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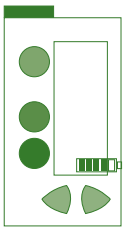
Insulin pump use in Australia



Australian Government
Australian Institute of Health and Welfare

Authoritative information and statistics to promote better health and wellbeing

DIABETES SERIES
Number 18

Insulin pump use in Australia

Australian Institute of Health and Welfare
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Contents

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Abbreviations

ABS	Australian Bureau of Statistics
ACT	Australian Capital Territory
AIHW	Australian Institute of Health and Welfare
ARIA	Accessibility/Remoteness Index for Australia
CGM	continuous glucose monitor
CSII	continuous subcutaneous insulin infusion
DA	Diabetes Australia
IPC	insulin pump consumable
IRSD	Index of Relative Socioeconomic Disadvantage
JDRF	Juvenile Diabetes Research Foundation
MDI	multiple daily injection
NDDWG	National Diabetes Data Working Group
NDSS	National Diabetes Services Scheme
NSW	New South Wales
NT	Northern Territory
Qld	Queensland
SA	South Australia
Tas	Tasmania
Vic	Victoria
WA	Western Australia

Symbols

–	nil or zero rounding
. .	not applicable
<	less than
>	more than

Summary

This report examines the use of insulin pumps by people with Type 1 diabetes. It represents the most up-to-date national reporting of this information in Australia. The findings are based on administrative data supplied by Diabetes Australia and data from the Insulin Pump User Survey, conducted by the Australian Institute of Health and Welfare in 2011.

Pump users

- As at 30 June 2011, there were 10,510 insulin pump users in Australia—representing 10% of people with Type 1 diabetes.
- Almost half of all insulin pump users were under 25 years old.
- Compared with the national average of 10%, the Australian Capital Territory (15%), Western Australia (12%) and Tasmania (11%) had a higher proportion of pump users among people with Type 1 diabetes, while the Northern Territory had the lowest proportion (7%).
- Insulin pump use was more common among people with Type 1 diabetes living in areas of high socioeconomic status (14%) than among those in low socioeconomic status areas (6%).

How have things changed?

- The number of people with Type 1 diabetes commencing insulin pump therapy increased from 107 per month in 2004 to 140 per month in 2010.
- People with Type 1 diabetes now begin using insulin pump therapy relatively sooner after diagnosis than in the past. In 1997, less than 1% began using an insulin pump within 2 years of diagnosis; in 2009, this had risen to 18%.

Financing insulin pump use

- Approximately 80% of insulin pump users with Type 1 diabetes obtained a private health insurance rebate for the purchase of their pump.
- Insulin pump therapy is more expensive than multiple daily injections. The pump itself costs between $4,000 and $9,000 and the average expenditure on consumables was $29 per month in 2010–11, compared with $6 per month for injection therapy.

Insulin pump use experience

- The largest motivating factor for choosing to use a pump was better control of diabetes—88% of survey respondents indicated this.
- For most insulin pump users, the benefits of pump use outweighed any problems they encountered.
- The fact that insulin pump therapy fitted in with the lifestyle of the user was the most frequently cited benefit (86% of survey respondents). The most commonly cited problem was that insulin pump consumables were too expensive (32%).
- Twenty-three per cent of survey respondents attended an emergency department or were admitted to hospital for diabetes management while using a pump.
- In spite of recommendations for contact with a diabetes health professional every 3–6 months, 10% of insulin pump users had not had contact with a professional in over 6 months.

1 Introduction

Key points

- As at 30 June 2011, there were 10,510 insulin pump users in Australia—representing 10% of people with Type 1 diabetes.
- The average number of new pump users increased from 107 per month in 2004 to 140 per month in 2010.
- The clinical benefits of insulin pump use include lower mean blood glucose levels, lower HbA1c levels, lower insulin requirements and improvements in glycaemic control compared with people using injection therapy—the alternative treatment for diabetes requiring insulin treatment.
- Improved lifestyle is one of the main benefits of insulin pump therapy; for instance, the precision in insulin dosage with a pump allows for greater flexibility in diet and exercise than when using multiple daily injections.
- Before commencing insulin pump therapy, potential users need to undergo comprehensive assessment and training. Once using a pump, follow-up with health professionals is recommended every 3–6 months.
- Insulin pump therapy is more expensive than multiple daily injections. The pump itself costs between $4,000 and $9,000 and the average expenditure on consumables that enable continued use was $29 per month in 2010–11, compared with $6 per month for people using injection therapy.
- In Australia, those who are eligible are provided with financial assistance for purchasing an insulin pump and the consumables associated with its use.

Insulin pumps are a form of diabetes treatment that is increasingly being used as an alternative to the traditional method of injecting insulin several times a day with a pen or syringe. Insulin pumps are small computerised devices that deliver insulin subcutaneously (that is, under the skin) and are controlled by the user.

Insulin pump therapy is also known as continuous subcutaneous insulin infusion (CSII) therapy and these terms are used interchangeably throughout this report.

This report presents the most up-to-date information available about the number and characteristics of people using insulin pumps in Australia. The report also includes information about the purchase of the consumables to support insulin pump use and the trends in use since 2004. This information is supplemented with the results of the first national survey of insulin pump users, which provides insights into the experiences of those using pumps in Australia, including why they chose to use a pump and the benefits and problems they encountered. The survey goes beyond other studies covering similar issues because it is based on a large, representative sample of all pump users in Australia.

This report considers only people with Type 1 diabetes and is based on data from the National Diabetes Services Scheme (NDSS) database (registrant and sales data) and the Insulin Pump User Survey conducted by the Australian Institute of Health and Welfare (AIHW).

There are a number of reasons for basing the analysis on Type 1 diabetes only:

- The NDSS registrant data contain close to the entire population of people with Type 1 diabetes in Australia. Because all people with Type 1 diabetes require insulin for survival, almost everyone will join the NDSS to access subsidised consumables to manage their diabetes, whereas people with other types of diabetes can sometimes manage their condition with lifestyle changes alone.
- Almost all insulin pump users registered on the NDSS have Type 1 diabetes. Except in special circumstances, only people with Type 1 diabetes are eligible to obtain subsidised consumables for insulin pumps, such as infusion sets, catheters and reservoirs.

These two points mean that, with a high degree of confidence, the results in this report represent all people in Australia with Type 1 diabetes and a subset of these—all insulin pump users.

Data sources

As already stated, the information presented in this report is derived from the NDSS registrant data, the NDSS sales data and the Insulin Pump User Survey.

National Diabetes Services Scheme data

The NDSS is administered by Diabetes Australia (DA) on behalf of the Australian Government and provides access to diabetes consumables (such as syringes, pen needles, blood glucose test strips, pump reservoirs and infusion sets) at subsidised rates. To access the NDSS, individuals with diabetes must have their diabetes diagnosis certified by a health professional.

This report uses de-identified NDSS registrant details as well as information from the NDSS sales database, which records the consumables purchased by registrants from their time of registration. The data extracted for the report were based on purchases made between 1 January 2004 and 30 June 2011 and the registrants who made these purchases. Only registrants known to be living and still eligible for insulin pump consumable subsidies as of June 2011 were included in the analyses.

The sales data were used as a proxy for pump use and to derive the date of pump commencement, which was taken as the date the first insulin pump consumable was purchased from 2004 to 2011. It should be noted that the proportion of pump users who actually commenced their pump use (that is, purchased their first consumable) before 2004 was estimated to be less than 2%.

It should also be noted that the registrant characteristics that are held on the NDSS database are captured at the time of registration and are not always updated. This potentially means that in some cases the type of diabetes may be incorrect, because it is not always confirmed at the time of registration and may not be updated in the NDSS database even if verified at a later date.

Insulin Pump User Survey

The Insulin Pump User Survey was developed by the AIHW to collect information about the experiences of insulin pump users in Australia. Diabetes Australia distributed the survey in October–November 2011 on behalf of the AIHW to pump users on the NDSS who had

consented to be contacted for research purposes. The survey was sent to almost 10,000 people and included a reminder posted approximately 3 weeks after the initial mail-out. Participants were provided with a postage paid envelope to return completed questionnaires to the AIHW directly and anonymously. In total, 5,680 survey responses were analysed, representing a response rate of 59%.

The survey provided information about the factors that influenced people's choice to commence CSII therapy and the benefits and problems they experienced. More detail about the survey methodology can be found in 'Appendix A: Survey methodology', a copy of the survey instrument is at 'Appendix B: Insulin Pump User Survey' and the data quality statement for the survey can be found at 'Appendix E: Data Quality Statement'.

Report structure

This first chapter provides background and context to the results presented in the following chapters, including information about the number of pump users and expenditure on insulin pump consumables (IPCs). This introductory material also discusses why insulin pumps are chosen as an alternative to multiple daily injections (MDIs) and explains how they work. This information, which highlights the complexity of life for people with insulin-treated diabetes, is important in providing context to the survey results. This chapter also discusses the process for acquiring an insulin pump and the financial assistance that is available in Australia.

Chapter 2 examines trends in insulin pump use and the average time taken from diagnosis of Type 1 diabetes to commencing CSII therapy. This chapter also covers the demographic and socioeconomic characteristics of insulin pump users and compares these to all people with Type 1 diabetes.

Chapter 3 deals mainly with the motivations and day-to-day experiences of insulin pump users. This chapter looks at the decision to commence pump therapy, how people primarily fund the purchase of their pump and the benefits and problems they experience, including information about discontinuing CSII. This chapter also provides information about any contact pump users have with health professionals after they commence their insulin pump.

Chapter 4 highlights the important findings from the research.

Type 1 diabetes

Although there is currently no definitive measure of the prevalence of Type 1 diabetes in Australia, figures obtained from the NDSS indicate that there were 110,500 people with Type 1 diabetes in Australia as at 30 June 2011. The estimate in the self-reported 2007–08 National Health Survey puts the number at around 87,000 (95% CI: 73,700–100,500) or 0.4% of the Australian population (Australian Bureau of Statistics 2009).

Type 1 diabetes is a serious lifelong autoimmune disease, not related to either poor diet or lack of activity, which destroys the body's ability to produce insulin. It impacts on quality of life and life expectancy. Without insulin, glucose remains in the blood and is unable to be moved into the cells where it is converted to energy or stored until needed. Daily insulin is therefore required for survival. Although Type 1 diabetes can occur at any age, it mainly develops during childhood and adolescence (Craig et al. 2011) and once a person is diagnosed, they will require insulin treatment every day throughout their life. The amount

of insulin required will vary according to factors such as food intake, physical activity, age, weight, illness and hormonal changes (Australasian Paediatric Endocrine Group 2005).

Optimal management of Type 1 diabetes is essential to reduce the risk of complications associated with low blood glucose levels (hypoglycaemia) and high blood glucose levels (hyperglycaemia) (The Diabetes Control and Complications Trial Research Group 1993). Long-term complications of diabetes include kidney failure, blindness, nerve damage, heart attack and stroke, and short-term complications include diabetic ketoacidosis, hypoglycaemia, increased susceptibility to infections and reduced ability to heal (Australian Institute of Health and Welfare 2010). The risk of these serious health problems increases markedly the longer blood glucose levels remain out of normal range.

In 1993, the Diabetes Control and Complications Trial Research Group showed that the risk of short- and long-term complications associated with Type 1 diabetes could be reduced over time by around 50% with intensive insulin therapy, which can either be delivered via multiple daily injections (MDIs) or insulin pump therapy. As a result, intensive insulin therapy is now the standard recommended treatment for optimal diabetes management.

