 2013
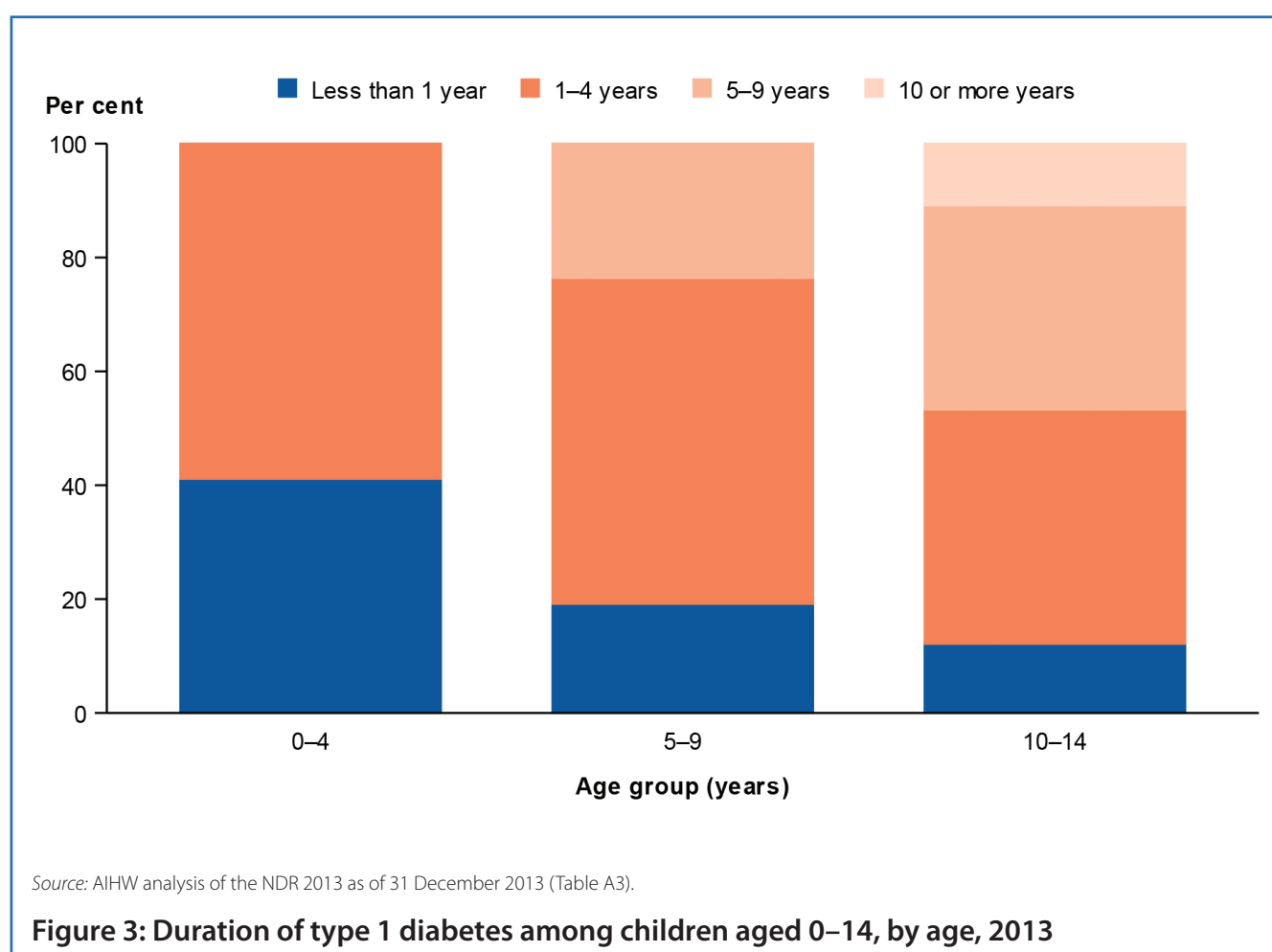
Highest rate was in Tasmania

Prevalence of type 1 diabetes among children was highest for children living in Tasmania (166 cases per 100,000 population) and lowest in the Northern Territory (50 cases per 100,000). The rates in other states and the Australian Capital Territory ranged from 131 to 159 per 100,000 (Figure 4).

The low rate in the Northern Territory may be due to the high proportion of Aboriginal and Torres Strait Islander children living there (43%, compared with 6% in Australia; ABS 2013). Indigenous Australians have lower rates of type 1 diabetes than other Australians.

Source: AIHW analysis of the NDR 2013 as of 31 December 2013 (Table A1).

