

# **The National (insulin-treated) Diabetes Register 2016; Quality Statement**

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# The National (insulin-treated) Diabetes Register 2016; Quality Statement

## Identifying and definitional attributes

Metadata item type:	Data Quality Statement
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## Data quality

Data quality statement summary:	<p><b>Description of the National (insulin-treated) Diabetes Register (NDR)</b></p> <p>The NDR is a database of Australians who use insulin to treat diabetes. It was established in 1999 to monitor the incidence of insulin-treated diabetes in Australia, and aims to record all cases of people who begin to use insulin to treat their diabetes.</p> <p>The NDR includes people with type 1 diabetes, insulin-treated type 2 and gestational and other types of diabetes.</p> <p>Data for the NDR are sourced from the National Diabetes Services Scheme (NDSS) Registrant data; the NDSS Sales data; the Australasian Paediatric Endocrine Group's (APEG) state-based registers; and the National Death Index (NDI).</p> <p><u>NDSS Registrant data</u>: relates to people who have registered with the NDSS. The NDSS is an Australian Government scheme administered by Diabetes Australia (DA) to provide people with diagnosed diabetes with timely, affordable and reliable access to supplies and services required for the effective management of their condition. The NDSS was established in 1987 and the registrant data provide demographic information as well as basic clinical details.</p> <p><u>NDSS Sales data</u>: for any registrant on the NDSS who has purchased a product relating to the use of insulin (such as pens or needles to administer insulin), the NDR 2016 lists the date of the first time such a product was purchased—this information is used to assess when insulin use began.</p> <p><u>APEG data</u>: the APEG data source used to derive the NDR relates to children who use insulin to treat their diabetes from 1999 onwards and who were less than 15 years old when they started using insulin.</p> <p><u>NDI data</u>: a database housed at the AIHW, which 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. These data are used to flag anyone on the NDR that is deceased and the date of their death.</p> <p>The methods to create the NDR 2016 have changed from previous years and the derivation of the register applies these new processes retrospectively across all years. Results from the NDR 2016 cannot be compared directly with results in AIHW publications based on previous NDR data.</p>
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**Institutional environment:** The AIHW is a major national agency set up by the Australian Government under the [Australian Institute of Health and Welfare Act 1987](#) to provide reliable, regular and relevant information and statistics on Australia's health and welfare. It is an independent statutory authority established in 1987, governed by a [management Board](#), and accountable to the Australian Parliament through the Health portfolio.

The AIHW aims to improve the health and wellbeing of Australians through better health and welfare information and statistics. It collects and reports information on a wide range of topics and issues, ranging from health and welfare expenditure, hospitals, disease and injury, and mental health, to ageing, homelessness, disability and child protection.

The AIHW also plays a role in developing and maintaining national metadata standards. This work contributes to improving the quality and consistency of national health and welfare statistics. The AIHW works closely with governments and non-government organisations to achieve greater adherence to these standards in administrative data collections to promote national consistency and comparability of data and reporting.

The [Australian Institute of Health and Welfare Act 1987](#), in conjunction with compliance to the [Privacy Act 1988](#), (Cth) ensures that the data collections managed by the AIHW are kept securely and under the strictest conditions with respect to privacy and confidentiality.

For further information see the AIHW website [www.aihw.gov.au](http://www.aihw.gov.au).

The AIHW is contracted by the Australian Government Department of Health (Health) to produce the NDR annually through the *Schedule to procure services in relation to National (insulin-treated) Diabetes Register under the Memorandum of Understanding for the period 2011–2016 between the Department of Health and the Australian Institute of Health and Welfare for the provision of information services (1 July 2015 to 30 June 2018)*.

The NDSS data supplied by Diabetes Australia (DA) to the AIHW to create the NDR are mandated under the contract between DA and Health through the *National Diabetes Services Scheme Agreement between the Commonwealth of Australia as represented by the Department of Health and Diabetes Australia (31 August 2016–30 June 2020)*.

APEG are contracted to provide data for the purposes of the NDR through the *Agreement in relation to consultancy services for the National (insulin-treated) Diabetes Register: Australian Institute of Health and Welfare and The Australasian Paediatric Endocrine Group (16 July 2015–15 July 2018)*.