Number of people using insulin pump therapy

National Diabetes Services Scheme registrant data showed that there were 10,510 insulin pump users in Australia as at 30 June 2011: about 10% of people with Type 1 diabetes. These were people registered for the insulin pump consumable subsidy who had made one or more purchases of IPCs for their pump any time between 1 January 2004 and 30 June 2011. Because of the data extraction method it is possible that not all these people were actively using an insulin pump at 30 June 2011, but could have been taking a break or stopped using one permanently. However, the Insulin Pump User Survey showed that the number of people who cease to use insulin pumps permanently is minimal—about 2%—suggesting that 10,510 is a good estimate of the number currently using CSII therapy.

For the period 2004–2011, there was an increase in the average number of people commencing insulin pump use per month from 107 in 2004 to 140 in 2010. This may have been influenced in part by improvements in pump technology, which have resulted in smaller and easier to use 'smart' pumps that include features that simplify the tasks involved in delivering insulin, provide safety alarms and support the integration of blood glucose meters with wireless technology.

Furthermore, the introduction of subsidies has decreased costs associated with using insulin pumps, making them a more accessible treatment option. Details on these subsidies are provided later in this chapter.

Insulin pump use in other countries

There is limited information on the numbers using insulin pumps in other countries. Recognising this, the National Health Service in England undertook an insulin pump audit in 2009 to evaluate their uptake (National Diabetes Information Service 2010). The audit identified 1,812 children (under 18 years old) and 3,855 adults using an insulin pump, which equated to 8% of children with Type 1 diabetes and at least 2% of adults. However, as the interim findings indicated, these figures are 'probably considerable underestimates and should be used with extreme caution'.

In Scotland, of the 27,367 people recorded as having Type 1 diabetes, 553—less than 2%—were on CSII therapy (Scottish Diabetes Survey Monitoring Group 2010). And in other European countries such as Sweden, the Netherlands and Germany, approximately 10% of people with Type 1 diabetes used insulin pumps (Selam 2006)—a similar proportion to Australia.

Insulin pump use appears to be much higher in the United States than in Australia and European countries, with estimates of between 20%–25% of people with Type 1 diabetes using this type of treatment (Alsaleh et al. 2010).

Managing diabetes with insulin pump therapy

Insulin pumps are worn 24 hours a day. A pump holds a cartridge (reservoir) that delivers insulin through an infusion set. The infusion set, which is changed every three days, consists of a tube that connects to the reservoir and a cannula that is inserted under the skin. Insulin pumps simulate the natural pattern of pancreatic insulin secretion by delivering continuous basal and mealtime bolus doses of insulin (Shalitin & Phillip 2008). The basal dose is a continuous dose of insulin designed to keep blood glucose levels within the normal range between meals without inducing hypoglycaemia and the bolus dose is administered at meal times or when blood glucose levels are high, to prevent hyperglycaemia.

Current pumps require the user to modify insulin bolus and basal rates throughout the day based on their blood glucose levels, food intake and intensity of physical activity. Frequent monitoring of blood glucose levels is essential, and usually involves pricking the tip of the finger and placing a drop of blood on a reagent strip which gives a reading to guide the patient on their insulin requirement (Australasian Paediatric Endocrine Group 2005).

Insulin pump users sometimes use continuous glucose monitors (CGMs) together with their insulin pumps. CGMs are devices that provide frequent (every few minutes) measurements of interstitial glucose (Taylor 2009), thereby allowing a user to gauge the trends in their glucose levels and the short-term responses to various activities such as exercise, food intake or medication (Neithercott 2012). Through the use of alarms and trends shown on the monitor, a CGM can be used to alert the user to extremes in blood glucose levels, thereby facilitating better glycaemic control while limiting the risk of hypoglycaemia (Kamath et al. 2010).

Benefits and challenges of insulin pumps

There are both clinical and lifestyle benefits to using insulin pump therapy. Studies have shown that people using pumps have lower HbA1c levels, lower insulin requirements and improvements in glycaemic control compared with people using MDIs (Pickup et al. 2002). This is because the increased precision of insulin dosing achievable with CSII therapy more closely replicates the body's natural insulin production (Australasian Paediatric Endocrine Group 2005). This improvement in the overall management of diabetes also reduces the risk of long-term health complications such as retinopathy, nephropathy and neuropathy (The Diabetes Control and Complications Trial Research Group 1993).

Insulin pump users report a better quality of life compared to people injecting several times a day. The continuous delivery of basal insulin, via rapid acting insulin, along with the accuracy of bolus dosing means that the pump allows increased flexibility with meal times and carbohydrate intake (Smart et al. 2008) and greater variations of intensity in physical

activity (Shalitin & Phillip 2008). For many people, an insulin pump is more discreet and convenient than injecting and the avoidance of needles is a significant benefit.

In spite of the benefits, operating an insulin pump is not without challenges. A number of insulin pump users find that the continual reliance on an external device, with the need to program the pump and change cartridges and infusion sets, make pumps difficult to manage (Barnard et al. 2007). Pump failure, caused by the cannula kinking, air bubbles affecting insulin delivery, unintentional misuse or mechanical problems can increase the risk of diabetic ketoacidosis (Shalitin & Phillip 2008), and infection and skin irritation at the site of the catheter is also a problem for many (Shalitin & Phillip 2008; Smart et al. 2008). Additionally, while some users find an insulin pump discreet, others don't like wearing it because they find it difficult to conceal under clothing and inconvenient.

Insulin pump therapy is more expensive than MDIs (Craig et al. 2011). Pump users spent an average of $345 on NDSS consumables in 2010–11, compared with $73 for non-pump users. However, this expense is thought to be a more cost-effective option in the long term for most users due to the improvements in lifestyle and in the reduction in long-term medical complications.

Acquiring an insulin pump

Pumps are often recommended for people with Type 1 diabetes who are not managing their diabetes well, who present with repeated episodes of diabetic ketoacidosis or frequent unpredictable hypoglycaemia, fail to achieve HbA1c goals or have erratic eating or lifestyle patterns (Owen 2006). People with Type 1 diabetes may also request to use an insulin pump because of the lifestyle benefits pumps offer. Babies and children newly diagnosed with Type 1 diabetes are now regularly placed directly onto insulin pump therapy, without ever undergoing MDI therapy (Foskett et al. 2011). These patients have been found to have better results in achieving effective glycaemic control and maintaining stability than those who initially have MDIs (Foskett et al. 2011). It has also been found that the younger a person begins on pump therapy, the less likely they are to discontinue pump use (Hofer et al. 2010).

The decision to begin CSII therapy is made in consultation with health professionals who consider the benefits that may be achieved from insulin pump use balanced against the challenges of managing a pump for that individual. Potential users need to be committed to undergo comprehensive training to learn how to use a pump effectively and have adequate support from health professionals and pump company representatives. Those who are claiming the cost of their pump through private health insurance also need to have health fund membership for at least 1 year to be eligible for the rebate.

In Australia, best practice guidelines indicate that a potential pump user needs to be assessed against an extensive set of criteria (Box 1.1) by a multidisciplinary team, incorporating a physician, a credentialled diabetes educator, a dietician and possibly a psychologist, to ensure their suitability for pump use.

Once the assessment is complete and a person with diabetes has been accepted to commence CSII therapy, the insulin pump needs to be fitted by a health professional. Some private health insurance companies require the pump to be initiated during an inpatient hospital admission, but it can also occur as an outpatient. Following commencement on the pump, the pump user needs to retain close contact with health professionals for appropriate adjustment of the pump rates until blood glucose levels are stable and the user is confident in managing the pump themselves.

It is recommended that people using an insulin pump follow up regularly with a specialist physician or credentialled diabetes educator at approximately 3–6 month intervals (Victorian CSII Working Party 2009).

Box 1.1: Criteria to determine suitability for insulin pump therapy

- Person confirmed as having Type I diabetes
- Lifestyle allows for wearing of a pump
- Lifestyle choices to facilitate adequate time for initial stabilization and education
- Person requires less than 300 Units of insulin per 2-3 days
- Consistent home blood glucose monitoring and recording or is willing to increase monitoring (and subsequently demonstrates has done so)
- Ability to measure blood or urine ketone levels
- Basic numeracy
- Willing and able to learn how to count carbohydrates and to calculate doses of insulin
- Willing to communicate on a regular basis with the health care team
- Able to comply with treatment plans or scheduled visits
- Absence of any severe or unstable psychiatric condition: eating disorder, psychosis, depression. It is noted that the presence of an eating disorder or depression does not preclude insulin pump use
- Reasonable level of motivation and able to accept responsibility for care of diabetes
- No significant visual impairment
- No major restriction in manual dexterity, or lack of required assistance
- Adequate condition of subcutaneous tissue and skin
- Satisfactory hygiene
- Funds available to purchase pump and consumables.

Source: Victorian CSII Working Party 2009.

Paying for an insulin pump and consumables

Insulin pump therapy is more expensive than MDIs (Cohen et al. 2007) and includes the cost of the pump as well as the ongoing costs of the associated consumables. The cost of an insulin pump ranges from approximately $4,000 to $9,000 (Juvenile Diabetes Research Foundation 2011b). Most health insurance providers cover the full cost of the pump and initial supplies for their members with Type 1 diabetes, but for many people the financial burden is a major obstacle to commencing CSII therapy (Australian Healthcare Associates 2008).

In Australia, there are subsidies available for young people with Type 1 diabetes who opt to use insulin pump therapy—a subsidy for insulin pump consumables, as well as one for the pump itself. Since 1 September 2004, the NDSS has subsidised the purchase of IPCs for eligible registrants (Box 1.2). This subsidy, which covers items such as infusion sets and

pump reservoirs, has reduced the average monthly out-of-pocket expenses from approximately $300 to $30 per month (Australian Healthcare Associates 2008). The 2010–11 NDSS sales data showed that the average subsidised expenditure per pump user was $29 per month. Although the introduction of subsidies has significantly reduced the cost borne by pump users, numerous survey respondents indicated that the cost of consumables, which also includes items such as lancets and batteries not subsidised by the NDSS, remains too high; one respondent commented that 'at times the cost of consumables causes strain on the family budget'.

Box 1.2: Eligibility for the insulin pump consumables subsidy

- All children under 18 with Type 1 diabetes, adults with Type 1 and a demonstrated clinical need for a pump
- Women with gestational diabetes and women whose pre-existing Type 1 diabetes presents difficulties during their pregnancy and require treatment with a pump
- Transitioning adults with Type 1 diabetes (those who turned 18 in the past 6 months)
- Existing pump users where the person with Type 1 commenced using a pump before 1 September 2004.

Source: National Diabetes Services Scheme & Diabetes Australia 2011.

The Type 1 Diabetes Insulin Pump Program assists Australians on low incomes to purchase an insulin pump and was introduced on 1 November 2008 (Minister for Health and Ageing 2008). The program, which is administered by the Juvenile Diabetes Research Foundation (JDRF) on behalf of the Australian Government, is available to people aged under 18 and provides a subsidy of 80% of the cost of the insulin pump up to $6,400 to families who have an annual income up to $67,398 or receive income support payments from Centrelink. This subsidy reduces on a sliding scale to families with an income over the threshold and cuts out entirely at $101,312. Eligible families with two or more children with Type 1 diabetes are entitled to the calculated subsidy for the first child and the maximum subsidy for subsequent children, irrespective of the family's income. As at December 2010, 116 children with diabetes had received a subsidy from this program (Juvenile Diabetes Research Foundation 2011a).