Figure 4: Prevalence of type 1 diabetes among children aged 0–14, by state/territory of residence, 2013 (Number per 100,000 population)
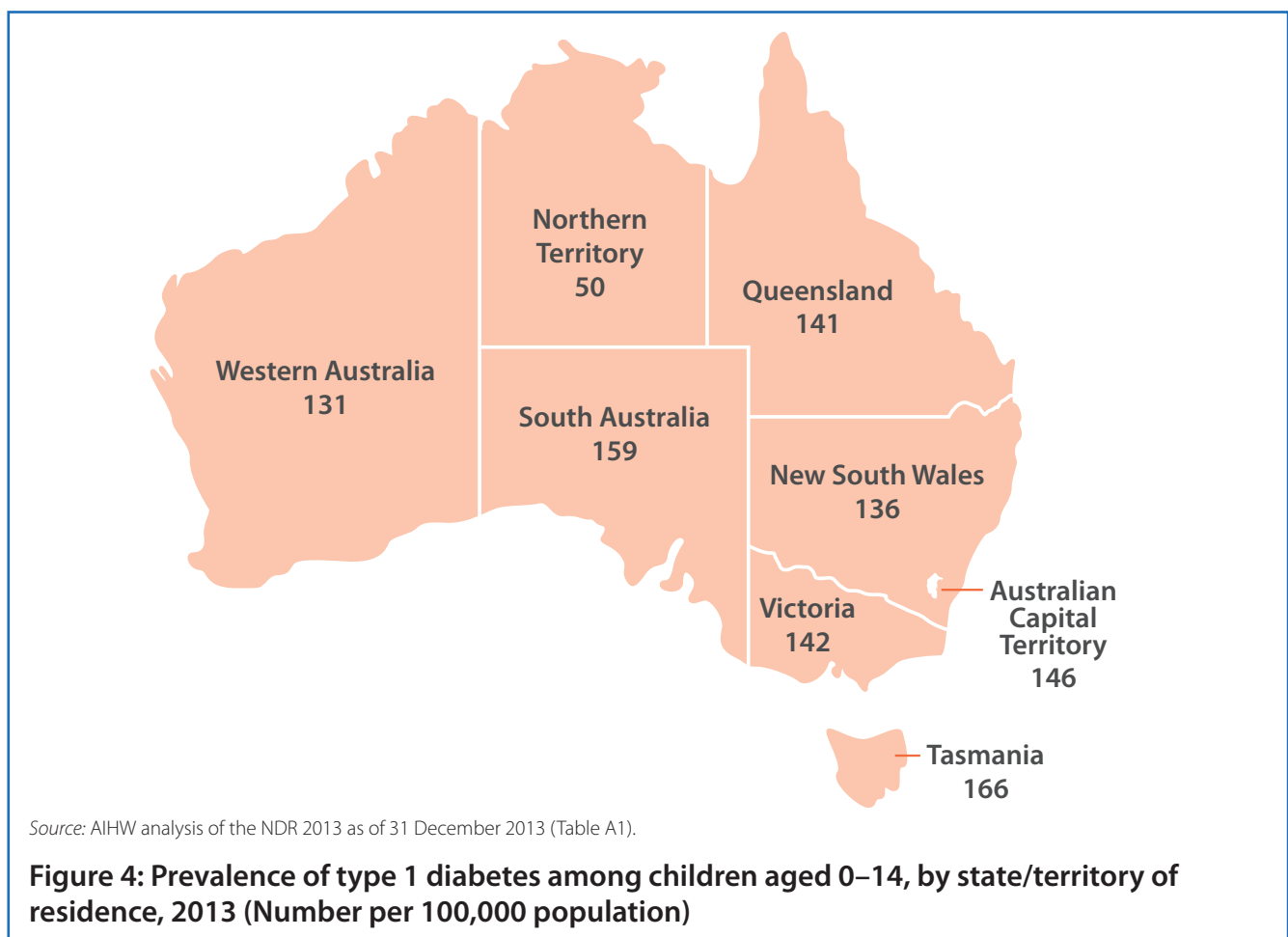
Lowest rates were in remote areas and among Indigenous children

Social, economic and environmental conditions can strongly influence health. Typically, health varies among different population groups depending on determinants such as geographical remoteness, area of socioeconomic disadvantage and Aboriginal and Torres Strait Islander status. However, these results show that the prevalence of type 1 diabetes does not appear to be related to these social determinants.

Remoteness

The majority of children with type 1 diabetes lived in *Major cities* (66%), followed by *Inner regional* areas (23%), *Outer regional* areas (9%), and *Remote and very remote* areas (2%). This pattern reflects the overall population distributions for these regions in Australia.

