

Insulin pump use in Australia- DQS

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Identifying and definitional attributes

Metadata item type:	Data Quality Statement
METEOR identifier:	494791
Registration status:	AIHW Data Quality Statements , Standard 15/08/2012

Data quality

Data quality statement summary:

- The Insulin Pump User Survey was conducted by the Australian Institute of Health and Welfare in October–November 2011 as part of a project examining insulin pump use in Australia.
- The survey was developed to provide information about the factors that influenced people's choice to commence insulin pump therapy and the benefits and problems they experienced.
- Participants were registrants of the National Diabetes Services Scheme, administered on behalf of the Australian Government by Diabetes Australia to provide diabetes-related products at subsidised prices.
- To ensure anonymity, the survey form and associated documentation were distributed on behalf of the Australian Institute of Health and Welfare by Diabetes Australia.
- In total 5,680 survey responses were analysed, representing a response rate of 59%.

Description

The Insulin Pump User Survey was developed for a project on insulin pump use in Australia to gain an understanding of the experiences of insulin pump users and what motivations they had for starting, interrupting and ceasing insulin pump use.

Specifically, the survey covered the following:

- demographic information
- age at diagnosis of diabetes and age at start of insulin pump use
- funding of insulin pumps
- factors that influenced the choice to use an insulin pump
- benefits of using an insulin pump
- problems with using an insulin pump, including whether hospitalisation or attendance at an emergency department for diabetes control issues while using a pump had been required
- information about temporary breaks from insulin pump use, and permanent stoppage
- frequency of contact with a specialist diabetes doctor or diabetes educator.

Selection for participation was determined by registration on the National Diabetes Services Scheme (NDSS) which provides subsidised diabetes related products. This scheme is managed by Diabetes Australia (DA) on behalf of the Australian Government.

Participants were people who were eligible to purchase insulin pump consumables through the NDSS and had given consent to be contacted for research purposes. On the NDSS, approximately 90% of those eligible to purchase insulin pump consumables agreed to be contacted.

There were 9,618 people eligible to participate.

Participants were each mailed a survey pack consisting of a cover letter, survey form and reply-paid envelope addressed to the Australian Institute of Health and Welfare (AIHW). Three weeks after the initial mail-out, another pack was sent as a reminder.

To ensure anonymity of participants, the AIHW supplied DA with the survey pack and DA organised the mail-out.

A hotline and dedicated email address were available for participants who had queries or feedback about the survey.

Institutional environment: The 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 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, (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 www.aihw.gov.au.

Timeliness: The Insulin Pump User Survey was a one-off survey conducted in October–November 2011.

Accessibility: Results from the Insulin Pump User Survey are published in the report Insulin pump use in Australia available online at the AIHW website www.aihw.gov.au.

Detailed or unit record data from the survey results cannot be accessed outside of the scope of the project for which the survey was developed.

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.

Specific enquiries about the results of the survey can be made to:

The Project Officer
National Centre for Monitoring Diabetes
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
or email to diabetes@aihw.gov.au.

Interpretability: The results from the Insulin Pump User Survey can broadly be generalised to all insulin pump users in Australia.

The survey achieved a 59% response rate and these respondents were a relatively representative sample of all pump users registered on the NDSS. The sample and full population of insulin pump users had similar distributions for sex, state or territory of current residence and region.

For age, the distribution varied more. Younger and older age groups were over-represented and those between the ages of around 15 and 40 under-represented by the survey data, particularly those aged 15 to 29.

Testing the impact of applying a weighting to account for the differences in age distributions showed that the difference in the results were minimal and therefore the sample data were not weighted for analysis purposes.

Where the analyses are not presented by age group, the reader should consider any impact that this under-representation of those 15 to 29 may have had.

Relevance: The Insulin Pump User Survey is the first national survey of insulin pump users. The survey goes beyond other studies covering similar issues because it is based on a large and representative sample of all pump users in Australia.

The Insulin Pump User Survey was conducted in October–November 2011.

Accuracy: It was assumed that, because of the eligibility criteria for purchasing insulin pump consumables through the NDSS, all respondents to the survey had Type 1 diabetes. However, it was possible that some people with other forms of diabetes with special circumstances may have been able to obtain subsidised consumables and were also sent a survey to complete.

The final survey dataset may have included duplicate responses. With no identifying information on the survey form, the AIHW were not able to determine who had responded to the survey after the initial mail-out and the reminder survey pack was distributed to all participants. Based on testing key information, where the probability of two survey forms being a duplicate was high, one of the responses was deleted.

Where insulin pump users were young, the survey was addressed to their carer. It was not possible to determine when a survey had been completed by the insulin pump user or their carer and whether this had any bearing on the results.

The number of people registered on the NDSS for insulin pump consumables who had stopped using an insulin pump may be underestimated in the survey due to a misunderstanding of the overall purpose of the survey. Feedback from a few participants indicated they did not think the survey was applicable to them as they were not currently using a pump—it was not possible to determine how many other participants in similar circumstances did not return the survey form at all.

Coherence: The Insulin Pump User Survey was a one-off national survey of insulin pump users.