People with diabetes who do not have private health insurance and do not qualify for a government subsidy may occasionally be able to obtain a pump through enrolment in clinical trials or donations from charitable organisations. The JDRF gives a small number of free insulin pumps to families in financial need each year, provided the families can afford the ongoing cost of consumables. Some people pay the entire cost of the pump themselves.

2 Insulin pump use and pump user characteristics

Key points

- The number of people with Type 1 diabetes commencing insulin pump therapy increased from 107 per month in 2004 to 140 per month in 2010.
- People with Type 1 diabetes now begin using insulin pump therapy relatively sooner after diagnosis than in the past. In 1997, less than 1% began using an insulin pump within 2 years of diagnosis; in 2009, this had risen to 18%.
- In Australia, approximately 10% of people with Type 1 diabetes used an insulin pump.
- Almost half of all insulin pump users were under 25 years old.
- Compared with the national average of 10%; the Australian Capital Territory (15%), Western Australia (12%) and Tasmania (11%) had a higher proportion of pump users of people with Type 1 diabetes, while the Northern Territory had the lowest proportion (7%).
- Insulin pump use was more common among people with Type 1 diabetes living in areas of high socioeconomic status (14%) than among those in low socioeconomic status areas (6%).
- People with Type 1 diabetes in *Remote and very remote* areas (8%) were less likely to use insulin pumps compared with those in *Major cities*, *Inner regional* and *Outer regional* areas, where rates were closer to the national average.

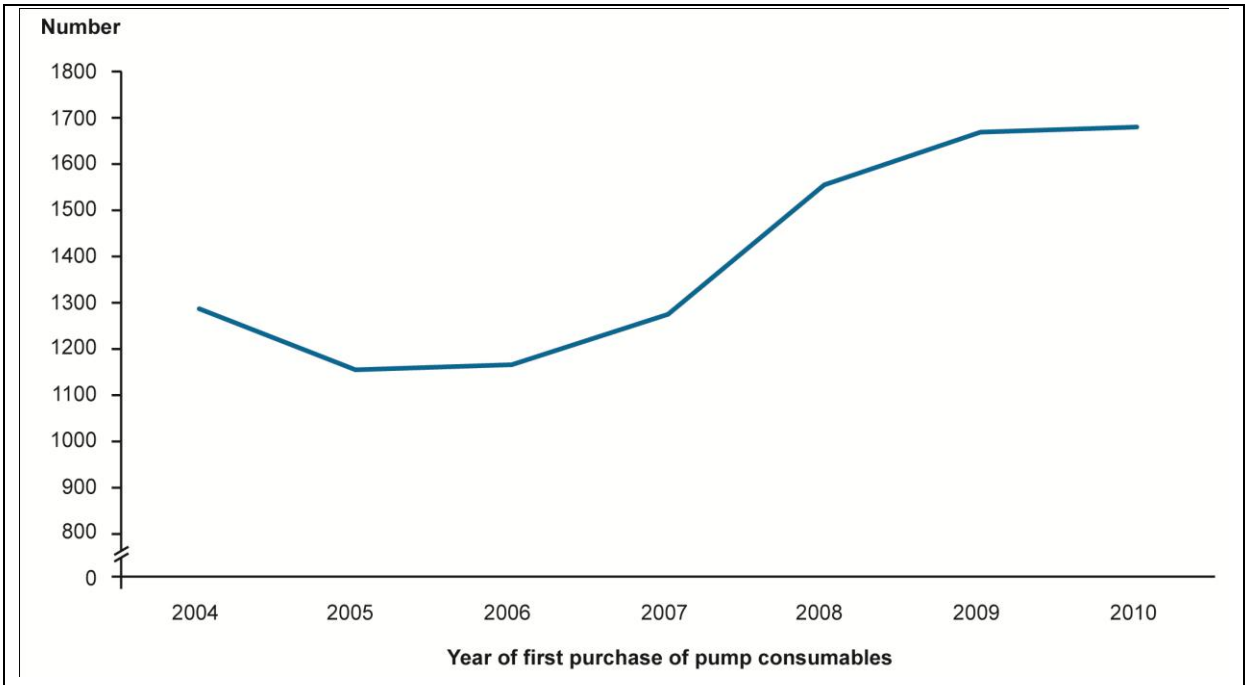
This chapter examines the trends in insulin pump use and characteristics of insulin pump users. Two trends are discussed; firstly, the increase in the number of new users since 2004 and, secondly, the reduction of the time between diagnosis of Type 1 diabetes and commencement of pump therapy. The section on characteristics of insulin pump users examines demographic and socioeconomic factors, and compares these characteristics with all people with Type 1 diabetes.

Trends in commencement of insulin pump therapy

As discussed in the previous chapter, there are a number of factors that may have influenced the growth in insulin pump use in Australia, including improved technology and the introduction of subsidies to assist people to initiate CSII therapy. Figure 2.1 shows the increase in number of new pump users over the period 2004–2010 by using the number of people who purchased insulin pump consumables for the first time as a proxy for beginning CSII. By assessing available data earlier than 2004, the proportion of pump users who actually commenced their pump use (that is, purchased their first consumable) before 2004 was estimated to be less than 2%.

In 2004, there were a relatively high number of new pump users, presumably as a result of the introduction of the IPC subsidy towards the end of that year. After this influx of new users, there was a drop in 2005, followed by a gradual increase until 2008 when there were 20% additional users compared with 2007. Although the insulin pump subsidy for low

income families with children with Type 1 diabetes introduced at the end of 2008 may have contributed to this growth, there was an equal increase in uptake by adult pump users. From 2008 to 2010, the proportion of new insulin pump users under the age of 18 remained at around 40% of all new users. In 2009 and 2010, the overall number of new users stabilised at a new high of just under 1,700.



Notes

1. The insulin pump consumable subsidy began in September (Quarter 3) 2004.
2. The insulin pump subsidy began in November (Quarter 4) 2008.

Source: AIHW analysis of NDSS data.

Figure 2.1: Number of people purchasing insulin pump consumables from the National Diabetes Services Scheme for the first time, Australia, 2004–2010

The same data as used in the chart above is presented in Table 2.1, which shows the number of new users per quarter. From quarter 3 of 2004, when IPCs were first subsidised, there was a sharp increase in the number of people first purchasing insulin pump consumables. Quarters 3 and 4 combined showed over 1,000 new users compared with 145 for quarters 1 and 2 in 2004. After this, the rate of pump uptake steadied at an average of 316 new pump users each quarter until the introduction of the insulin pump subsidy in late 2008. At this point, the number of new users increased to an average of just over 400 per quarter.

Table 2.1: Number of people purchasing insulin pump consumables from the National Diabetes Services Scheme for the first time, annually by quarter, Australia, 1 January 2004–30 June 2011

	2004	2005	2006	2007	2008	2009	2010	2011
Quarter1	100	301	288	280	355	432	412	353
Quarter 2	45	294	304	326	392	445	434	370
Quarter 3	552[(a)]	287	269	322	397	426	451	. .
Quarter 4	590	273	305	347	411[(b)]	366	383	. .
Annual	**1,287**	**1,155**	**1,166**	**1,275**	**1,555**	**1,669**	**1,680**	. .

(a) The insulin pump consumable subsidy began in September (Quarter 3) 2004.

(b) The insulin pump subsidy began in November (Quarter 4) 2008.

Source: AIHW analysis of NDSS data.

Trends in time from diagnosis to commencement of insulin pump therapy

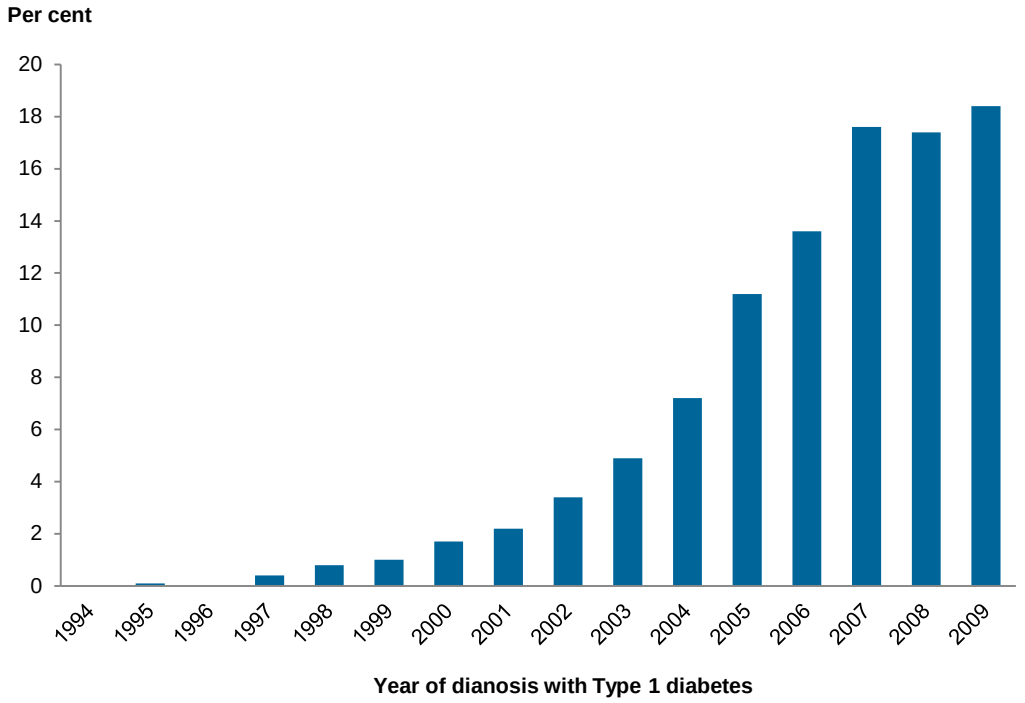
Insulin pump therapy is a relatively recent treatment in the management of diabetes, with early versions of the pump first released in the 1970s, and therefore people who were diagnosed with Type 1 diabetes before the use of insulin pumps became common had less opportunity to commence pump use early in their diabetes treatment than those who were diagnosed more recently. This needs to be considered when analysing the time taken from diagnosis of Type 1 diabetes to commencement of insulin pump therapy.

For the above reason, the analysis of commencement time of CSII therapy from diagnosis of Type 1 diabetes was conducted for those people who were diagnosed from 1994 onwards, after the results from the *Diabetes Control and Complications Trial* led to an increase in pump use (Sherr & Tamborlane 2008).

Of the survey respondents diagnosed from 1994 onwards, the more recently they were diagnosed with Type 1 diabetes, the higher the likelihood they started insulin pump therapy within 2 years of diagnosis. For those diagnosed between 1994 and 1997, less than 1% commenced using insulin pumps in the first 2 years after diagnosis (Figure 2.2). In 2004, over 7% of people diagnosed in that year commenced insulin pump use within 2 years. By 2009, the proportion of people commencing pump use within 2 years exceeded 18%, suggesting that pumps became more accessible and acceptable to people with Type 1 diabetes.

The reduction in the time for pump uptake after diagnosis was evident in both children and adults.

This increase in accessibility is likely to be due in part to the introduction of the insulin pump consumables subsidy via the NDSS in 2004—it is after this that the rate of uptake within 2 years of diagnosis exceeds 10%. Until a full year of data become available for 2011, it is not possible to tell if the insulin pump subsidy introduced in late 2008 has had any impact.