Children living in *Remote and very remote* areas had the lowest prevalence rate (82 cases per 100,000 population), followed by *Major cities* (133 per 100,000), and *Outer regional* areas (137 per 100,000). Children living in *Inner regional* areas had the highest rate of type 1 diabetes (169 per 100,000), more than twice as high as for those living in *Remote and very remote* areas (Figure 5).

Socioeconomic disadvantage

The prevalence of type 1 diabetes among children was relatively similar across all socioeconomic groups (based on area of usual residence), ranging from 132 per 100,000 population to 150 per 100,000 (Figure 5).

Note: See Appendix C for remoteness and socioeconomic classifications used in this report.

Source: AIHW analysis of the NDR 2013 as of 31 December 2013 (Table A1).

Figure 5: Prevalence of type 1 diabetes among children aged 0–14, by remoteness area and socioeconomic group, 2013
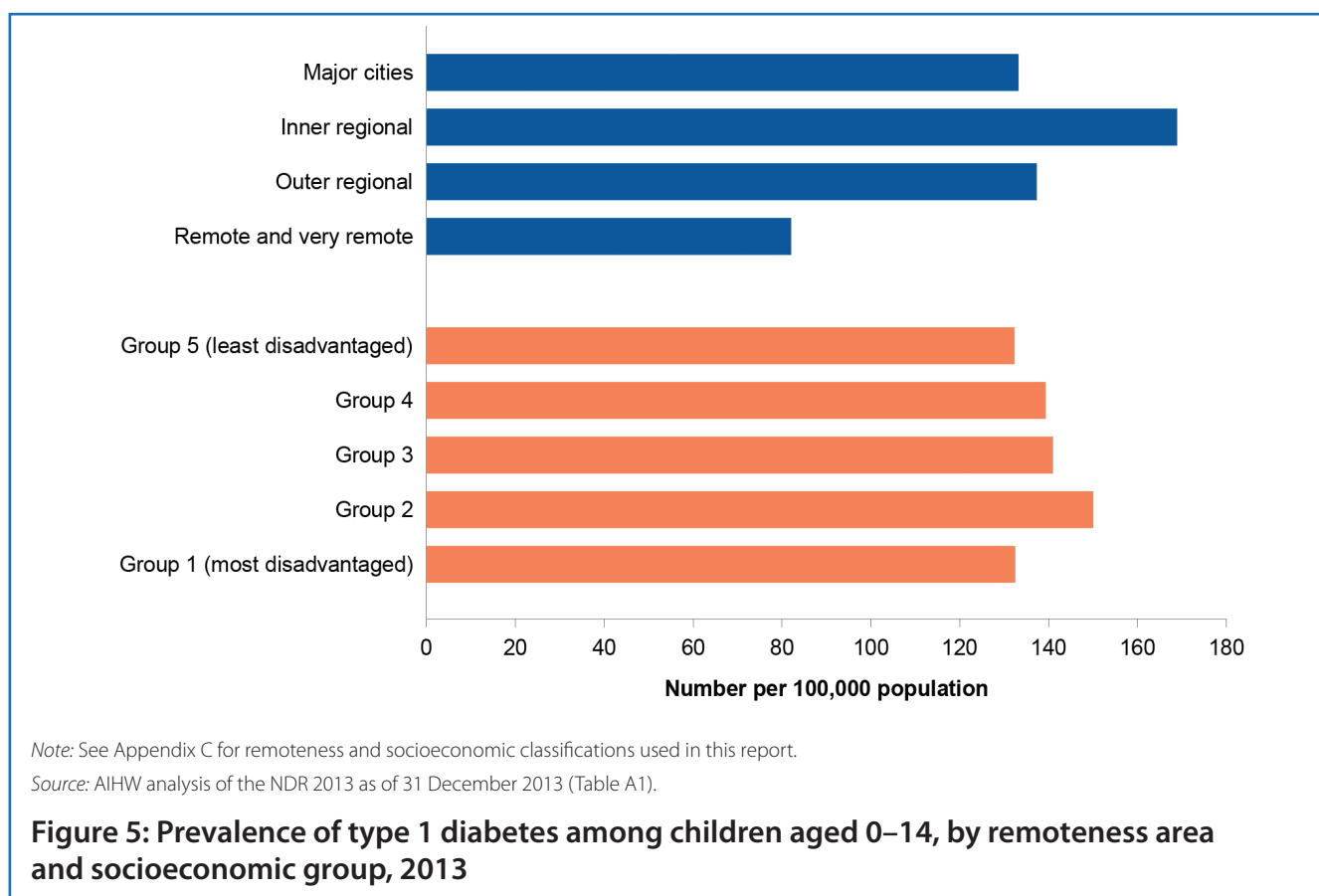
Aboriginal and Torres Strait Islander children

As of 31 December 2013, 167 Aboriginal and Torres Strait Islander children had type 1 diabetes, representing a rate of 69 per 100,000 Indigenous children, or 1 in almost 1,500.

