

Data Quality Statement: National Diabetes Register 2009

Summary of Key Issues

- The National Diabetes Register records cases of insulin-treated diabetes mellitus in Australia where insulin use commenced on or after 1 January 1999. It is an incident-case register designed to record the number of new cases of insulin-treated diabetes.
- The AIHW compiles the National Diabetes Register using data from the National Diabetes Services Scheme database, maintained by Diabetes Australia, and state and territory registers maintained by the Australasian Paediatric Endocrine group.
- Some duplication may occur where the same person has registered multiple times with the National Diabetes Services Scheme, and efforts are made to detect and merge duplicate records. The level of duplication is small, about 0.4% of all records.
- The National Diabetes Register is available to researchers for epidemiological or clinical studies.
- The proportion of people with insulin-treated diabetes who are included in the register exceeds 97% for children aged 0 to 14 years. For those 15 and over the proportion is not known.

<p>Description</p>	<p>The National Diabetes Register (NDR) is a register of people living in Australia with insulin-treated diabetes mellitus, including Type 1, Type 2, gestational diabetes mellitus and other types of diabetes. The NDR was established in 1999 and aims to record all new cases of people who use insulin to treat their diabetes, meaning it should cover all new cases of Type 1 diabetes (as those with Type 1 require insulin treatment for survival). Only a proportion of Type 2 and gestational diabetes cases require insulin treatment; those that do not are excluded from the NDR. The decision to establish a register based on insulin treatment rather than type of diabetes was made because a person's type of diabetes is not as easily defined as a person's insulin-using status.</p> <p>The NDR is currently used to monitor the incidence of new cases of insulin-treated diabetes; that is, the number of new cases since 1999. Data are sourced from the National Diabetes Services Scheme database, maintained by Diabetes Australia and state and territory registers maintained by the Australasian Paediatric Endocrine Group.</p>
<p>Institutional environment</p>	<p>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.</p> <p>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.</p>

	<p>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.</p> <p>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.</p> <p>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.</p> <p>The supply of National Diabetes Services Scheme data from Diabetes Australia is mandated under the contract between Diabetes Australia and the Commonwealth Department of Health and Ageing and managed through a memorandum of understanding between the Institute and Diabetes Australia. Data supply from the Australasian Paediatric Endocrine Group is managed through a contractual arrangement between the Institute and the Group and funded by the Department of Health and Ageing.</p> <p>For further information see the AIHW website www.aihw.gov.au</p>
Timeliness	<p>The National Diabetes Register is compiled annually. Data from the end of June are used to compile the NDR for the previous year (i.e. end of June 2010 to compile the 2009 version), this allows for late registrations.</p> <p>The most recent version of the NDR pertains to 2009.</p> <p>Although the Register contains data from 1999 onwards, data coverage issues with the first year of data means that reporting usually covers the incidence of insulin-treated diabetes from 2000 onwards.</p> <p>Delays in the creation of the Register are frequent and are often due to data delays or persistent data quality issues. There was no Register compiled in 2008 due to pervasive data quality concerns.</p>
Accessibility	<p>For the 2009 version, tables relating to the National Diabetes Register will be published on the AIHW website (http://www.aihw.gov.au/national-diabetes-register/). Older versions of the Register are described in various reports (e.g. Insulin-treated diabetes in Australia, 2000-2007).</p> <p>Users can request data not available online or in reports via the National Centre for Monitoring Diabetes at the Australian Institute of Health and Welfare on (02) 6244 1000 or via email to diabetes@aihw.gov.au. Requests that take longer than half an hour to compile are charged for on a cost-recovery basis.</p> <p>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.</p>