Notes

1. Based on n = 1,095.
2. The proportion of people diagnosed in 2009 and commencing insulin pump therapy may increase in future because the pump user data for 2011 was collected in October/November and may not have captured all new insulin pump users for the full year.

Source: AIHW Insulin Pump User Survey.

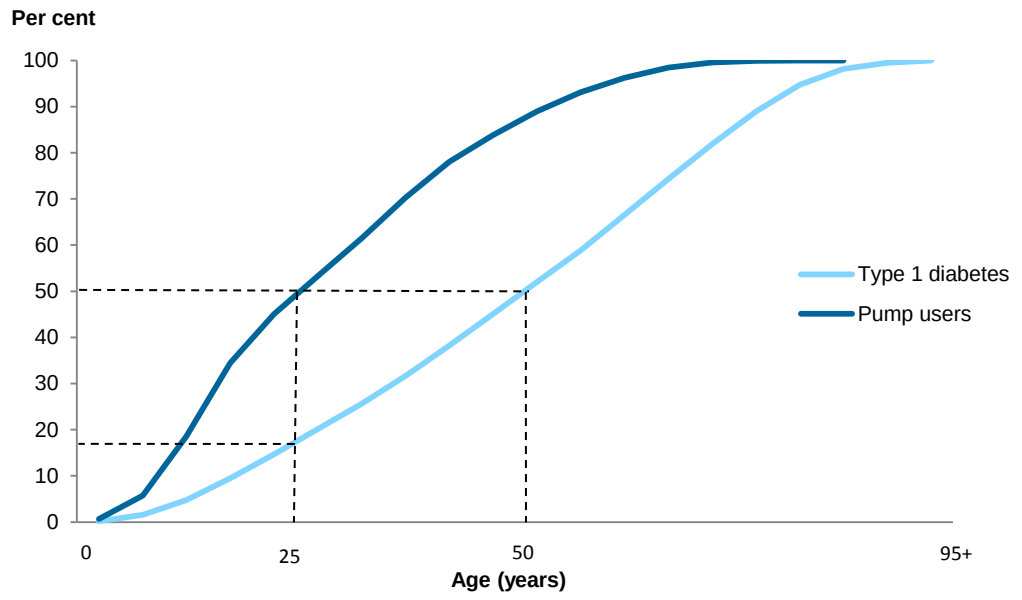
Figure 2.2: Proportion of people diagnosed with Type 1 diabetes commencing insulin pump therapy within 2 years of diagnosis by year of diagnosis, Australia, 2011

Characteristics of insulin pump users

Age and sex

Females (61%) comprised a higher proportion of the 10,510 insulin pump users than males (39%). This contrasts with all people with Type 1 diabetes, where there were more males than females (55% and 45%, respectively). This difference is highlighted further by the fact that 12% of females with Type 1 diabetes used an insulin pump compared with 7% of males.

Insulin pump users had a younger age profile than all people with Type 1 diabetes. The median age of pump users was 27, compared with 55 for all those with Type 1 diabetes. Another way of looking at this is to consider that around one in every two pump users, and fewer than one in five people with Type 1 diabetes, were under the age of 25 (Figure 2.3).



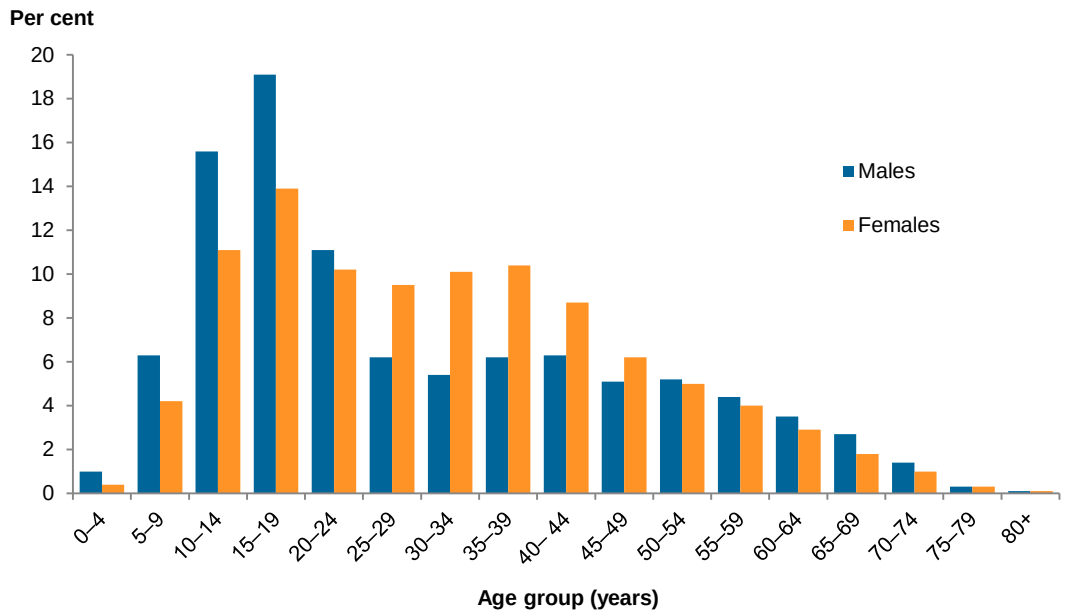
Source: AIHW analysis of NDSS data.

Figure 2.3: Cumulative proportion of people with Type 1 diabetes by age and whether an insulin pump user, Australia, 1 January 2004–30 June 2011

There are a number of reasons that may account for this difference in the age structures of those with Type 1 diabetes compared with pump users. For example, the current insulin pump subsidy program is aimed at children (see 'Paying for an insulin pump and consumables' in Chapter 1), making this a more affordable option for those aged under 18 than for adults. Another reason may be related to the fact that older people who were diagnosed with Type 1 diabetes before the availability of insulin pumps are managing their diabetes successfully and therefore have less motivation to change. For young newly diagnosed people with Type 1 diabetes, an insulin pump offers many benefits, including the potential to prevent long-term health complications.

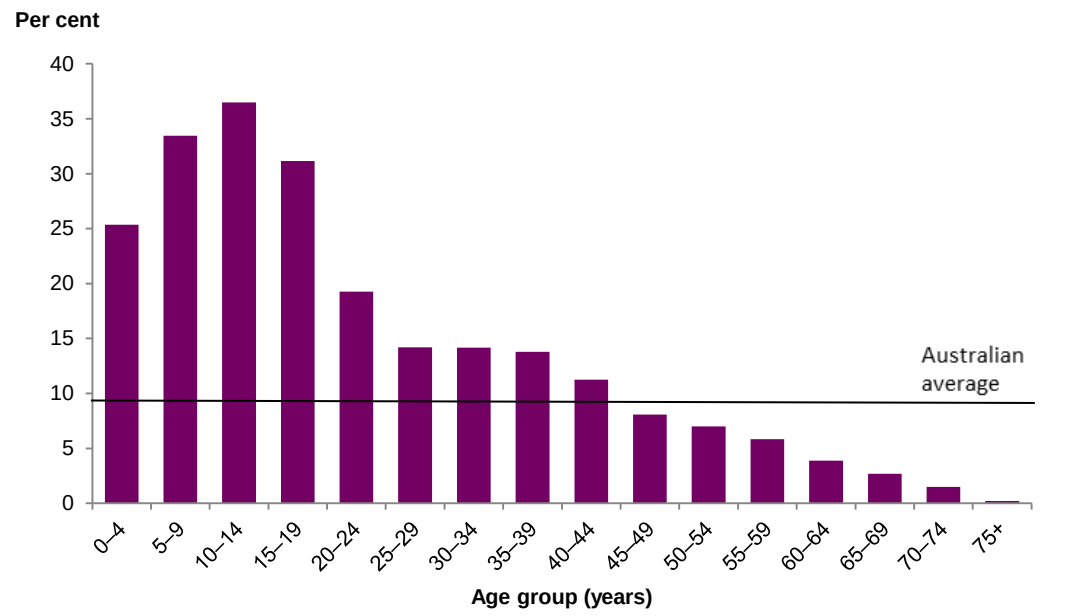
Among all insulin pump users, male users were younger on average than females—the median age of males was 23 and for females it was 30. The higher median age for females can be explained by the fact that there were a higher proportion of females to males in the adult years, between ages 25 and 50, compared with younger age groups (Figure 2.4). This may be due to the fact that women with Type 1 diabetes who are planning a pregnancy are advised to achieve and maintain optimal glycaemic control before conception (Craig et al. 2011) and therefore initiate CSII therapy to assist with this. In the Insulin Pump User Survey, 13% of women had begun insulin pump therapy for pregnancy reasons.

The rates of insulin pump use for people with Type 1 diabetes was highest in the 10–14 age group and then declined for each subsequent age group. On average, almost one-third of people with Type 1 diabetes aged under 20 used a pump, while from age 20 onwards the proportion of people using an insulin pump decreased from 19% to less than 1% for those 75 and over (Figure 2.5).



Source: AIHW analysis of NDSS data.

Figure 2.4: Proportion of insulin pump users by age and sex, Australia, 1 January 2004–30 June 2011



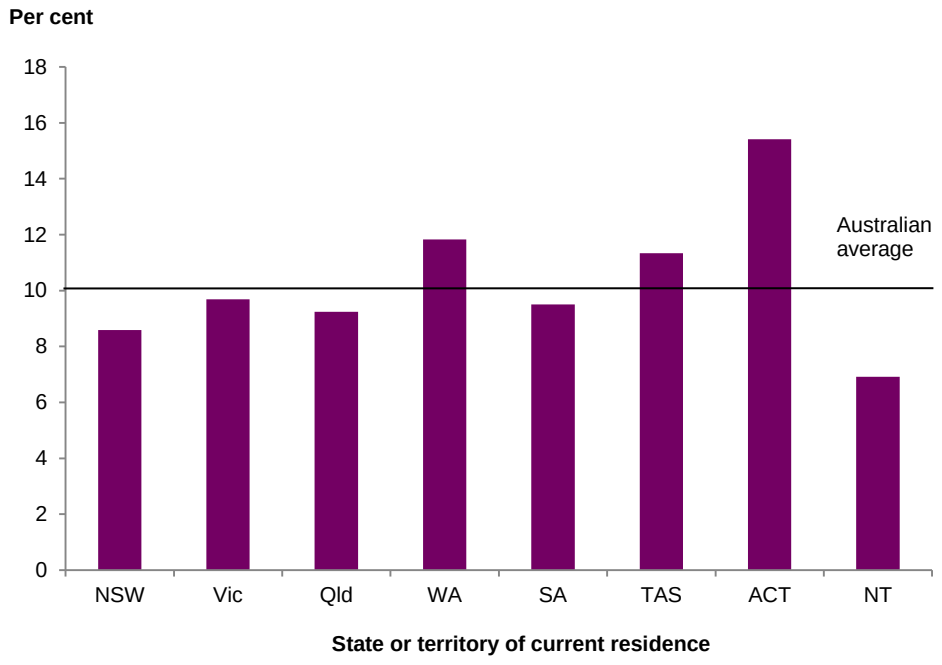
Source: AIHW analysis of NDSS data.

Figure 2.5: Proportion of people with Type 1 diabetes using an insulin pump by age, Australia, 1 January 2004–30 June 2011

State and territory

New South Wales had the highest number of people using an insulin pump, with 32% of all insulin pump users. Twenty-five per cent of pump users lived in Victoria and 17% in Queensland. These were followed by Western Australia (12%), South Australia (8%), Tasmania (3%), Australian Capital Territory (2.5%) and the Northern Territory (0.5%).