For information about the limitations of data on Aboriginal and Torres Strait Islander people, see Appendix C.

Australia's prevalence rate was 10th highest among similar countries

Worldwide, an estimated 497,100 children aged 0–14 have type 1 diabetes (International Diabetes Federation 2013). Rates varied considerably across Organisation for Economic Co-operation and Development (OECD) member countries—from 7 cases per 100,000 population in the Republic of South Korea to 415 per 100,000 in Finland.

Australia's prevalence rate of 139 cases per 100,000 population places it as the 10th highest among the 34 OECD countries. It was above the OECD average, and in the top third of the member countries. The Australian rate was similar to or lower than other, comparable Western countries such as the United States of America (137 per 100,000 population), Canada (161), and the United Kingdom (173), but was higher than New Zealand (110) (Figure 6).
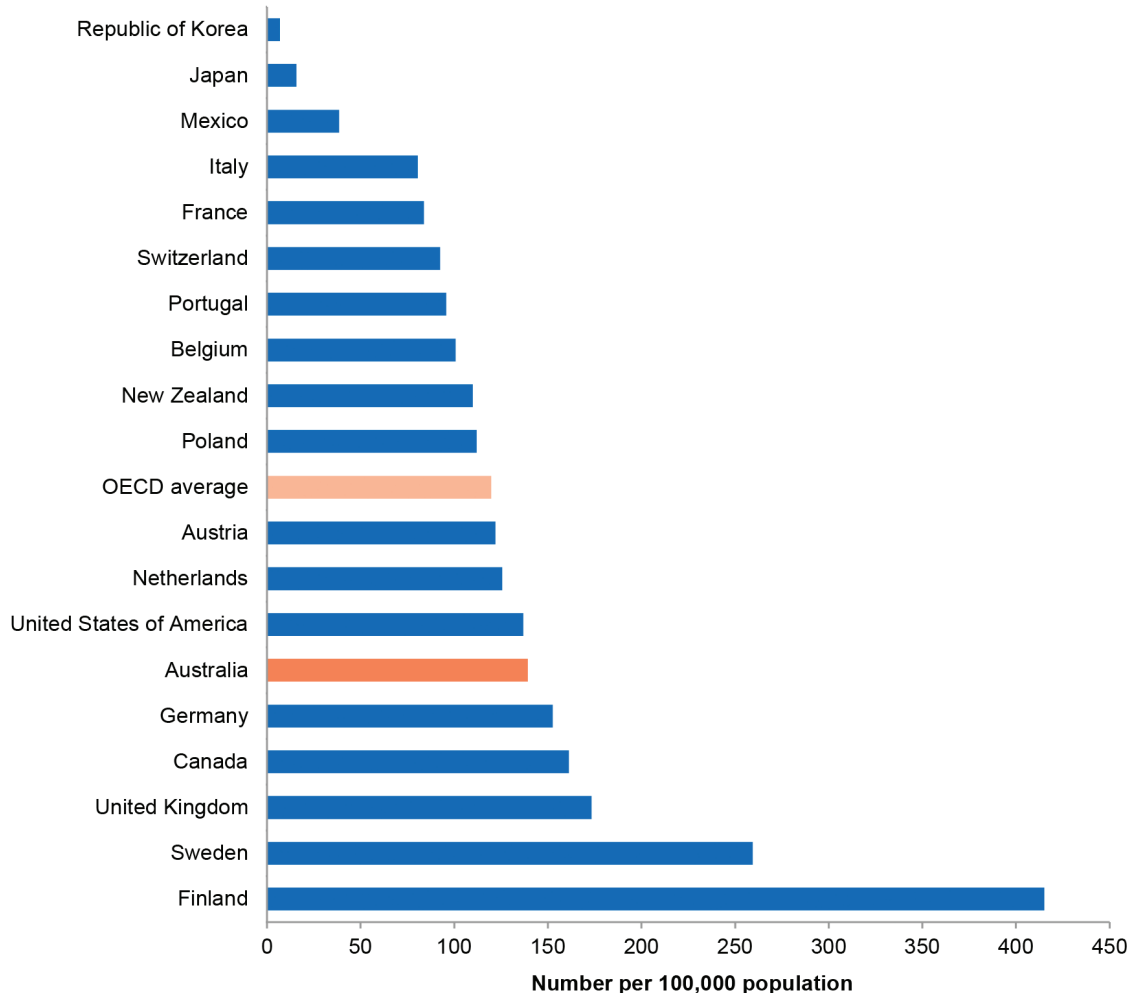
Notes

1. The method and data period on which prevalence has been estimated varies for each country. See Table A4 for further details.
2. For OECD countries (excluding Australia) prevalence rates were calculated using 2010 United Nations population projections.

