

The National (insulin-treated) Diabetes Register 2014; Quality Statement

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The National (insulin-treated) Diabetes Register 2014; Quality Statement

Identifying and definitional attributes

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Data quality

Data quality statement summary:

- The 2014 National (insulin-treated) Diabetes Register (NDR) records new cases of insulin-treated diabetes occurring in 2014 in Australia, as well as cases where insulin use commenced since the NDR's establishment on 1 January 1999.
- The Australian Institute of Health and Welfare (AIHW) compiles the NDR using data from the National Diabetes Services Scheme (NDSS); the Australasian Paediatric Endocrine Group's (APEG) state-based registers; and the National Death Index (NDI).
- The methods to create the NDR 2014 have changed from previous years and the derivation of the register applies these new processes retrospectively across all years. Results from the NDR 2014 cannot be compared directly with results in AIHW publications based on previous NDR data.

Description of the National (insulin-treated) Diabetes Register

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.

The NDR includes people with type 1, type 2, gestational and other types of diabetes.

- As people with type 1 diabetes require insulin for survival, almost all new cases of type 1 diabetes are likely to be covered by the NDR.
- Currently, around 20% of people with type 2 diabetes and around 32% of women with gestational diabetes require insulin and are included on the NDR; those that do not use insulin, are not within the scope of the NDR.

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).

NDSS Registrant data: 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 information and access to supplies to monitor and/or treat their diabetes at subsidised prices. The NDSS was established in 1987 and the registrant data provide demographic information as well as basic clinical details.

NDSS Sales data: 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 2014 lists the date of the first time such a product was purchased—this information is used as an indicator of when insulin use began.

APEG data: 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.

NDI data: 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.

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.

One of the main functions of the AIHW is to work with the states and territories to improve the quality of administrative data and, where possible, to compile national datasets based on data from each jurisdiction, to analyse these datasets and disseminate information and statistics.

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.

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)*.

Diabetes Australia (DA) is the national body for people at risk of and affected by all types of diabetes. The NDSS is administered by DA.

The NDSS data supplied by DA to the AIHW to create the NDR are mandated under the contract between DA and Health and managed through a memorandum of understanding between the AIHW and DA:

- *Agreement between the Commonwealth of Australia as represented by the Department of Health and Ageing and Diabetes Australia for the National Diabetes Services Scheme (1 July 2011–30 June 2016)*.
- *Memorandum of Understanding between Diabetes Australia Limited and the Australian Institute of Health and Welfare regarding National Diabetes Services Scheme data for the period 2013–2016*.

The APEG is the professional body which represents those involved in management and research of children with disorders of the endocrine system, including diabetes.

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 2014 was created using data from the NDSS extracted in April 2015 and APEG data to 31 March 2015; the final NDR 2014 dataset was derived in November 2015.

Accessibility: The report, *Incidence of insulin-treated diabetes in Australia 2014* is based on the NDR 2014 and available at:

<http://www.aihw.gov.au/publication-detail?id=60129554837>

Additional data not available in the report 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.

Interpretability: The report, *Incidence of insulin-treated diabetes in Australia 2014*, which is based on the NDR 2014, is available online at:

<http://www.aihw.gov.au/publication-detail?id=60129554837>

Relevance: The NDR was established as an important part of Australia's monitoring system for diabetes. This monitoring is essential to improve Australia's capacity to plan preventive and treatment services, focus on priority population groups, track the impact of environmental change and of prevention and control strategies, and make decisions for cost-effective allocation of resources.

The NDR 2014 includes all new cases of insulin-treated diabetes where insulin use occurred between 1 January 1999 and 31 December 2014.

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.

Although the NDR 2014 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.

- Registration with the NDSS is voluntary. However, those who require insulin are more likely to register to obtain products at subsidised prices. Where people manage their diabetes through diet and exercise only, or obtain their diabetes-related products through other programs, they may be less inclined to join the NDSS.
- APEG data include only records of insulin-treated diabetes where consent to be included on the NDR has been obtained.

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 the NDR, is determined primarily through evidence of the purchase of insulin-related products through the NDSS. Currently, around 20% of people with type 2 diabetes and 32% women with gestational diabetes require insulin to treat their diabetes and are therefore likely 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 2000–2014 the NDR captured an estimated 99.7% of children with type 1 diabetes in Australia, and 99.4% in 2014. 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.

Numerous strategies and checks have been introduced over the years to reduce the number of duplicate records on the NDR. These duplicate records can occur through the same person registering multiple times on the NDSS; an APEG registrant moving interstate; or a person being captured by both the NDSS and APEG.

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.

Eligibility for registration with either the NDSS or APEG is confirmed by a diagnosis of diabetes and record of the diabetes type, as certified by a GP, endocrinologist, other specialist or a credentialed diabetes educator. However, on the NDSS, date of diagnosis is provided by the registrant at the time of first registration with the scheme, which can result in inaccurate or missing data on this important field.

The 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 mean that the NDR underestimates the number of people with diabetes using insulin in these areas.

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

- Changes in the recording of Indigenous status in 2005 for new registrants to the NDSS meant that before 2005 the default for no response was non-Indigenous, however from 2005 onwards, the default became not stated.
- Indigenous status was unknown for 10% of all registrants on the NDR from 2005–2014, and 9% in 2014.
- Identifying as Indigenous is voluntary, and people may not declare that they are of Aboriginal or Torres Strait Islander origin when registering with the

NDSS or APEG.

- 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 diabetes-related products and services may be obtained through targeted Indigenous programs or through Section 100.

Coherence:

The NDR 2014 contains data on the incidence of insulin-treated diabetes since 1999.

Results from the NDR 2014 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.