When comparing the distribution of insulin pump users to all people with Type 1 diabetes across jurisdictions, it was evident that pump users were more represented in some states and territories than others. The Australian Capital Territory (15%), Western Australia (12%) and Tasmania (11%) had a higher proportion of people with Type 1 diabetes who were pump users than the national average of 10% (Figure 2.6). In contrast, the Northern Territory had the lowest proportion, with 7% of people with Type 1 diabetes using insulin pumps. The proportions for New South Wales, Victoria, Queensland and South Australia were relatively close to the national average.



Source: AIHW analysis of NDSS data.

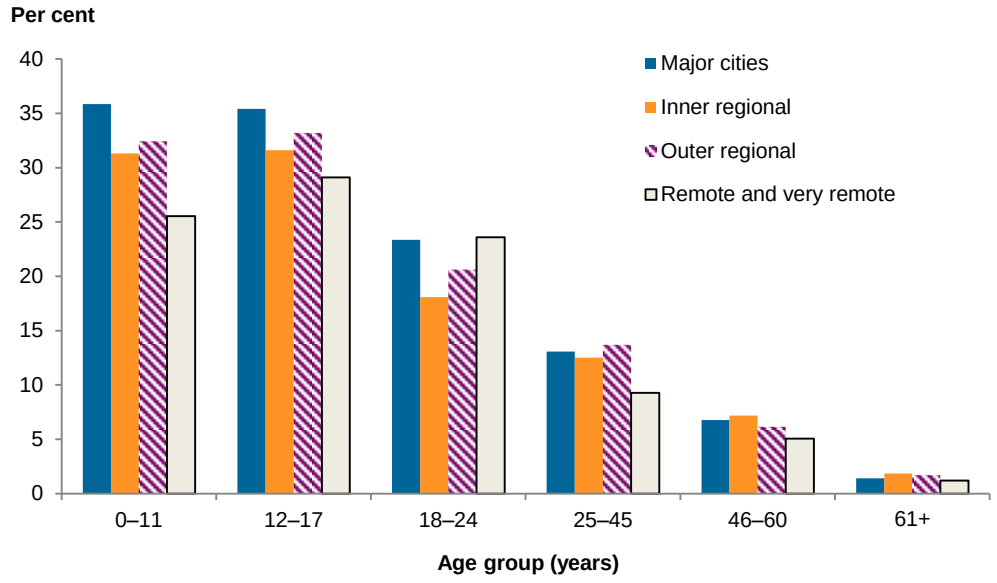
Figure 2.6: Proportion of people with Type 1 diabetes using an insulin pump by state or territory of current residence, Australia, 1 January 2004–30 June 2011

The much higher proportion of insulin pump users in the Australian Capital Territory (ACT) compared with other jurisdictions is possibly related to the socioeconomic status of the ACT population. The ACT has a higher average income, a larger proportion of people with higher education levels and a greater proportion of the population covered by private health insurance. For instance, more than half (56%) of people in the ACT have private health insurance, compared with an average of 45% for the rest of Australia (Private Health Insurance Administration Council 2012).

Remoteness

Seventy per cent of pump users were located in *Major cities*, a further 21% in *Inner regional* areas, 9% in *Outer regional* and just over 1% in *Remote and very remote* areas.

Major cities, *Inner regional* and *Outer regional* areas had similar proportions of insulin pump users to all Australians with Type 1 diabetes—around 10%. In *Remote and very remote* areas, 8% of people with Type 1 diabetes used pumps, possibly reflecting the added difficulty that people in remote areas face in finding qualified health professionals who are able to initiate and support CSII therapy (Diabetes Australia 2010). In Australia, this service is predominantly available in diabetes clinics in major metropolitan teaching hospitals (Victorian CSII Working Party 2009), although private (community) credentialled diabetes educators and a number of smaller regional hospitals do also provide pump therapy services.



(a) Remoteness was derived using the ABS ASGC.

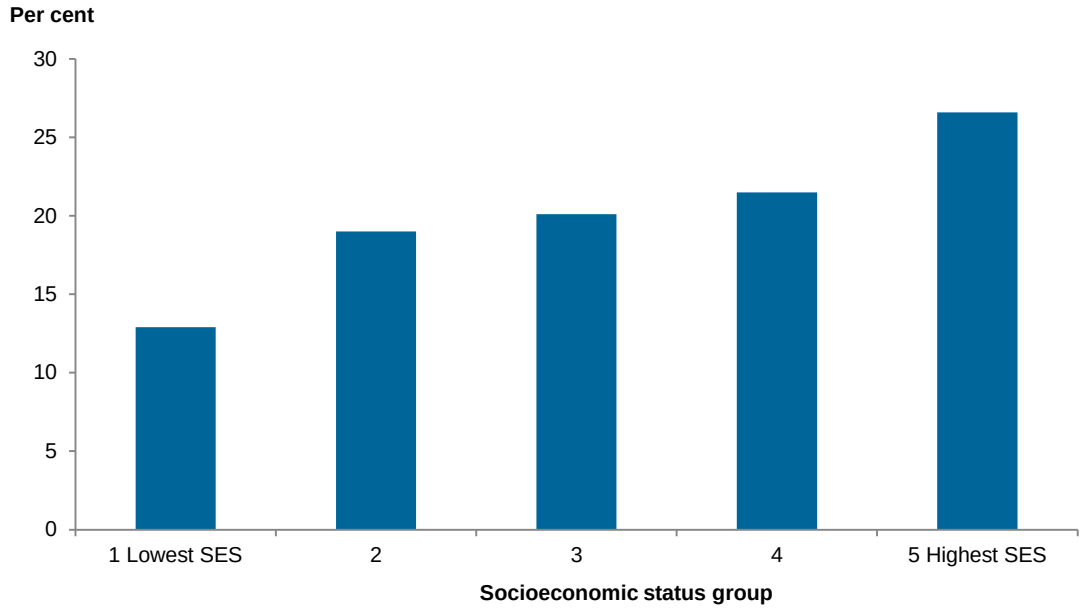
Source: AIHW analysis of NDSS data.

Figure 2.7: Proportion of people with Type 1 diabetes using an insulin pump by age group and remoteness[(a)], Australia, 1 January 2004–30 June 2011

The relationship between pump use and remoteness was also analysed by age group to account for the fact that regional locations have a higher proportion of older people than metropolitan areas. Because insulin pump use is more prevalent in younger people, the relationship between usage and region may have been influenced by this age structure. Figure 2.7 shows that once age is accounted for, there is less variation in the proportion of adult pump users for people with Type 1 diabetes by remoteness, but that this relationship remains evident in the under 18s, and to a lesser extent for those aged 25 to 45.

Socioeconomic status

Socioeconomic status (SES) was strongly associated with being an insulin pump user: as socioeconomic status increased from the lowest to the highest SES group, so did the proportion of insulin pump users within these groups. For example, 13% of insulin pump users lived in the lowest socioeconomic status areas (most disadvantaged) and 27% lived in areas classified into the highest SES group (least disadvantaged) (Figure 2.8).



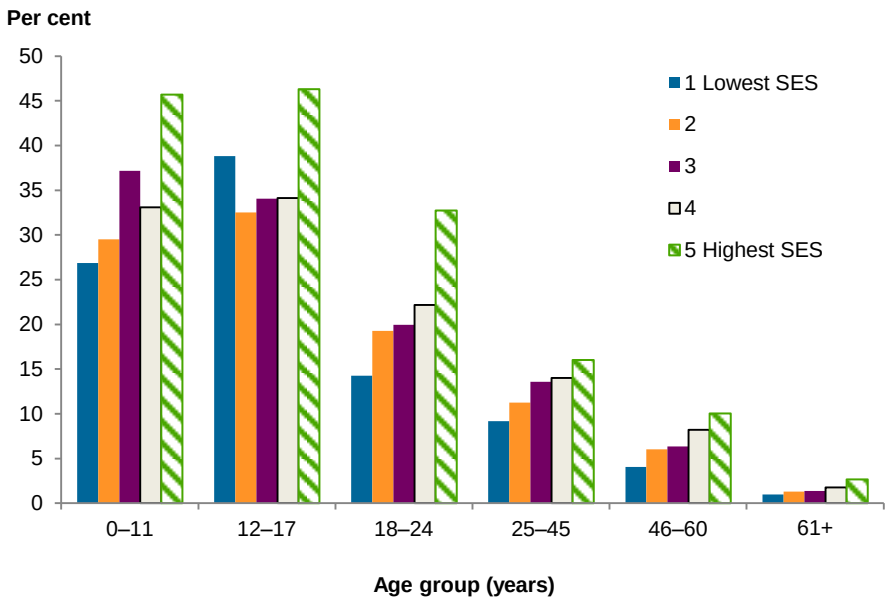
(a) Socioeconomic status was derived using the ABS IRSD.

Source: AIHW analysis of NDSS data.

Figure 2.8: Proportion of insulin pump users by socioeconomic status[(a)], Australia, 1 January 2004–30 June 2011

Of people with Type 1 diabetes, there were higher proportions of pump users in areas of high SES compared with low SES areas—14% of people with Type 1 diabetes in the highest SES group used a pump, compared with 6% of those in the lowest group.

Further analysis of this information by age showed that this relationship did not hold for all age groups (Figure 2.9). For adults, the proportion of pump users increased with SES—higher proportions of people with Type 1 diabetes used pumps as disadvantage reduced. However, in children and young people there was more variation, which may have been due to the availability of subsidies or other assistance, such as the loaning of pumps, for those living in areas of higher disadvantage. For example, for 12–17 year olds, the highest proportion of insulin pump users were in the highest SES group (46%) followed by the lowest SES group (39%).



(a) Socioeconomic status was derived using the ABS IRSD.

Source: AIHW analysis of NDSS data.

Figure 2.9: Proportion of people with Type 1 diabetes using an insulin pump by age group and socioeconomic status[(a)], Australia, 1 January 2004–30 June 2011

3 Experiences of insulin pump users

Key points

- The majority (89%) of insulin pump users received financial assistance for the purchase of their pump, with almost all of these obtaining a private health insurance rebate.
- The largest motivating factor for choosing to use a pump was better control of diabetes (88%); this was followed by lifestyle reasons (67%) and the prevention of long-term health complications (66%).
- For most insulin pump users, the benefits of continuous subcutaneous insulin infusion therapy outweighed any problems they had.
- The fact that insulin pump therapy fitted in with the lifestyle of the user was the most frequently cited benefit, with 86% of survey respondents indicating this.
- The most commonly cited problem (32%) was that insulin pump consumables were too expensive.
- Twenty-three per cent of survey respondents attended an emergency department or were admitted to hospital for diabetes management while using a pump, with women and those under 25 years more likely to be admitted.
- Twenty-three per cent of survey respondents had taken at least one temporary break from using their insulin pump.
- In spite of recommendations for contact with a diabetes health professional every 3–6 months, 10% of insulin pump users had not had contact with a professional in over 6 months.
- People living in *Major cities* were more likely to have had recent contact with a healthcare professional about their diabetes than those in other areas.
- Five per cent of survey respondents were not currently using an insulin pump and 42% of these had no intention of recommencing pump use.