Source: AIHW derived from Patterson et al. (2014) for OECD countries other than Australia; AIHW analysis of NDR 2013 as of 31 December 2013 for Australia.

Figure 6: Estimates of the prevalence of type 1 diabetes for children aged 0–14, by selected OECD countries, 2013 (or nearest available year)

More than 2 in 5 children used an insulin pump

Of the 6,091 children aged 0–14 with type 1 diabetes, 2,612 children, or just over 2 in 5 (43%), were using an insulin pump to administer insulin (Table A5). Of these, 51% were girls (1,344) and 49% were boys (1,268).

The majority of insulin pump users were aged 10–14 (66%), 29% were aged 5–9 and 6% were aged less than 5. These proportions reflect the age distribution of children with type 1 diabetes.

Over half (53%) of insulin pump users had been diagnosed with type 1 diabetes for fewer than 5 years (6% for less than 1 year), 38% for 5–9 years, 9% for 10 years or longer.

Insulin pump users had diabetes for longer and were from higher socioeconomic groups

In comparing insulin pump users with non-insulin pump users, patterns varied among the subgroups.

Children with type 1 diabetes using an insulin pump were more likely to:

- have had type 1 diabetes for longer—15% of children diagnosed with type 1 diabetes for less than 1 year used an insulin pump, compared with 56% of children diagnosed for 10 years or longer

- live in the Australian Capital Territory and New South Wales—55% and 52% of children with type 1 diabetes living in the Australian Capital Territory and New South Wales were using an insulin pump, respectively, which was higher than in Victoria (29%) and Tasmania (41%)

- be from higher socioeconomic groups—55% of children with type 1 diabetes from the highest socioeconomic group used an insulin pump, compared with 33% in the lowest socioeconomic group.

The pattern of insulin pump use among children with type 1 diabetes did not vary greatly by:

- sex—46% of girls used an insulin pump, compared with 40% of boys

- age—37% of those aged 0–4 had used a pump, compared with 42% of those aged 5–9, and 44% of those aged 10–14

- remoteness areas—the proportion ranged from 39% to 44% across remoteness areas.

Appendix A: Summary tables

Table A1: Characteristics of children aged 0–14 with type 1 diabetes, by sex, 2013

	Number			Number per 100,000 population		
	Males	Females	Persons	Males	Females	Persons
Age group (years)						
0–4	228	178	406	29.3	24.1	26.8
5–9	895	899	1,794	119.7	127.1	123.3
10–14	2,020	1,870	3,891	281.9	274.2	278.2
State/territory of residence						
New South Wales	966	935	1,901	134.4	137.7	136.0
Victoria	743	752	1,495	137.8	146.9	142.2
Queensland	702	600	1,302	147.9	133.6	140.9
Western Australia	321	310	631	130.4	131.3	130.8
South Australia	255	214	469	168.5	148.5	158.7
Tasmania	85	73	158	172.9	158.8	166.1
Australian Capital Territory	56	47	103	154.8	136.8	146.0
Northern Territory	14	13	27	50.4	49.6	50.0
Remoteness area						
Major cities	2,034	1,995	4,029	131.0	135.5	133.2
Inner regional	746	638	1,384	177.0	160.2	168.9
Outer regional	308	258	566	146.1	128.0	137.3
Remote and very remote	50	44	94	84.6	79.4	82.0
Socioeconomic group						
Group 5 (least disadvantaged)	592	582	1,174	129.9	134.1	132.0
Group 4	619	590	1,209	139.1	139.8	139.4
Group 3	621	605	1,226	139.3	143.7	141.4
Group 2	661	604	1,265	152.3	146.4	149.5
Group 1 (most disadvantaged)	643	552	1,195	138.7	125.9	132.5
Australia	3,143	2,947	6,091	140.1	138.5	139.4

Note: Totals do not add to the total number of children with type 1 diabetes due to missing information on some variables.

Source: AIHW analysis of the NDR 2013 as of 31 December 2013.

Table A2: Children with type 1 diabetes, by age at diagnosis, 2013

Age at diagnosis (years)	Number	Per cent
0	118	1.9
1	534	8.8
2	600	9.9
3	576	9.5
4	593	9.7
0–4	*2,421*	*39.8*
5	501	8.2
6	551	9.0
7	492	8.1
8	529	8.7
9	416	6.8
5–9	*2,489*	*40.9*
10	436	7.2
11	305	5.0
12	231	3.8
13	154	2.5
14	53	0.9
10–14	*1,179*	*19.4*
Total	6,089	100.0

Note: Totals do not add to the total number of children with type 1 diabetes due to missing information on some variables.