	<p>The NDR is available for epidemiological research. To access the data researchers must review the National Diabetes Register Information Package (315KB PDF) and contact the NDR project officer at:</p> <p>The Project Officer, National Diabetes Register National Centre for Monitoring Diabetes Australian Institute of Health and Welfare GPO Box 570 Canberra ACT 2601</p>
Interpretability	<p>Information on the National Diabetes Register is available on the AIHW website.</p> <p>While numbers of new cases of insulin-treated diabetes are easy to interpret, other statistical calculations (e.g. calculations of age-standardised rates and confidence intervals) are more complex and their concepts may be confusing to some users. In most publications there is an appendix on statistical methods, as well as technical notes that should be read in conjunction with the report.</p>
Relevance	<p>The National Diabetes Register was set up 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.</p> <p>The 2009 version of the NDR reports on the incidence of insulin-treated diabetes from 1 January 2000 to 31 December 2009.</p> <p>Although data on Indigenous status are collected these are not reported in the NDR tables due to data quality and coverage issues, including coding errors prior to 2006 and unknown level of participation in the National Diabetes Services Scheme by Indigenous people in remote areas.</p> <p>Similarly, data on country of birth and linguistic background are not included due to quality issues.</p> <p>Data are collected at postcode level and breakdowns based on remoteness or other geographic areas are included in older versions of the NDR but not the 2009 version. Geographical breakdowns may be reinstated in future versions.</p>
Accuracy	<p>Data for the National Diabetes Register are provided by Diabetes Australia and the Australasian Paediatric Endocrine Group. Although there are no formal business rules around data collected, both organisations provide their data to the AIHW in accordance with data definitions as specified in contracts with the AIHW. In both cases registration on either the National Diabetes Services Scheme or the Australasian Paediatric Endocrine Group registers is facilitated by a GP, endocrinologist or other specialist or a credentialed diabetes educator.</p>

	<p>The AIHW undertakes numerous checks on the data in order to reduce the number of duplicate records, accurately determine insulin use status and validate diabetes type.</p> <p>The diabetes type recorded in the National Diabetes Services Scheme has significant potential for errors because registrants often register without having pathological testing undertaken. Many cases of diabetes that are diagnosed by a GP and recorded as Type 1 are in fact Type 2. The AIHW applies an algorithm developed by the National Diabetes Data Working Group to recode apparently anomalous cases of Type 1 or gestational diabetes, as well as cases of Type 2 diabetes in children. For Type 2 diabetes all cases under the age of 11 are recoded to 'unknown' Type; the NDR should not therefore be used as a marker of the youngest known cases of Type 2 diabetes. Although cases of Type 2 diabetes do occur in children as young as five the majority of cases of Type 2 diabetes reported in children less than 11 are due to data error. Because it is not possible to determine which are legitimate and which are erroneous, all such cases are recoded to diabetes type 'unknown' in the NDR.</p> <p>Over the years the coverage rate (that is, the number of people who are on the Register compared to the number that are eligible to be on the Register) of the NDR has improved such that the overall rate from 2000-2009 is now over 97% for children 0-14 years. For those aged 15 and over the coverage rate is not known because there is no means of counting missed cases. The cases that are missed relate mainly to instances of people choosing not to register with the National Diabetes Services Scheme (estimated to be rare in cases where insulin is used) and to cases where no consent to be listed on the NDR was provided (prior to 2003 registrants on the National Diabetes Services Scheme had to opt-in to the National Diabetes Register). We do have a measure of the proportion of people who have provided consent to be on the NDR compared to those that haven't and currently the overall (2000 to 2009) rate exceeds 89%.</p> <p>Further information on both data quality and coverage rates is provided within the appendices of historical reports and also accompanies the online tables for the 2009 NDR.</p>
Coherence	<p>The current methodology for creating the National Diabetes Register requires the entire register being rebuilt in each case. Therefore, incidence cases and rates may differ between annual versions of the NDR because the statistics are recalculated for the entire period (i.e. 2000 onwards) to ensure the trends are internally consistent.</p> <p>There have been no significant changes to data collection processes with the exception of changes to consent arrangements within the National Diabetes Services Scheme in 2003 and efforts by Diabetes Australia to promote registration. These have resulted in ongoing increases in the proportion of people with insulin-treated diabetes who are reported in the NDR.</p> <p>Although there are no comparable register data available it is possible to derive estimates of diabetes prevalence from the ABS National Health</p>

	<p>Survey. The latest results from the survey are published on the AIHW diabetes web site and the numbers are generally consistent for Type 1 diabetes after various issues have been accounted for.</p>
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