This chapter examines the experiences of insulin pump users based on the responses to the Insulin Pump User Survey conducted by the AIHW in October–November 2011. Further information about the survey can be found in 'Appendix A: Survey methodology', the survey instrument at 'Appendix B: Insulin Pump User Survey' and the data quality statement at 'Appendix E: Data Quality Statement'

The survey achieved a 59% response rate and because these respondents were representative of all pump users registered on the NDSS on most demographic variables, the findings based on the survey responses can be generalised broadly to all pump users in Australia. The characteristics of the survey respondents were similar to the registrants on the NDSS regarding sex, state or territory of current residence and remoteness. It should be noted, however, that some age groups were not as well represented as others and this should be considered when interpreting results that are not presented by age. In comparison with all pump users, younger and older age groups were over-represented, while those between the ages of about 15–40 were under-represented by the survey data, especially those aged 15–29. For more detailed information about the survey representativeness see 'Appendix A: Survey methodology' and 'Appendix E: Data Quality Statement'.

Of the 5,860 respondents to the survey, 37% were male and 63% female, which are similar proportions to all pump users registered on the NDSS where 39% were male and 61% female. In the survey, the median age of males was 23 and for females it was 32; for all pump users on the NDSS, the median ages were 23 and 30, respectively.

Almost all respondents (95%) indicated they were currently using an insulin pump. Three per cent were taking a temporary break and another 2% were not currently using a pump and had no intention of doing so in the future. Females were slightly more likely than males to be having a temporary break, and teenagers and adults were more likely to be having a temporary break than the very young or older pump users. Respondents aged over 60 were more likely than all others to have permanently stopped using their insulin pump, with 5% of those over 60 no longer using a pump and having no intention of doing so in the future, compared with 2% of all those aged 60 or under.

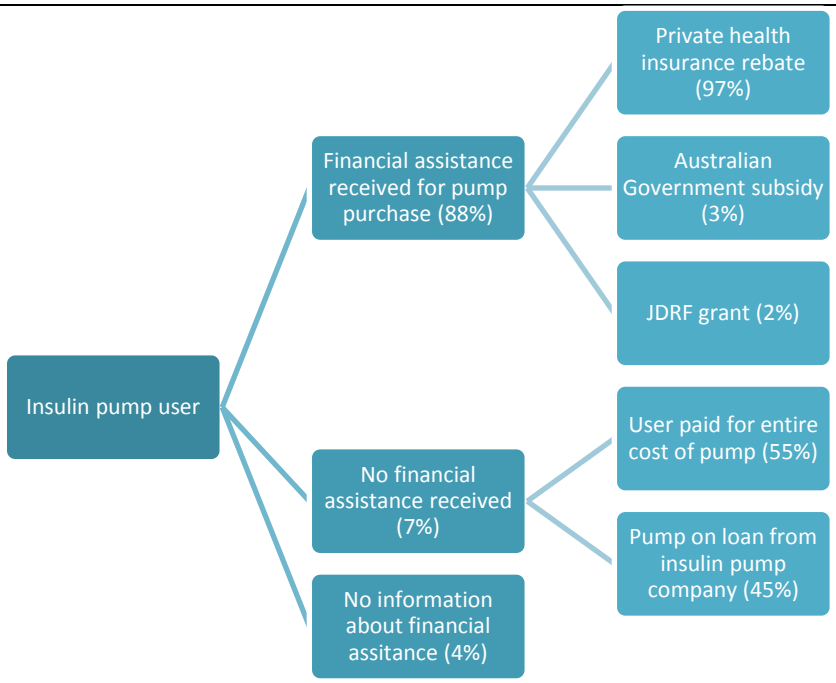
It should be noted that people not currently using an insulin pump, but who had used one in the past and were still registered on the NDSS may be under-represented in the survey due to possible misunderstanding of the purpose of the survey questionnaire itself. Feedback from a few participants indicated they did not think the survey was applicable to them as they were not currently using a pump—it is not possible to determine how many other participants in similar circumstances did not return the survey form at all.

Funding the purchase of insulin pumps

Insulin pumps cost between $4,000 to $9,000 each (Juvenile Diabetes Research Foundation 2011b). There are a number of ways of funding this expense and most respondents to the survey indicated they received some kind of financial assistance to help them purchase their current (or last, for those not currently using a pump) insulin pump, with 88% indicating this to be the case. Another 7% received no financial assistance, paying for the entire cost of the insulin pump themselves or using a pump that had been loaned to them. The remaining 4% were either not sure about the funding arrangements or it was not possible to determine from their response whether they received funding or not.

Of the 4,977 insulin pump users who received funding, the majority (97%) received a rebate through private health insurance, 3% indicated they received a Commonwealth Government subsidy and 2% a JDRF grant (Figure 3.1). Approximately half (55%) of those who did not receive any subsidy paid the full cost of the pump and the other half (45%) had a pump on loan from a pump company.

National data from the Hospital Casemix Protocol, which provides information on all procedures conducted in Australian hospitals for privately insured patients, showed that in 2010 there were 1,319 hospital separations for patients being fitted with an insulin pump. This equated to almost 80% of all new pump users who purchased IPCs for the first time through the NDSS in 2010 (1,690). The survey confirmed this estimate, with 4,817 of all 5,860 respondents indicating they received a private health insurance rebate, which is 82%.



Notes

1. Whether financial assistance was received does not total to 100 due to rounding.
2. The types of financial assistance received totals more than 100% because some survey respondents indicated more than one type.

Source: AIHW Insulin Pump User Survey.

Figure 3.1: Funding the purchase of insulin pumps, Australia, 2011

Reasons for choosing an insulin pump

When asked to indicate why they first chose to use an insulin pump, 88% of survey respondents said that it was to gain better control of their diabetes. The second most frequently cited reason was for lifestyle reasons, such as flexibility with meal times, food quantities or to be able to sleep in—67% of respondents gave this as a reason for first choosing to use an insulin pump. The prevention of long-term health complications (66%) and recommendation by a specialist diabetes doctor or diabetes educator (60%) were also important factors (Table 3.1). These results reflect the findings from a previous study that concluded that the most frequently cited reasons for commencing insulin pump therapy were improved blood glucose control, increased flexibility in lifestyle and a reduction in overnight hypoglycaemia (Smart et al. 2008).

Control of diabetes was the most commonly cited reason by both males and females for choosing to use an insulin pump—89% and 88%, respectively. Males considered the prevention of long-term health conditions (70%) and lifestyle issues (69%) to be the next most important reasons. This contrasted with females who rated lifestyle (66%) as a more influential reason than the long-term health preventions that a pump might offer (64%). Sixty-two per cent of males compared with 58% of females initiated CSII because it was recommended to them by a doctor or diabetes educator. Of female respondents aged 16 years and over, 13% indicated they chose to use an insulin pump because of pregnancy.

The main reasons respondents gave for first choosing to use an insulin pump also varied with age (Table 3.1). Better control of diabetes was more frequently a reason for choosing an insulin pump by younger and older age groups, with it being less of a reason for teenagers and young adults. Preventing long-term health complications was important for those under 12 years old, with 72% giving this as one of the reasons for choosing an insulin pump, while 59% of 18–24 year olds considered this to play a part in their decision making. Those aged over 45 years were more likely to choose a pump to improve awareness of low blood glucose levels. For example, 35% of those aged over 60 selected this reason compared with 16% of 18–24 year olds. Lifestyle reasons were more important to young people and children and less important to those over 60, while this latter age group were most likely to have been recommended the pump by a doctor or diabetes educator—in 76% of cases.

Table 3.1: Insulin pump users indicating factor as a reason for first choosing to use an insulin pump by age, Australia, 2011

	0–11 years	12–17 years	18–24 years	25–45 years	46–60 years	61+ years	Total
				Number			
To better control my diabetes**	683	890	575	1,509	890	434	**4,981**
To prevent long-term health complications**	544	652	396	1,163	679	310	**3,744**
To improve awareness of low blood sugar events**	173	182	106	326	300	168	**1,255**
For lifestyle reasons**	563	808	528	1,083	579	228	**3,789**
Recommended by doctor or diabetes educator**	442	592	419	910	637	368	**3,368**
				Per cent			
To better control my diabetes**	90.1	85.3	86.1	88.0	89.6	89.7	**88.0**
To prevent long-term health complications**	71.8	62.5	59.3	67.9	68.4	64.1	**66.1**
To improve awareness of low blood sugar events**	22.8	17.4	15.9	19.0	30.2	34.7	**22.2**
For lifestyle reasons**	74.3	77.4	79.0	63.2	58.3	47.1	**66.9**
Recommended by doctor or diabetes educator**	58.3	56.7	62.7	53.1	64.2	76.0	**59.5**

Notes

1. **p < 0.01 for the chi-square test of significance for differences between age groups.
2. The response 'Due to pregnancy' as a reason for first choosing to use an insulin pump was not analysed for variation with age.

Source: AIHW analysis of Insulin Pump User Survey.

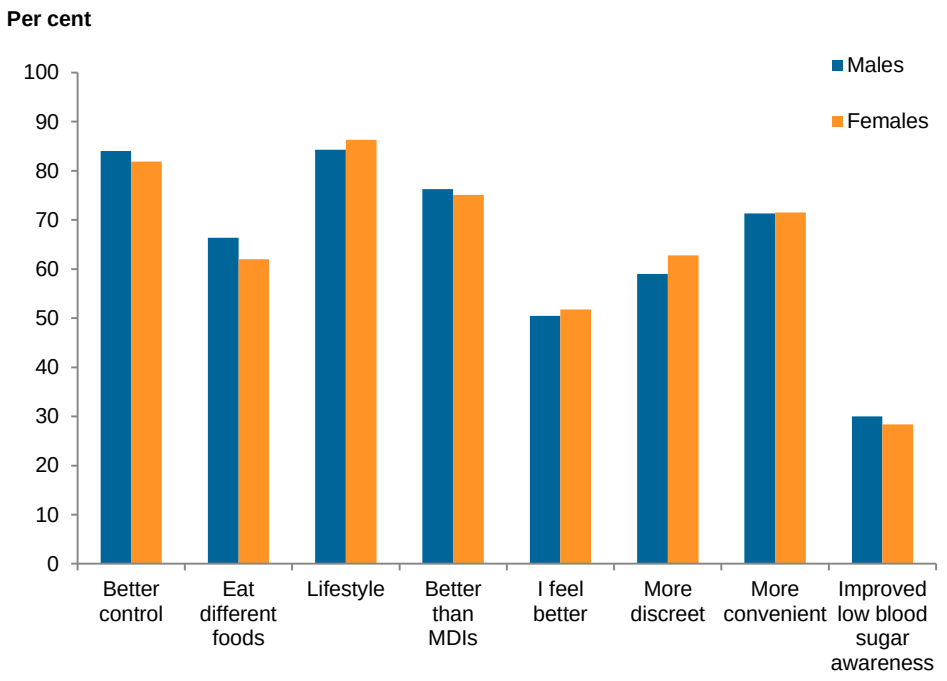
An additional major reason given for initiating insulin pump therapy was difficulties with managing diabetes with injections—either due to a dislike or phobia of needles, their perceived inconvenience or a desire to reduce the number of injections per day. Other reasons for initiating pump therapy included knowing someone who was already using a pump, or being recommended to use one by another user. For young people, it was often parents who were encouraging CSII therapy or making the choice on behalf of their children.

One respondent stated that 'Mum wanted me to try' and another said the reason was to 'enjoy childhood—my parent's choice and decision'.