Source: AIHW analysis of the NDR 2013 as of 31 December 2013.

Table A3: Duration of type 1 diabetes, by age, 2013

Age group (years)	Duration of type 1 diabetes (years)				Total
	Less than 1	1–4	5–9	10 or more	
0–4	167	239	. .	. .	406
5–9	344	1,027	423	. .	1,794
10–14	473	1,601	1,396	421	3,891
Total	984	2,867	1,819	421	6,091

. . Not applicable.

Source: AIHW analysis of the NDR 2013 as of 31 December 2013.

Table A4: Prevalence of type 1 diabetes among children aged 0–14, in OECD countries

Country	Data source period	Number per 100,000 population
Finland	2000–2005	415.1
Sweden	2005–2007	259.5
Norway	2004–2008	202.6
United Kingdom	2004–2008	173.3
Canada	1990–2010	161.3
Germany	2004–2008	152.6
Denmark	2004–2008	152.3
Estonia	1999–2006	147.2
Iceland	1994–1998	147.0
Australia	2013	139.4
United States of America	2002–2003	136.9
Spain	1995–2011	127.8
Netherlands	1996–1999	125.7
Hungary	2004–2009	123.3
Austria	2004–2008	122.1
Czech Republic	2004–2008	119.7
Poland	2004	112.1
Ireland	1997	110.1
New Zealand	1999–2000	110.0
Luxembourg	2004–2008	108.3
Slovenia	2004–2008	101.6
Belgium	2004–2008	100.8
Portugal	1994–1998	95.7
Switzerland	2004–2008	92.5
Israel	2006–2007	88.6
Slovakia	1999–2003	85.4
France	1998–2004	83.7
Italy	1990–2003	80.6
Greece	2004–2008	79.9
Mexico	2010	38.5
Chile	2000–2005	37.7
Turkey[a]	. .	19.8
Japan	1998–2001	15.7
Republic of Korea	1990–1991	6.8

. . Not applicable.

(a) Extrapolated using rates from different country.

Notes

1. The majority of data in the International Diabetes Federation 2013 report is sourced from published literature about incidence rates. Prevalence rates were derived from these incidence rates and applied to United Nations 2012 revision population estimates for 2013 for each country to obtain estimates of the number of prevalent cases (Patterson et al. 2014).

2. For OECD countries (excluding Australia) prevalence rates were calculated using 2010 United Nations population projections.

Source: AIHW derived from Patterson et al. (2014) for OECD countries other than Australia; AIHW analysis of NDR 2013 as of 31 December 2013 for Australia.

Table A5: Insulin pump use among children aged 0–14 with type 1 diabetes, by selected characteristics, 2013

	Non-insulin pump users	Insulin pump users	Total
Sex			
Male	1,875	1,268	3,143
Female	1,603	1,344	2,947
Age group (years)			
0–4	255	151	406
5–9	1,046	748	1,794
10–14	2,178	1,713	3,891
Duration of type 1 diabetes (years)			
Less than 1	832	152	984
1–4	1,623	1,244	2,867
5–9	839	980	1,819
10 or more	185	236	421
State/ territory of residence			
New South Wales	907	994	1,901
Victoria	1,059	436	1,495
Queensland	709	593	1,302
Western Australia	371	260	631
South Australia	274	195	469
Tasmania	94	65	159
Australian Capital Territory	46	57	103
Northern Territory	15	12	27
Remoteness area			
Major cities	2,280	1,749	4,029
Inner regional	815	568	1,384
Outer regional	320	248	567
Remote and very remote	57	37	94
Socioeconomic group			
Group 5 (least disadvantaged)	531	643	1,174
Group 4	670	539	1,209
Group 3	705	521	1,226
Group 2	767	498	1,265
Group 1 (most disadvantaged)	797	399	1,196
Australia	3,479	2,612	6,091

Note: Totals do not add to the total number of children with type 1 diabetes due to missing information on some variables.

Source: AIHW analysis of the NDR 2013 as of 31 December 2013.

Appendix B: National data sources for type 1 diabetes in children

The analysis presented in this report is based on the 2013 National (insulin-treated) Diabetes Register (NDR), which captures new cases of insulin-treated diabetes in Australia. The NDR is derived from 2 datasets—National Diabetes Services Scheme and Australasian Paediatric Endocrine Group—resulting in robust prevalence estimates for children aged 0–14 with type 1 diabetes.

National Diabetes Services Scheme

The National Diabetes Services Scheme (NDSS) 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 to register with the NDSS.

For children, the NDSS provides valid and up-to-date estimates of prevalence of type 1 diabetes. As of 31 December 2013, this was reported to be 7,292 people aged 15 or under with type 1 diabetes (National Diabetes Services Scheme 2013).

