

National Diabetes Register

**Impact of changed consent arrangements
on ascertainment from the
National Diabetes Services Scheme**

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Australian Institute of Health and Welfare

Board Chair
Hon. Peter Collins, AM, QC

Director
Penny Allbon

Any enquiries about or comments on this publication should be directed to:

National Centre for Monitoring Diabetes
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Phone: (02) 6244 1000
Email: diabetes@aihw.gov.au

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Abbreviations

AIHW	Australian Institute of Health and Welfare
APEG	Australasian Paediatric Endocrine Group
CDE	credentialed diabetes educator
NDR	National Diabetes Register
NDSS	National Diabetes Services Scheme

Glossary of terms

NDR-eligible NDSS registrant	An NDSS registrant who began using insulin to manage his or her diabetes on or after 1 January 1999 and is therefore eligible to be on the NDR.
NDSS ascertainment for the NDR	The number of NDR-eligible NDSS registrants on the NDR compared with the total number of NDR-eligible NDSS registrants.
New NDSS registration form	The NDSS registration form introduced in July 2003 that had the separate NDR consent section removed (see Old NDSS registration form).
Old NDSS registration form	A version of the NDSS registration form that included a separate NDR consent section.

Executive summary

Background

The National Diabetes Register (NDR) is a register of people living in Australia with insulin-treated diabetes. People are eligible to be on the NDR only if they use insulin to treat their diabetes and their insulin use began on or after 1 January 1999.

The NDR has two main sources of data:

- the National Diabetes Services Scheme (NDSS) database, administered by Diabetes Australia
- the Australasian Paediatric Endocrine Group's (APEG) state and territory databases.

The NDSS has been operating since 1987. When the NDR was established in 1999, the NDSS registration form was updated to include a section for NDSS registrants to consent to be included on the NDR. In July 2003, Diabetes Australia introduced a new NDSS registration form that changed the NDSS consent arrangements for the NDR by removing the NDR opt-in consent section. This meant that, from August 2003, all people registering for the NDSS on the new form who are eligible to be on the NDR are automatically included on the NDR unless they specifically ask not to be. As a result, NDSS ascertainment for the NDR has improved since August 2003 and therefore notification of new cases of insulin-treated diabetes to the NDR from the NDSS has increased since that time. However, NDSS ascertainment for the NDR has not yet reached 100% for two reasons:

- old versions of the NDSS form are still being used to register people on the NDSS
- changes in insulin status for existing NDSS registrants are not always being notified to the NDSS by completion of a new version of the NDSS registration form.

As NDR data sourced from APEG are not affected by the changed NDSS consent arrangements for the NDR, this information paper examines only ascertainment for the NDR from the NDSS.

Purpose

This information paper describes the phasing in of the new NDSS registration form since August 2003 and the resulting improvement in NDSS ascertainment for the NDR.

When interpreting trends over time in the incidence of insulin-treated diabetes based on data from the NDR, it is important to be able to differentiate between the underlying trend and the effect of the changed NDSS consent arrangements for the NDR on any increase in incidence. Therefore, this information paper also provides information to help users of NDR data understand the impact of the changed consent arrangements on NDSS ascertainment for the NDR so that the data can be appropriately used and interpreted, particularly with respect to comparisons over time.

Highlights

Of all people registering with the NDSS who were eligible to be on the NDR – that is, people who began using insulin on or after 1 January 1999 – the proportion on the NDR improved from 73% for those registering with the NDSS in January to July 2003 to 81% for those registering in August to December 2003. NDSS ascertainment for the NDR then further improved to 92% for those registering with the NDSS in 2004 and 93% for those registering in the first half of 2005.

Overall, as at 1 July 2005, 55% of NDSS registrants who were eligible to be on the NDR were registered on it. However, NDSS ascertainment rates for the NDR (that is, the proportion of NDSS registrants eligible to be on the NDR who are on it) varied considerably by year of first insulin use, type of diabetes and the sociodemographic characteristics of NDR-eligible NDSS registrants:

- Despite the overall low NDSS ascertainment rate for the NDR, the rate has improved over time from 39% for NDR-eligible NDSS registrants who began using insulin in 1999 to 70% for those who began using insulin in 2005.
- 72% of NDR-eligible NDSS registrants with Type 1 diabetes were on the NDR compared with only 51% of NDR-eligible NDSS registrants with Type 2 diabetes.
- 74% of NDR-eligible women with gestational diabetes who were registered on the NDSS were also on the NDR.
- Ascertainment rates by age at first insulin use were highest for NDR-eligible NDSS registrants aged 0–14 years (86%), then fell with increasing age to 49% for 70–79 year olds but increased slightly again for people aged 80 years and over (50%).
- 86% of NDR-eligible NDSS registrants with Type 1 diabetes who were aged 0–14 years at first insulin use were on the NDR compared with 67% of those aged 15–39 years at first insulin use.
- 75% of NDR-eligible NDSS registrants living in Western Australia were on the NDR compared with 40% of those living in the Northern Territory and 40% of those living in South Australia.
- 72% of NDR-eligible NDSS registrants who were born in Australia were on the NDR compared with 65% of those born overseas.

Recommendations

There is clearly scope to improve NDSS ascertainment for the NDR. The following actions, aimed at further improving NDSS ascertainment for the NDR, are therefore recommended:

- Old versions of the NDSS registration form should no longer be used for NDSS registration.
- Changes in insulin status for existing NDSS registrants should be notified to the NDSS by completion of a new NDSS registration form.
- NDR-eligible NDSS registrants who registered with the NDSS on an old form and did not complete the separate NDR consent section need to be encouraged to join the NDR. Note that Diabetes Australia's proposed back-capture project should help with this.

- Attention should be given to raising the NDSS ascertainment rate for the NDR in all states, but particularly in the Northern Territory and South Australia where ascertainment rates are lower than 50%.
- Appropriate steps should be taken to improve the completeness of NDSS data items, such as date of diagnosis and date of first insulin use, which are crucial variables for the NDR's data quality.