The National (insulin-treated) Diabetes Register 2019; Quality Statement

Exported from METEOR (AIHW's Metadata Online Registry)

The National (insulin-treated) Diabetes Register 2019; Quality Statement

Identifying and definitional attributes

Metadata item type:	Data Quality Statement
METEOR identifier:	736441
Registration status:	AIHW Data Quality Statements, Superseded 19/01/2022

Data quality

Data quality statement summary:

Description of the National (insulin-treated) Diabetes Register (NDR)

The NDR, established in 1999, is a database that aims to monitor the incidence of Australians who use insulin to treat diabetes.

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

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 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.

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 lists the date of the first time such a product was purchased—this information is used to assess 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 that 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 who is deceased and the date of their death.

The capture of insulin-treated diabetes on the NDR is dependent on the coverage of the NDSS and APEG data sources and may be influenced by the following factors:

- APEG data include only records of insulin-treated diabetes where consent to be included on the NDR has been obtained.
- Based on the capture-recapture method, the NDR captured an estimated 99.5% of children with type 1 diabetes in Australia. However, this methodology assumes that all individuals have the same probability of being captured by both APEG and NDSS.
- The NDSS database contains substantial missing information on some variables such as date of diagnosis.
- Diabetes type is classified by a health practitioner prior to NDSS registration. However, the recorded type might not always be correct as the symptoms of type 1 and type 2 diabetes may be similar.
- NDSS Access Points may be limited in rural Australia and unavailable in remote communities.
- Aboriginal and Torres Strait Islander people who use insulin to treat their diabetes may be under-represented on the NDR.

For detailed information on these issues see 'Accuracy' section.

Institutional environment: Australian Institute of Health and Welfare (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 Commonwealth entity 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 Institute 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 Institute 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](#), 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 Official Order *AIHW Monitoring of Chronic Conditions in Australia and Management of the National Diabetes Register 2018-21.*

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 NDSS Agreement between the Commonwealth of Australia as represented by Health and DA (31 August 2016–30 June 2021). There is a Memorandum of Understanding (MoU) between DA and AIHW for the supply of this data (2016–30 June 2021).

APEG are contracted to provide data for the purposes of the NDR through the Agreement in relation to consultancy services for the NDR: AIHW and APEG (16 July 2020–15 July 2022).

Timeliness: The NDR is compiled and reported annually.

The NDR 2019 was created using data from the NDSS extracted in April 2020 and APEG data to 31 March 2020. The final NDR 2019 dataset was derived in September 2020.

Accessibility: The *Incidence of insulin-treated diabetes in Australia* web report and supplementary data tables, which is based on the NDR 2019, is available online at:

https://www.aihw.gov.au/reports/diabetes/incidence-of-insulin-treated-diabetes/data

Additional data not available in the supplementary tables can be requested via the [AIHW data request management system](#).

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 *Incidence of insulin-treated diabetes in Australia* web report and supplementary data tables, which is based on the NDR 2019, is available online from the 9 December 2020 at: https://www.aihw.gov.au/reports/diabetes/incidence-of-insulin-treated-diabetes/contents/incidence-of-insulin-treated-diabetes-in-australia
Relevance:	The scope of the NDR 2019 includes all new cases of insulin-treated diabetes where insulin use occurred between 1 January 1999 and 31 December 2019.

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
- 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 areas and Indigenous status)
- geographical areas (e.g. state/territory).

Trends, crude rates and age-standardised rates are generally reported in the annual NDR report.

The methodology for deriving incidence rates has changed in recent years. Population data sourced from the Australian Bureau of Statistics (ABS) are used to derive incidence rates of type 1 diabetes and insulin-treated type 2 diabetes in previous publications. For NDR 2019, incidence rates of

insulin-treated type 2 diabetes were derived using the prevalent population including all registrants with type 2 diabetes on the NDSS. Because of this change, results based on the NDR 2019 cannot be directly compared with earlier publications or results based on previous NDR data. Due to changes in the reporting of Indigenous status on the NDSS in 2005, the prevalent population for type 2 diabetes by Indigenous status is unable to be derived. See Accuracy section for more detail.

Although the NDR 2019 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. People with type 1 diabetes use insulin and are therefore more likely to obtain subsidised products through the NDSS, and thus 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. Only a proportion of people registered with the NDSS with type 2 diabetes, gestational diabetes and other forms of diabetes require insulin treatment; those who do not are not captured on 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 1999–2019 the NDR captured an estimated 99.5% 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 some variables with substantially missing information. 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, the registration date is used.

Diabetes type is classified by a health practitioner prior to NDSS registration however, the recorded type might not always be correct as the symptoms of type 1 and type 2 diabetes may be similar. In addition, 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 females under the age of 14 with reported gestational diabetes to their diabetes type being unable to be derived. Similarly, all females aged 50 and over with their diabetes type recorded as gestational diabetes are reclassified as 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.

Coherence:	The NDR 2019 contains data on the incidence of insulin-treated diabetes since 1999.

Results from the NDR 2019 cannot be directly 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 mellitus (IDDM) and non-insulin-dependent diabetes mellitus 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.

Diabetes Australia produces NDSS quarterly snapshots on key national statistics relating to all types of diabetes—type 1 diabetes, type 2 diabetes and gestational diabetes—as well as insulin therapy. For more information see the NDSS website https://www.ndss.com.au/about-the-ndss/diabetes-facts-and-figures/diabetes-data-snapshots

Data reported from the NDSS may vary from the NDR due to the reclassification algorithm outlined in the 'Accuracy' section.

Source and reference attributes

Submitting organisation:	The Australian Institute of Health and Welfare

Relational attributes

Related metadata references:	Has been superseded by The National (insulin-treated) Diabetes Register 2020; Quality Statement
	AIHW Data Quality Statements, Standard 19/01/2022