Although the requirement for insulin is a strong motivator to register with the NDSS to access subsidised diabetes-related products, the diabetes type reported on the NDSS may not always be accurate, and some children, especially those with other family members with type 1 diabetes, may not be registered.

Australasian Paediatric Endocrine Group

The Australasian Paediatric Endocrine Group (APEG) is a professional body that represents health professionals involved in managing and researching disorders of the endocrine system, including diabetes in children and adolescents.

The APEG maintains clinic-based state and territory diabetes registers about children aged under 15 with diabetes.

The National (insulin-treated) Diabetes Register

The NDR was established in 1999, and collects information about new cases of insulin-treated diabetes in Australia. The AIHW maintains the NDR under contract with the Department of Health. For further information about the NDR see <http://meteor.aihw.gov.au/content/index.phtml/itemId/608449>.

The NDR is primarily derived from the NDSS and APEG. The NDR 2013 spans 14 years (1999–2013), so for the first time captures all children aged 0–14 with type 1 diabetes. The AIHW previously released a report on the prevalence of type 1 diabetes in children, but this was based on the NDR 2008, and reported on prevalence estimates for children aged 0–9, and projected estimates for those aged 10–14 (AIHW 2011).

By combining the NDSS and APEG, the NDR provides a reliable and robust data source for reporting on type 1 diabetes in children in Australia that captures almost all children with type 1 diabetes (AIHW 2015b). The Australian Bureau of Statistics (ABS) Australian Health Survey also collects data on diabetes (based on self-report and measured data), but it is very limited in its ability to produce comprehensive estimates on children with type 1 diabetes (see Box 2).

Coverage of type 1 diabetes for children aged 0–14 on the NDR

The capture–recapture method (LaPorte et al. 1993) was used to determine coverage of the NDR. This method compares data from several independent, but overlapping, data sources (in this case, the NDSS and APEG) to calculate the completeness of a dataset.

The capture–recapture method was applied to all new cases registered on the NDR in 1999–2013 to establish the number of children that may not have been registered on either data source. Over the period, the coverage of children with type 1 diabetes on the NDR was estimated to be 99.7%.

Accuracy of diabetes type on the NDR

As part of processing information from the NDSS and APEG to derive the NDR, the reported diabetes type is checked. This procedure is unique to the NDR, and helps to ensure that the recorded diabetes type is as accurate as possible. This is achieved through:

- verifying diabetes type is consistent for those cases on both the NDSS and APEG—where a discrepancy is found, the diabetes type is checked by contacting APEG data managers who have access to clinical record information

- verifying type 1 diabetes status against a set of criteria—because people with type 1 diabetes need insulin to survive, the time from diagnosis to first insulin use is a good indicator of a person's diabetes type. Where this time lag is 1 year or less, diabetes type is considered to be type 1. In cases where diabetes is recorded as type 1, but the time interval is more than 1 year, or where information on dates is missing, and validation cannot be done, the diabetes type is set to 'missing'.

Box 2: Other type 1 diabetes prevalence data sources

The ABS 2011–12 Australian Health Survey provides self-reported and biomedical data that can be used to estimate the national prevalence of diabetes. The biomedical component of the survey contained 2 tests to detect biomedical signs of diabetes: a measure of fasting plasma glucose, and a measure of glycated haemoglobin (HbA1c). However, these biomedical estimates cannot determine diabetes type.

Information on type 1 diabetes based on parents and/or guardians self-reporting the diabetes status of children in their care is not considered accurate enough to provide a true reflection of the number of children with type 1 diabetes in Australia.

The ABS estimates that 3,000 children aged less than 15 have type 1 diabetes (ABS 2012), but this estimate excludes children under 2, and has a high degree of error (a relative standard error of almost 50%), and should be interpreted with caution.

Appendix C: Statistical notes and methods

Data quality statement for the NDR

Information about limitations and issues in the NDR are found in the *Data Quality Statement: National (insulin-treated) Diabetes Register 2013* at: <http://meteor.aihw.gov.au/content/index.phtml/itemld/608449>.

Age of children with type 1 diabetes

These prevalence statistics are presented as of 31 December 2013, so the age of children in the analysis is calculated as of that date.

Rates

All rates presented in this report are crude rates per 100,000 population (not age-standardised rates). The crude rate is the prevalence of type 1 diabetes relative to the total number of people in the population or sub-population of interest.

Estimated resident populations

Throughout this report, population data were used to derive rates of diabetes prevalence. Population data held by the AIHW are sourced from the ABS, and are updated as revised or new estimates become available.

All population estimates currently produced by ABS are based on a usual residence concept; that is, where people usually reside. These estimated resident populations are derived from the ABS Census of Population and Housing, and adjusted for deaths, births and net migration. The estimated resident populations used in this report are based on the preliminary population estimates for 30 June 2013.

