The National (insulin-treated) Diabetes Register 2020; Quality Statement

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Identifying and definitional attributes

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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: The Australian Institute of Health and Welfare (AIHW) is an independent corporate Commonwealth entity under the Australian Institute of Health and Welfare Act 1987 (AIHW Act), governed by a management Board and accountable to the Australian Parliament through the Health portfolio.

The AIHW is a nationally recognised information management agency. Its purpose is to create authoritative and accessible information and statistics that inform decisions and improve the health and welfare of all Australians.
Compliance with the confidentiality requirements in the AIHW Act, the Privacy Principles in the Privacy Act 1988 (Cth) and AIHW's data governance arrangements ensures that the AIHW is well positioned to release information for public benefit while protecting the identity of individuals and organisations.

For further information see the AIHW website www.aihw.gov.au/about-us, which includes details about the AIHW's governance (www.aihw.gov.au/about-us/our-governance) and vision and strategic goals (www.aihw.gov.au/about-us/our-vision-and-strategic-goals).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.

The NDSS data supplied by Diabetes Australia (DA) to the AIHW to create the NDR 2020 was 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). A Memorandum of Understanding (MoU) between DA and AIHW was used 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 2020 was created using data from the NDSS extracted in April 2021 and APEG data to 31 March 2021; the final NDR 2020 dataset was derived in September 2021.

Accessibility: The Incidence of insulin-treated diabetes in Australia web report and supplementary data tables, which is based on the NDR 2020, is available in the Incidence of insulin-treated diabetes in Australia report online from the 8 February 2022.

Additional data not available in the 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.

Interpretability:

The Incidence of insulin-treated diabetes in Australia fact sheet and supplementary data tables, which is based on the NDR 2020, is available in the Incidence of insulin-treated diabetes in Australia report online from the 8 February 2022.

Relevance:

The scope of the NDR 2020 includes all new cases of insulin-treated diabetes where insulin use occurred between 1 January 1999 and 31 December 2020.

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).

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 2020, 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 2020 cannot be directly compared with earlier publications or results based on previous NDR data. See Accuracy section for more detail.

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 are therefore 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. 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 1999–2020 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 substantial missing information on some variables. This in turn flows through to the NDR.

Although the NDR 2020 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.
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, 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 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 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, and may have other programmes available in these areas to assist with the purchase of diabetes-related products. This may result in lower coverage of the NDSS in rural, remote and very remote areas or across states and territories with large remote communities, and therefore could 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 might 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. According to the NDR 2020, Indigenous status was unknown for around 7.9% of all people registered in 2020.
- Indigenous Australians may not register with the NDSS at all. Where Indigenous people live in rural, remote and very remote locations, NDSS Access Points may be limited, or consumables may be obtained through bulk supplies provided to health services through the NDSS. Diabetes-related products can also be accessed through other programs. 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.

Coherence:

The NDR 2020 contains data on the incidence of insulin-treated diabetes since 1999.

Analysis of the NDR 2020 cannot be directly compared with analysis based on previous NDR data in AIHW publications. 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. This 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. 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.

Data products

Implementation start date: 19/01/2022

Source and reference attributes

Submitting organisation: Australian Institute of Health and Welfare

Relational attributes

Related metadata references:

Supersedes The National (insulin-treated) Diabetes Register 2019; Quality Statement
AIHW Data Quality Statements, Superseded 19/01/2022