

National Diabetes Services Scheme—Australian Paediatric Endocrine Group dataset

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National Diabetes Services Scheme—Australian Paediatric Endocrine Group dataset

Identifying and definitional attributes

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Data quality

Data quality statement summary:	<p>Summary of Key Issues</p> <ul style="list-style-type: none">• The National Diabetes Services Scheme—Australian Paediatric Endocrine Group dataset (NDSS–APEG) contains information about people with diabetes in Australia.• The NDSS–APEG dataset includes data from several administrative datasets: NDSS Registrant data; NDSS Sales data; APEG data; and the National Death Index (NDI).• Some duplication may occur; however, efforts are made to detect and merge or delete duplicate records. <p>The NDSS–APEG dataset is available only for internal use by the Australian Institute of Health and Welfare (AIHW) and is intended for use in projects approved by the Department of Health (Health) as data custodian for the NDSS data.</p> <p>The NDSS–APEG dataset is a dataset of people with diabetes in Australia, which combines data from several sources—NDSS Registrant data; NDSS Sales data; APEG data; and the National Death Index (NDI).</p> <p>NDSS Registrant data: this 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 provides demographic information as well as basic clinical details.</p> <p>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 NDSS–APEG dataset lists the date of the first time such a product was purchased as an indicator of when insulin use may have begun.</p> <p>APEG data: the APEG data source used to derive the NDSS–APEG dataset relates to children who use insulin to treat their diabetes, whose insulin use started in 1999 onwards and who were less than 15 years old at the time insulin use began.</p> <p>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 NDSS–APEG dataset anyone that is deceased and their date of death.</p>
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Institutional environment: The 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 statutory authority established in 1987, governed by a [management Board](#), and accountable to the Australian Parliament through the Health and Ageing 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 <http://www.aihw.gov.au/>

The data supplied for the NDSS–APEG dataset are a result of agreements in place to facilitate various contractual arrangements. The two data suppliers are DA and APEG.

DA is the national body for people at risk of and affected by diabetes: the NDSS is administered by DA.

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

Ultimately the NDSS–APEG dataset is produced as a precursor to the National (insulin-treated) Diabetes Register (NDR) compiled annually by the AIHW.

Timeliness: The NDSS–APEG dataset is compiled annually. The most recent dataset, used in creating the NDR 2011, was based on data extracted from the NDSS in September 2012 and APEG data to 31 October 2012.

Accessibility: The NDSS–APEG dataset is not publicly available for data requests, but used solely for creating the NDR each year and for projects which have been approved for the AIHW by Health as data custodian for the NDSS data.

Interpretability: Information about the NDSS-APEG dataset will be available in any reporting made from this, or subsets of this, dataset by the National (insulin-treated) Diabetes Register team at the AIHW.

Relevance: The NDSS-APEG dataset includes all persons with diabetes who have registered with the NDSS from 1987 and/or started insulin from 1999 at less than 15 years old and registered with APEG.

The NDSS-APEG dataset captures demographic and clinical 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; postcode of residence at time of diagnosis; insulin-using status; and death status.

Accuracy:

The NDSS and APEG data are provided to the AIHW in accordance with data specifications outlined in the relevant agreements for data supply.

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 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.

Registration with the NDSS is voluntary. Those who need insulin to treat their diabetes are more likely to register, as the requirement of insulin is a driver to obtain the necessary products to administer it at subsidised prices through the NDSS.

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

The NDSS—APEG dataset contains both the reported diabetes type—the type reported by the health professional certifying the diagnosis at registration—and the derived diabetes type, based on quality checks at the AIHW. An algorithm, developed in conjunction with the National Diabetes Data 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 diabetes. 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. Reported gestational diabetes is tested against age criteria also, with an assumption that women need to be of child-bearing age to develop this type of diabetes. 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, but 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 often be obtained through targeted Indigenous programs, particularly in more remote areas.

The NDSS database contains substantial missing information on some variables. This in turn flows through to the NDSS—APEG dataset. 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 may be assigned instead.

Due to data quality issues, not one but multiple variables are used to derive the insulin using status of those on the NDSS—APEG dataset, potentially overestimating the actual number of people who are using insulin to treat their diabetes. For example, at the time of registering on the NDSS, people are often specified as insulin users to eradicate the need for later substantiation should they need to use insulin in future. Therefore from the data provided at registration alone it is not possible to determine who is and who is not actually using insulin, and other information is used in conjunction with this, such as evidence of purchasing insulin products.

Coherence:

The NDSS-APEG dataset contains data on persons with diabetes who registered with the NDSS from the schemes' inception in 1987, as well as on young people using insulin since 1999 where they were not also registered with the NDSS. The dataset includes information about which of these people have died.

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This dataset is created as a precursor to the NDR.

Data products

Implementation start date: 11/12/2013