Australia's Aboriginal and Torres Strait Islander population is calculated from the Census, but because of the smaller Indigenous population, it is difficult to measure population changes accurately between census years using the method described above. Therefore, the ABS developed experimental estimates and projections based on the 2011 Census. All calculations of rates for Aboriginal and Torres Strait Islander people use the Series B projected Indigenous 2013 populations.

Aboriginal and Torres Strait Islander information on the NDR

The NDR may underestimate the number of Aboriginal and Torres Strait Islander registrants with type 1 diabetes for several reasons, as outlined below.

Aboriginal or Torres Strait Islander status

Identifying as an Aboriginal or Torres Strait Islander person on both data sources of the NDR (NDSS and APEG) is voluntary.

NDSS registration form

On the NDSS registration form before 2005, if Indigenous status was not reported, the registrant was recorded as non-Indigenous, rather than not stated. This may have overestimated the number of non-Indigenous Australians registered, and consequently underestimated the number of Indigenous Australians registered. In 2005 the registration form was amended so that in the absence of information about Indigenous status, 'not stated' became the default value (Health Data Standards Committee 2006).

Accessing diabetes-related products through programs other than the NDSS

Other programs that provide Indigenous Australians access to diabetes-related products might result in low registration rates for the NDSS, and subsequently the NDR, among Aboriginal and Torres Strait Islander people.

For example, programs operating under Section 100 of the *National Health Act 1953*—such as Aboriginal Medical Services and the National Aboriginal Community Controlled Health Organisation—give Indigenous Australians access to products that people with insulin-treated diabetes need.

In addition, NDSS Access Points are not always available in remote areas, limiting the access of many Indigenous Australians to NDSS services.

Missing data

Indigenous status was unknown for 11% of the cohort for this report.

Australian Statistical Geography Standard

Geographic location was classified according to the ABS's Australian Statistical Geography Standard 2011 Remoteness Areas, which groups geographic areas into categories.

These categories are defined using the Accessibility/Remoteness Index for Australia—a measure of the remoteness of a location from the services provided by large towns or cities. Accessibility is judged purely on distance to 1 of the metropolitan centres, so it provides a relative indication of how difficult it might be for residents to access some services, such as health care and education.

The categories used in this publication are:

- *Major cities*
- *Inner regional*
- *Outer regional*
- *Remote and very remote*.

Some postcodes might not map to areas used in the 2011 Census, and were not included in relevant tables. Further, some postcodes might have changed remoteness area since the 2011 Census, but are still included under the area they were assigned in 2011.

Index of Relative Socio-Economic Disadvantage

Socioeconomic classifications were based on the ABS Index of Relative Socio-Economic Disadvantage. Geographic areas are assigned a score based on attributes such as income, educational attainment, levels of public sector housing, unemployment and jobs in skilled or unskilled occupations.

A low score means an area has more low-income families, people with little training, and high unemployment, and may be considered disadvantaged relative to other areas with higher scores. Areas with high index scores may be considered less disadvantaged relative to other areas.

High scores reflect a relative lack of disadvantage, rather than advantage, and the Index of Relative Socio-Economic Disadvantage relates to the average disadvantage of all people living in a geographic area. It cannot be presumed to apply to all individuals living in the area.

In this report, a person's socioeconomic status was classified using their residential postcode according to the Index of Relative Socio-Economic Disadvantage for 2011. Five population-based socioeconomic groups (fifths), based on the level of the index, were used for analyses, where group 1 represents the lowest socioeconomic status of the population, and group 5 the highest socioeconomic status.

Geographic areas may be excluded where no score is determined due to low populations or high levels of non-response in the underlying census. Additionally, some postcodes may not map to the areas used in the 2011 Census, and were also excluded. Further, some postcodes might have changed socioeconomic group since the 2011 Census, but are still included under the area they were assigned in 2011.

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Patterson C, Guariguata L, Dahlquist G, Soltesz G, Ogle G & Silink M 2014. Diabetes in the young: a global view and worldwide estimates of numbers of children with type 1 diabetes. Diabetes research and clinical practice 103:161–75.

Prevalence of type 1 diabetes among children aged 0–14 in Australia 2013 presents the first national picture of children aged 0–14 living with type 1 diabetes in Australia. The report, based on data from the National (insulin-treated) Diabetes Register, highlights that in 2013, 6,091 children aged 0–14 had type 1 diabetes in Australia—this represented 139 cases per 100,000 population. About 2 in 5 children with type 1 diabetes used an insulin pump to administer insulin. The prevalence of type 1 diabetes among children differed by age, state/territory, and residential remoteness areas.