**Timeliness:** The NDR is compiled and reported annually.

The NDR 2016 was created using data from the NDSS extracted in April 2017 and APEG data to 31 March 2017; the final NDR 2016 dataset was derived in August 2017.

**Accessibility:** The dynamic data display and supplementary data tables, Incidence of insulin-treated diabetes in Australia, which is based on the NDR 2016, is available online at:

<https://www.aihw.gov.au/reports/diabetes/incidence-insulin-treated-diabetes-australia-2016/>

Additional data not available in the dynamic data display and supplementary tables can be requested via the AIHW data request management system <https://datarequest.aihw.gov.au/pages/welcome.aspx>.

Requests that take longer than half an hour to compile are charged on a cost-recovery basis.

General enquiries about AIHW publications can be made to the Communications, Media and Marketing Unit on (02) 6244 1032 or via email to [info@aihw.gov.au](mailto:info@aihw.gov.au).

**Interpretability:**

The dynamic data display and supplementary data tables, Incidence of insulin-treated diabetes in Australia, which is based on the NDR 2016, is available online at:

<https://www.aihw.gov.au/reports/diabetes/incidence-insulin-treated-diabetes-australia-2016/>

**Relevance:**

The NDR 2016 includes all new cases of insulin-treated diabetes where insulin use occurred between 1 January 1999 and 31 December 2016.

The NDR captures demographic information including: age; sex; date of birth; postcode and state of current residence; postcode and state of diagnosis; Indigenous status; country of birth; main language spoken at home; type of diabetes; diagnosis date; and death status. These data allow for analyses of the number of new cases of insulin-treated diabetes by: diabetes type, age, sex, population groups (remoteness, socioeconomic groups and Indigenous status) and finer geographical areas (Primary Health Network and Statistical Area Level 3). Trends, crude rates and age-standardised rates are generally reported in the annual NDR report.

Although the NDR 2016 contains data from 1999 onwards, the AIHW generally report the incidence of insulin-treated diabetes from 2000 onwards due to data issues in the early stages of developing the register.

**Accuracy:**

The NDSS and APEG data are provided to the AIHW in accordance with data specifications outlined in the relevant schedules listed in the section on 'Institutional environment'.

The coverage of insulin-treated diabetes on the NDR is dependent on the coverage of its primary data sources—the NDSS and APEG.

APEG data include only records of insulin-treated diabetes where consent to be included on the NDR has been obtained.

Registration with the NDSS is voluntary. All people with type 1 diabetes use insulin and therefore most are likely to obtain subsidised products through the NDSS, and be represented on the NDR. For those with other types of diabetes, the use of insulin and therefore eligibility for inclusion on the NDR, is determined primarily through evidence of the purchase of insulin-related products through the NDSS. From 1999 to 2016, around 24% of people with type 2 diabetes and 29% of women with gestational diabetes require insulin to treat their diabetes (according to the NDSS) and are therefore likely to be covered by the NDR; those that do not are not within the scope of the NDR.

For those less than 15 years of age who use insulin to treat diabetes, the data are obtained from 2 sources; the NDSS and APEG. The capture-recapture method enables an estimation of a population's overall size when two independent populations are sampled. Based on this method, from 2000–2016 the NDR captured an estimated 99.6% of children with type 1 diabetes in Australia. However, it should be noted this methodology assumes that all individuals have the same probability of being captured by both data sources. Therefore, if the NDSS and the APEG both provide a biased sample and do not capture particular subgroups of the population of children with type 1 diabetes, the coverage of the NDR will be exaggerated.

Duplicate records on the NDSS and APEG datasets are identified and removed from the datasets through a series of reviews and checks.

The NDSS database contains substantial missing information on some variables. This in turn flows through to the NDR. In the case of missing information for date variables, the AIHW can use proxy variables to ensure the dataset is as complete as possible. For example, for registrants with type 1 diabetes, where date of diagnosis is not completed registration date is used.