Other respondents chose to use an insulin pump due to the greater acceptance of pumps in schools and the difficulties with using needles in this environment. Other reasons included increased flexibility with work, travel and particularly with exercise; with one person explaining that it was 'easier to modify insulin dosage when doing physical activity'. Management of other health conditions such as coeliac disease and cystic fibrosis and to assist in achieving good glycaemic control in preparation for pregnancy were also cited reasons for choosing CSII.

Benefits of using an insulin pump

Most people on CSII therapy considered the benefits to be numerous, with an average of five (out of eight) benefits identified by survey respondents. The main benefit of the insulin pump, selected by 86% of respondents, was that it fitted in with their lifestyle. The other important benefits were the achievement of better diabetes control (83%), that relocating a cannula was better than having several daily injections (76%) and that it was convenient (71%). Twenty-nine per cent of respondents considered that they had benefited through a greater awareness of their low blood sugar levels.



Note: Based on n = 5,860.

Source: AIHW Insulin Pump User Survey.

Figure 3.2: Factors indicated by insulin pump users as a benefit of using a pump by sex, Australia, 2011

Males and females highlighted similar benefits of using an insulin pump. However, improved diabetes control and being able to eat different types of foods were benefits selected slightly more frequently by males than females (Figure 3.2). Females, on the other hand, rated the fact that the insulin pump fitted into their lifestyle and that it was more discreet than administering injections in public slightly more highly than males.

Table 3.2: Factors indicated by insulin pump users as a benefit of using a pump by age, Australia, 2011

	0–11 years	12–17 years	18–24 years	25–45 years	46–60 years	61+ years	Total
				Number			
Better control of my diabetes**	635	793	524	1,467	848	412	**4,679**
Being able to eat different types of food**	586	791	502	974	497	254	**3,604**
Fits in with lifestyle**	671	948	605	1,476	814	332	**4,846**
Relocating the cannula/tubing every few days is better than several injections each day**	632	846	503	1,227	710	362	**4,280**
I feel better**	366	472	315	925	552	276	**2,906**
More discreet when administering insulin in public**	412	675	438	1,026	625	301	**3,477**
More convenient**	540	789	515	1,180	684	340	**4,048**
Low blood sugar awareness has improved**	218	241	139	480	361	204	**1,643**
				Per cent			
Better control of my diabetes**	83.8	76.0	78.4	85.6	85.4	85.1	**82.7**
Being able to eat different types of food**	77.3	75.8	75.2	56.8	50.1	52.5	**63.7**
Fits in with lifestyle**	88.5	90.8	90.6	86.1	82.0	68.8	**85.6**
Relocating the cannula/tubing every few days is better than several injections each day**	83.4	81.0	75.3	71.6	71.5	74.8	**75.6**
I feel better**	48.3	45.2	47.2	54.0	55.6	57.0	**51.3**
More discreet when administering insulin in public**	54.4	64.7	65.6	59.9	62.9	62.2	**61.4**
More convenient**	71.2	75.6	77.1	68.8	68.9	70.3	**71.5**
Low blood sugar awareness has improved**	28.8	23.1	20.8	28.0	36.4	42.2	**29.0**

Notes

1. **$p < 0.01$ for the chi-square test of significance for differences between age groups.
2. The response 'Due to pregnancy' as a reason for first choosing to use an insulin pump was not analysed for variation with age.

Source: AIHW analysis of Insulin Pump User Survey.

The perceived benefits of using an insulin pump varied with age, with many of the issues possibly being associated with priorities, lifestyles and attitudes related to different stages of

life. The benefit using an insulin pump played in controlling diabetes was less important for 12–24 year olds than for any other age group. However, this age group was more likely than others to highlight the benefits of the pump as fitting into their lifestyle, being discreet and being more convenient than injecting with pens or needles (Table 3.2). A study by Low et al. (2005) identified flexibility in terms of diet and meals, ease of insulin administration and glycaemic control as benefits of an insulin pump frequently mentioned by young people. But lifestyle benefits and the convenience of not having to carry syringes were the most important benefits with 78% describing these quality of life issues (Low et al. 2005).

Being able to eat different types of food was more often cited as a benefit for those aged under 25 and was less important for people over 45. Pump users aged over 45 rated the awareness of improvement in their blood sugar level higher than all those under 45, in particular this benefit was especially important for those 60 years and over.

Many respondents cited additional benefits such as ease during travel and exercise and 'being able to participate in physical activity for extended periods throughout the day'. Freedom from regulated meal times was a benefit to some, especially fussy eaters and adolescents who were able to '… go to parties and eat with other kids …'.

Respondents felt that their health improved while using an insulin pump, with weight loss, improvement of diabetes complications and improved night-time control of diabetes commonly cited benefits. A number of respondents noted that using an insulin pump allowed them greater control during pregnancy, resulting in 'healthy children due to well controlled diabetes during my pregnancy'.

A number of parents or carers who responded on behalf of their child found that insulin pumps were more acceptable to schools and childcare centres, making it 'easier for teachers to care for [name] while at school'. Parents and carers also cited psychological benefits, including behavioural improvements in children, better concentration, less mood swings and increased feelings of happiness and normality because 'being a child you like to be like your peers'. One respondent commented that 'at the time (6 years old) my son described it as though a cloud had come off his head. He was much more alert and he leapt ahead in his studies—so much more energy and he was so much more talkative'.

Sixty-seven survey respondents, or 1.2%, indicated they did not experience any benefits when using an insulin pump, but this may be an underestimate of the true number due to non-response of those not currently using an insulin pump, as stated in the introduction of this chapter. Most of these people (69%) were no longer using a pump and did not intend to use one again, another 16% were taking a temporary break and the remaining 15% were currently using a pump even though they did not consider there to be any benefits.

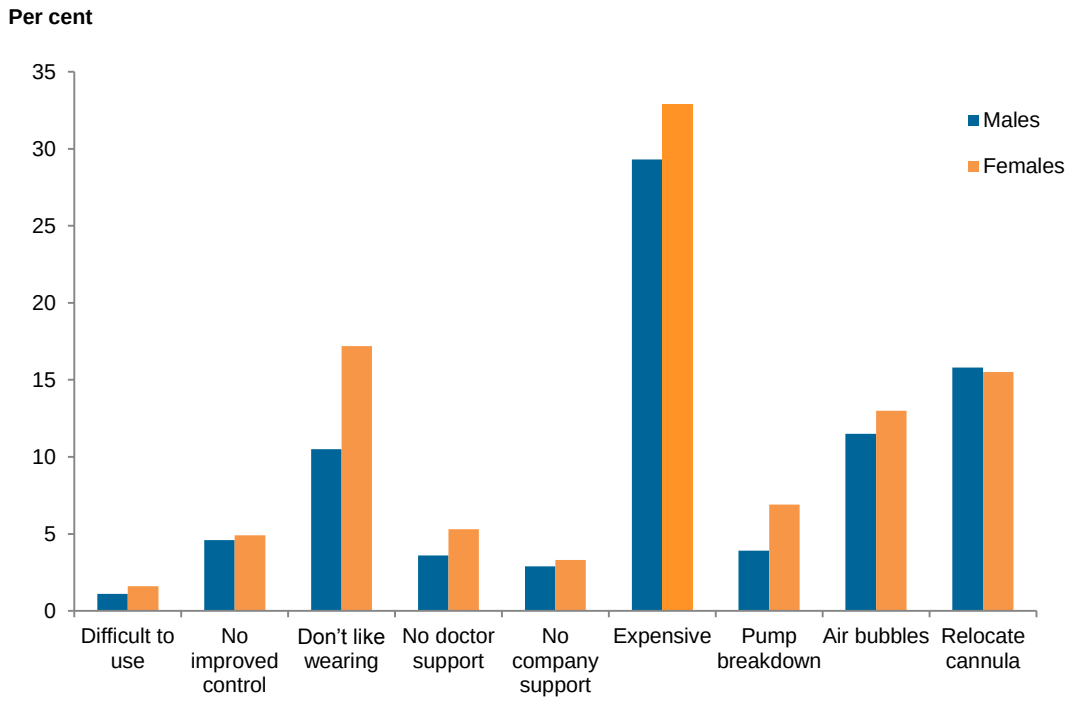
Problems using an insulin pump

On the whole, survey respondents did not consider they had many problems with their insulin pumps, with an average of one problem selected by each respondent. When compared with the average of five beneficial factors indicated by each respondent, this figure emphasises the level of satisfaction most insulin pump users have with CSII therapy.

One-third of respondents said they had no significant problems, with males more likely to indicate this than females—37% of males compared with 31% of females. Older respondents reported fewer significant problems than younger respondents, with 42% of those aged over 60 indicating they had no major problems, compared with 25% of 18–24 year olds.

The biggest issue for insulin pump users was the cost of IPCs, with 32% of respondents indicating that they were too expensive. Sixteen per cent had problems with relocating the cannula or tubing and 15% did not like wearing an insulin pump. Only 1% of respondents thought the insulin pump had been difficult to use, however 41% of these people were not currently using a pump, suggesting the problem may have had an impact on their decision to discontinue its use.

On some issues, females considered certain factors to be a bigger problem than males. Seventeen per cent of females disliked wearing the pump compared with 11% of males (Figure 3.3). Males and females also differed in their views about the expense of IPCs, with 33% of females considering this to be a problem, compared with 29% of males. Pump breakdown was considered a problem for 6% of respondents, with more females (7%) than males (4%) experiencing this.



Note: Based on n = 5,860.

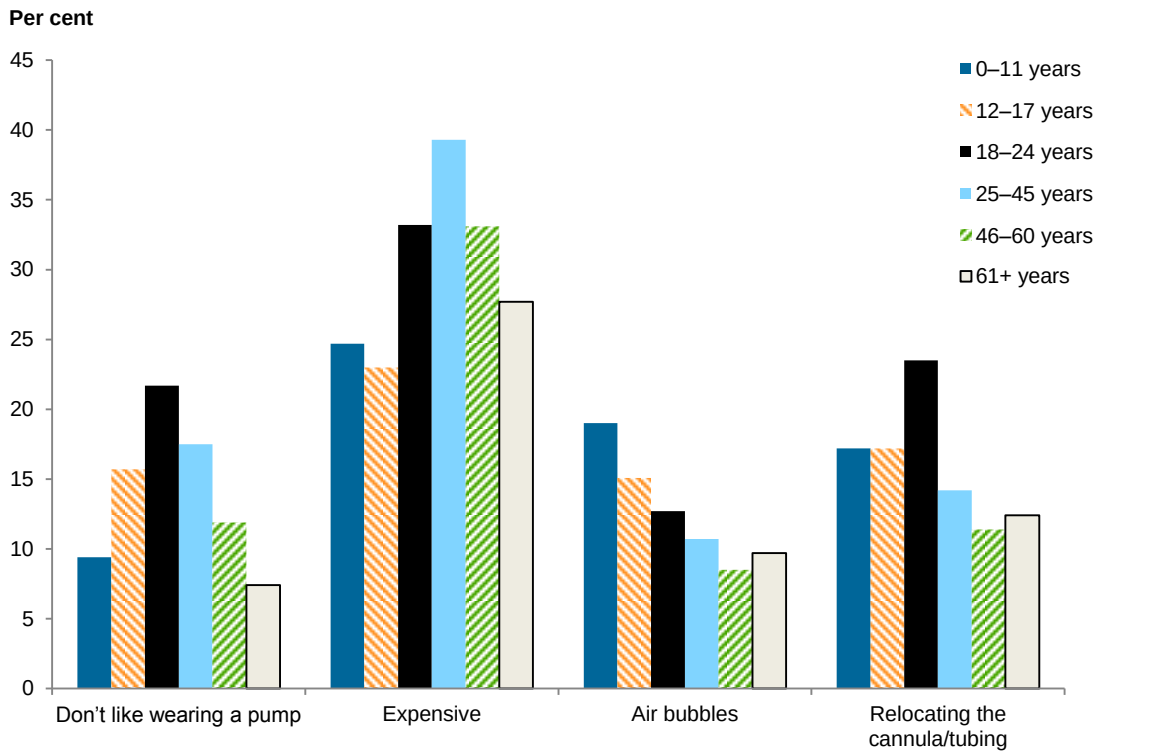
Source: AIHW Insulin Pump User Survey.

