

The National (insulin-treated) Diabetes Register 2013; Quality Statement

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The National (insulin-treated) Diabetes Register 2013; Quality Statement

Identifying and definitional attributes

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Data quality

Data quality statement summary:

- The National (insulin-treated) Diabetes Register 2013 (NDR) records new cases of insulin-treated diabetes in Australia, where insulin use commenced between 1 January 1999 and 31 December 2013.
- 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 and territory registers; and the National Death Index (NDI).
- Some duplication may occur, however efforts are made to detect and merge or delete duplicate records.
- The methods to create the NDR 2013 have changed from previous years and the derivation of the register applied the new processes retrospectively across all years.
- Results from the NDR 2013 cannot be compared with results in publications based on previous NDR data.

Description of the National (insulin-treated) Diabetes Register

The NDR is a database of people living in Australia with insulin-treated diabetes. It was established in 1999 to monitor the incidence and prevalence of insulin-treated diabetes in Australia.

The NDR aims to record all new cases of people who use insulin to treat their diabetes.

The NDR includes people with type 1, type 2, gestational and other forms 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.
- Only a proportion of type 2 and gestational diabetes cases require insulin treatment; those that do not are not within the scope of the NDR.

Data for the NDR are sourced from the National Diabetes Services Scheme (NDSS); 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, 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 2013 lists the date of the first time such a product was purchased as an indicator of when insulin use may have begun.

APEG data: the APEG data source used to derive the NDR relates to children who use insulin to treat their diabetes and whose insulin use started in 1999 onwards and who were less than 15 years old at the time insulin use began.

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 on the NDR anyone that is deceased and their date of death.

Although the NDR 2013 contains data from 1999 onwards, data coverage issues in the first year of data collection means that reporting of the incidence of insulin-treated diabetes is from 2000 onwards.

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 Diabetes Register under the Memorandum of Understanding for the period 2011–2015 between the Department of Health and Ageing and the Australian Institute of Health and Welfare (1 July 2014 to 30 June 2015)*.

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 Diabetes Register: Australian Institute of Health and Welfare and The Australasian Paediatric Endocrine Group (16 July 2014–15 July 2015)*.

Timeliness: The NDR is compiled annually.

The NDR 2013 was created using data from the NDSS extracted in April 2014 and APEG data to 31 March 2014.

Accessibility:

The report, *Incidence of type 1 diabetes in Australia, 2000–2013* is based on the NDR 2013 and available at: <http://www.aihw.gov.au/publication-detail/?id=60129550890>.

Additional data not available in the report can be requested via the National Centre for Monitoring Vascular Diseases at the AIHW on (02) 6244 1000 or via email to diabetes@aihw.gov.au.

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

Interpretability:

Information about the NDR is available at: <http://www.aihw.gov.au/national-diabetes-register>.

The report, *Incidence of type 1 diabetes in Australia, 2000–2013*, which is based on the NDR 2013, includes additional information available online:

- *Incidence of type 1 diabetes in Australia, 2000–2013: statistical notes and methods*
- *Incidence of type 1 diabetes in Australia, 2000–2013: detailed tables*

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 2013 includes all new cases of insulin-treated diabetes between 1st January 1999 and 31st December 2013. It captures demographic information including, age; sex; date of birth; postcode of current residence; Indigenous status; country of birth; main language spoken at home; height; weight; type of diabetes; diagnosis date; and death status.

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.

Registration with the NDSS is voluntary. Those who require insulin to treat their diabetes are more likely to register as there is a requirement for diabetes related products to administer insulin, which are available at subsidised prices through the NDSS.

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

Eligibility for registration with either the NDSS or APEG is confirmed by a GP, endocrinologist, other specialist or a credentialed diabetes educator.

Numerous checks are undertaken to reduce the number of duplicate records that can occur through the same person registering multiple times on the NDSS; an APEG registrant moving interstate and being recorded on the register in the new state also; or a person being captured by both the NDSS and APEG.

The NDR dataset contains both the reported diabetes type, the type reported at registration, and the derived diabetes type, based on quality checks at the AIHW. An algorithm, developed in conjunction with the Diabetes Expert Working Group, determines the plausibility of the reported type of diabetes based on age at diagnosis and, if insulin is used, the period between diagnosis and first insulin use. Those with type 1 diabetes require insulin immediately to treat their diabetes and young people who have started insulin within 1 year of diagnosis are assumed to have type 1. Because type 2 diabetes is generally uncommon in very young people, unless confirmed, those less than 10 years old who are reported at registration as having type 2 diabetes are considered to be non-derivable into a diabetes type. Additionally, in all cases where the type of diabetes remains unclear, the derived type is considered to be non-derivable.

While Indigenous status is available for all years, there were changes in the recording of this variable in 2005 for new registrants to the NDSS. Before 2005 the default for no response was *non-Indigenous*, however from 2005 onwards, the default became *not stated*. Additionally, Indigenous people may not declare their origin when registering or may not register with the NDSS at all, as diabetes-related products and services can be obtained through targeted Indigenous programs.

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, where date of diagnosis is not completed, registration date is used.

All those with type 1 diabetes use insulin and are therefore 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.

Coherence:

The NDR 2013 contains data on the incidence of insulin-treated diabetes since 1999. The methods to create the NDR 2013 have changed from previous years (both in the way data are processed, as well as how eligibility for the NDR is determined) and the derivation of the register applied these new methods retrospectively across all years.

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