Diabetes type is classified by a health practitioner at the time of NDSS registration; however, the recorded type might not always be correct as the symptoms of type 1 and type 2 diabetes may be similar, and changes in the classification of diabetes type in the NDSS data in 2002–2003 may have resulted in people with insulin-treated type 2 diabetes being misclassified as having type 1 diabetes. For these

reasons diabetes type recorded for a registrant on the NDR is validated against a set of criteria and revised to a derived diabetes type where their reported diabetes type is deemed unlikely based on the clinical understanding of the diabetes profile. This diabetes type 'algorithm' was developed in 1999 to improve the quality of the data on the NDR, and is reviewed and updated through ongoing consultation with the AIHW Diabetes Expert Advisory Group. The algorithm determines the plausibility of the reported diabetes type based on age at diagnosis and the period between diagnosis and first insulin use. The diabetes type algorithm makes the following changes:

- Almost all people with type 1 diabetes require insulin immediately to treat their diabetes, therefore people who have started insulin within 1 year of diagnosis and have a reported type 1 diabetes are assumed to have type 1 diabetes.
- For people with reported type 1 diabetes who started using insulin more than 1 year after their diagnosis, the algorithm reclassifies those under the age of 15 as unable to be derived, and those 15 and older as having type 2 diabetes.
- Because type 2 diabetes is generally uncommon in very young people, unless confirmed, the diabetes type of those less than 10 years old who are reported at registration as having type 2 diabetes is considered unable to be derived.
- The algorithm reclassifies women under the age of 14 with reported gestational diabetes to their diabetes type being unable to be derived. Similarly, all women aged 50 and over with gestational diabetes recorded as their diabetes type are reclassified to having type 2 diabetes.
- In all cases where the type of diabetes remains unclear, the derived type is considered to be non-derivable and the person's diabetes type is reported as unknown.

NDSS Access Points assist in delivering support services and products to people with diabetes in all states and territories. These Access Points may be limited in rural Australia and unavailable in remote communities, with other programmes being available in these areas to assist with the purchase of diabetes-related products. This may result in lower coverage of the NDSS in remote and very remote areas or across states and territories with large remote communities, which may influence estimates for the number of people with diabetes using insulin in these areas on the NDR.

The representation of Aboriginal and Torres Strait Islander people on the NDR may be influenced by the following factors, which may impact on the representation of the Indigenous population who use insulin to treat diabetes:

- The 'Indigenous' response for Indigenous status is taken where a person is registered through both APEG and the NDSS and their Indigenous status differs between the two datasets.
- Before 2005, data entry of Indigenous status coded all 'unknown' or 'not stated' responses to the Indigenous status question as 'non-Indigenous'. In 2005, the NDSS database was amended to add an extra value to the Indigenous status variable to indicate 'inadequate/not stated' where Indigenous status was not known. As a result of this issue, Indigenous status cannot be determined for 98% of people registered on the NDSS prior to 2005. Identifying as being of Indigenous origin on both data sources of the NDR (APEG and NDSS) is voluntary. Indigenous status was unknown for 8% of all people registered in 2016.
- Indigenous Australians may not register with the NDSS at all. Where Indigenous people live in remote and very remote locations, NDSS Access Points may be limited or other programs may provide access to diabetes-related products. These issues may 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—provide Indigenous Australians access to free and subsidised products that people with insulin-treated diabetes need.

In 2016, 134 records were identified as health/medical centres in the primary data source (NDSS) and were removed when deriving the NDR dataset.

**Coherence:** The NDR 2016 contains data on the incidence of insulin-treated diabetes since 1999.

Results from the NDR 2016 cannot be compared with results in AIHW publications based on previous NDR data. This is because the methods to create the NDR have changed—both in the way data are processed, as well as how eligibility for the NDR is determined. The derivation of the register applies these new methods retrospectively across all years.

The NDSS database underwent structural changes in 2003 and 2010. These affected the way records were retained in the dataset and should be considered when interpreting trends.

Over the years, the classifications and terminology used for the different types of diabetes have changed. Previous classifications such as juvenile-onset diabetes, insulin-dependent diabetes (IDDM) and non-insulin-dependent diabetes are no longer used in clinical practice and have been replaced with type 1 and type 2 diabetes. However, the NDSS registration form did not have an option for indicating insulin use among those with type 2 diabetes until 2002, and anyone using insulin or previously recorded as having juvenile-onset diabetes or IDDM were recorded as having type 1 diabetes until this option became available.

There were changes in the recording of Indigenous status in 2005 for new registrants to the NDSS. This impacts on comparisons relating to Aboriginal and Torres Strait Islander people before and after 2005. For more information on this and other issues relating to Indigenous reporting on the NDR, see the 'Accuracy' section.

## Source and reference attributes

**Submitting organisation:** The Australian Institute of Health and Welfare