Figure 3.3: Factors indicated by insulin pump users as a problem of using a pump by sex, Australia, 2011

What was regarded as a problem with using an insulin pump varied with the age of the pump user. Although those over 60 were highly likely to indicate that diabetes control had been a benefit of pump use, this age group were also more likely than the other age groups to say that it had provided little or no improvement to diabetes control. Seven per cent of those aged over 60 indicated this to be a problem, compared with 3% of those under 12.

The biggest issue, that IPCs were too expensive, differed in frequency among age groups, with more 25–45 year olds considering it a problem than did other age groups (Figure 3.4). Almost two in every five respondents aged 25–45 considered cost to be an issue.

Respondents aged 18–24 years most disliked wearing a pump (22%), while this was a factor least important to the very young (9%) and older people (7%). This finding, along with the result above that a greater proportion of females than males disliked wearing a pump, supports the results of other research that concluded that some adolescents, particularly females, find insulin pumps inconvenient to wear due to perceived difficulties in concealing it under clothing, or in finding an appropriate part of clothing onto which to attach the pump (Low et al. 2005).



Note: Based on n = 5,860.

Source: AIHW Insulin Pump User Survey.

Figure 3.4: Factors indicated by insulin pump users as a problem of using a pump by age, selected factors, Australia, 2011

Problems with the pump breaking down were higher among teens and young adults than the very young and older adults. This was possibly due to the lifestyle of young people who were also most likely to have problems with relocating the cannula or tubing, as well as issues with air bubbles affecting their insulin delivery. One study, which investigated adherence to daily tasks required for pump use, found that where young people did not adhere to the routines the efficacy of the pump was diminished (O'Connell et al. 2011). It is possible that young people's dislike of wearing the pump and their more active lifestyle leads to more problems generally with using it and with breakdowns. However, not all breakdowns are necessarily caused by the user, with one study finding that the majority of

adolescent pump users had experienced malfunction and returned at least one pump to the manufacturer due to this (Low et al. 2005).

In the open-ended 'other' category, respondents indicated additional problems using their insulin pumps that were not covered in the survey. Other common problems experienced included the cannula not attaching correctly due to humidity and sweat, skin irritations and infections, and the cannula catching on items and being pulled out. As one respondent summed up, 'the insulin line catches on everything and pulls out the needle causing pain, bruising and bleeding'. Discomfort while sleeping was a very common problem experienced by respondents, with a small number noting that the insulin pump affected their sleep patterns. Respondents also found that wearing an insulin pump made choosing clothing, particularly dresses, difficult.

A small number of pump users also noted that using an insulin pump sometimes made them complacent about their diabetes management. One respondent stated that it 'makes you lazy with checking levels'.

Although the benefits of continuous blood glucose monitors were highlighted, their expense was seen as an issue. For example, one person stated that they could not 'afford sensors for CGMS' while another said 'CGMS is very beneficial but too expensive. It needs to be funded …'. A number of respondents also noted that being able to purchase IPCs only from the NDSS was inconvenient, suggesting that 'it would be better if pump consumables were available at the chemist'.

Attending hospital

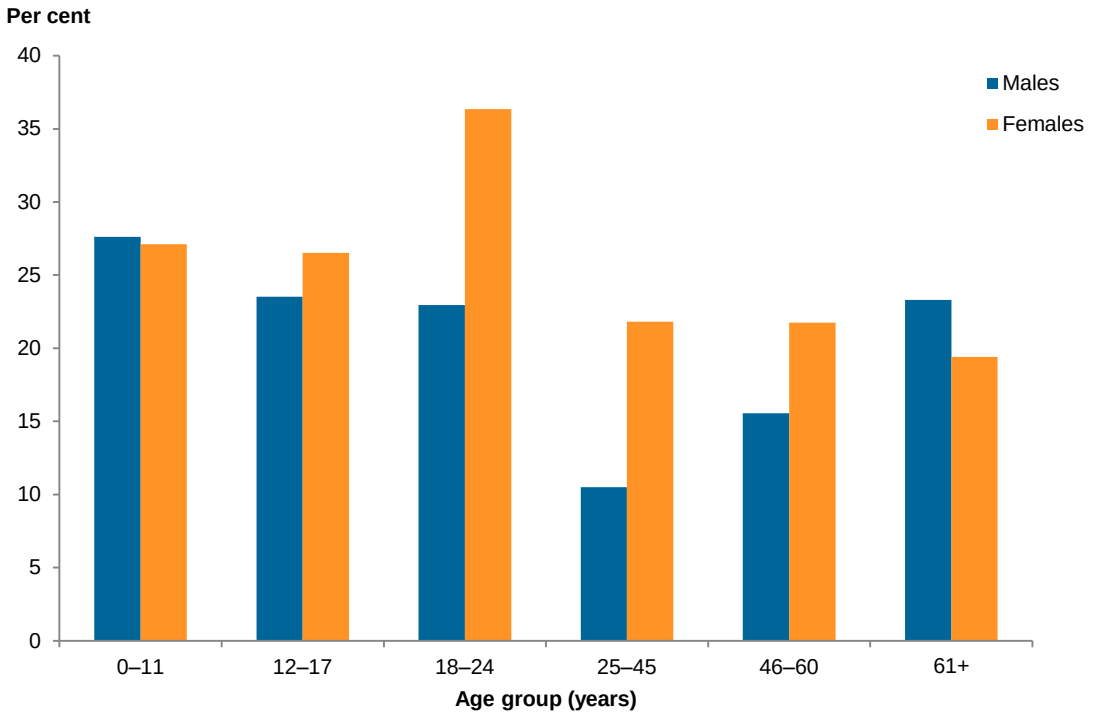
A study by Lynch et al. (2010) showed that the number of emergency department visits and inpatient hospital admissions decreased after using an insulin pump. Because the AIHW survey collected information only after people began using a pump, a change in pattern of hospital admissions could not be determined. However, the data do show the number of people who had to visit hospital specifically for diabetes management while using a pump and examines how that was related to a number of other variables, such as age, sex and general problems experienced with the pump.

The survey data showed that 23% of respondents attended an emergency department or were admitted to hospital for diabetes management. There was a significant difference between males (20%) and females (25%). Additionally, those aged under 25 were more likely to have had a hospital visit than those over 25. The survey showed that 31% of 18–24 year olds, 27% of 0–11 year olds and 25% of 12–17 year olds had attended hospital for diabetes management. As shown in Figure 3.5, the high rate for the 18–24 year olds was mainly attributable to females in this age group—36% compared with 23% of males.

Twenty-three per cent of those currently using their pump had been to hospital, while 28% of those who were not currently using (having a temporary break or permanently stopped using their insulin pump) had required a hospital visit. Those who had a hospital visit were more likely to indicate they had problems with their pump. For example, of those who had visited hospital, 22% had issues with relocating their cannula or tubing compared with 14% of those who had not visited hospital.

There appeared to be a relationship between the area in which a person lived and whether they had attended hospital, with a higher proportion of people in regional areas compared with those in metropolitan areas requiring a hospital visit. Twenty-two per cent of those in *Major cities*, 25% in *Inner regional* and 28% of those in *Outer regional* areas had visited an

emergency department or been admitted to hospital specifically for diabetes management while using a pump. Nineteen per cent of those in *Remote and very remote* areas visited hospital. However, because there were only a small number of pump users living in *Remote and very remote* regions (70 users or 1%) it is difficult to draw any firm conclusions about whether the data are unrepresentative or that people in remote areas actually have lower rates of hospital attendance, possibly because hospitals are not easily accessible.



Note: Based on n = 1,296.

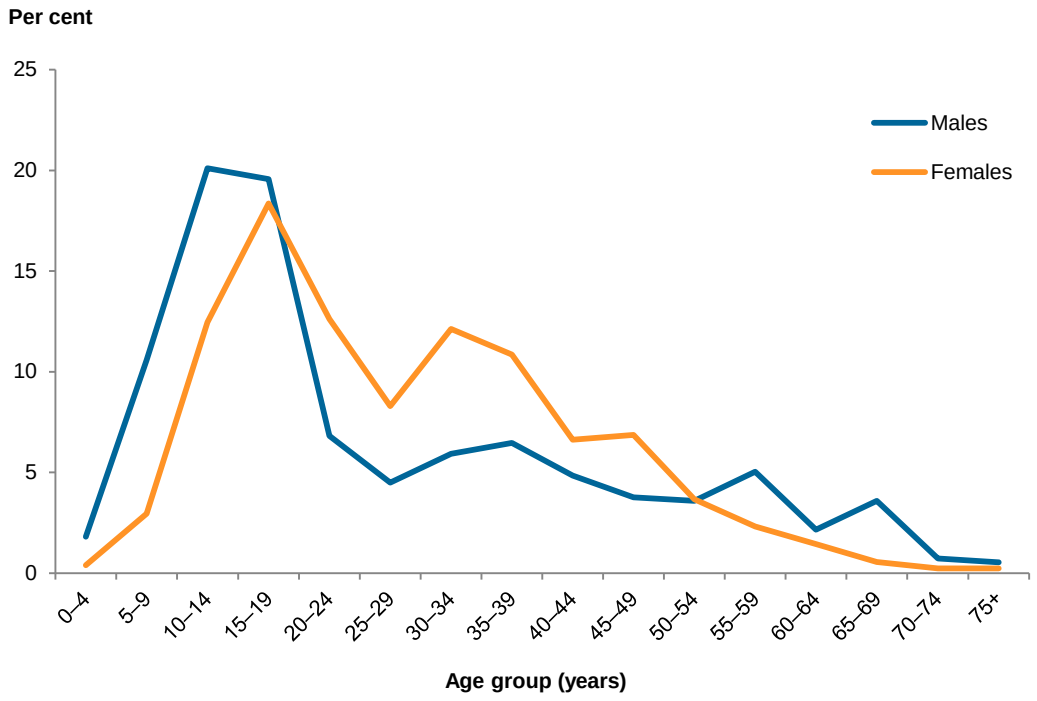
Source: AIHW Insulin Pump User Survey.

Figure 3.5: Proportion of insulin pump users attending hospital for diabetes management by age and sex, Australia, 2011

Taking a temporary break from using an insulin pump

The survey showed that taking a break, but returning to using a pump, was not uncommon, with 1,310 (23%) respondents having taken at least one break. The majority of these (64%) had taken one break only, 21% had had two breaks and 16% had taken three or more breaks from using their insulin pump. Females were more likely to have had a break than males, with 25% of females and 19% of males taking at least one break from using the pump.

Taking all breaks into consideration (excluding 88 people who took a break but did not provide details of when this was), the median age for taking a break was 24 years. Figure 3.6 shows that a higher percentage of breaks occurred around the teenage years. However, this should be interpreted in the context that most pump users are currently in the younger age groups and, as they age and possibly take further breaks from using their insulin pump, this distribution may change.



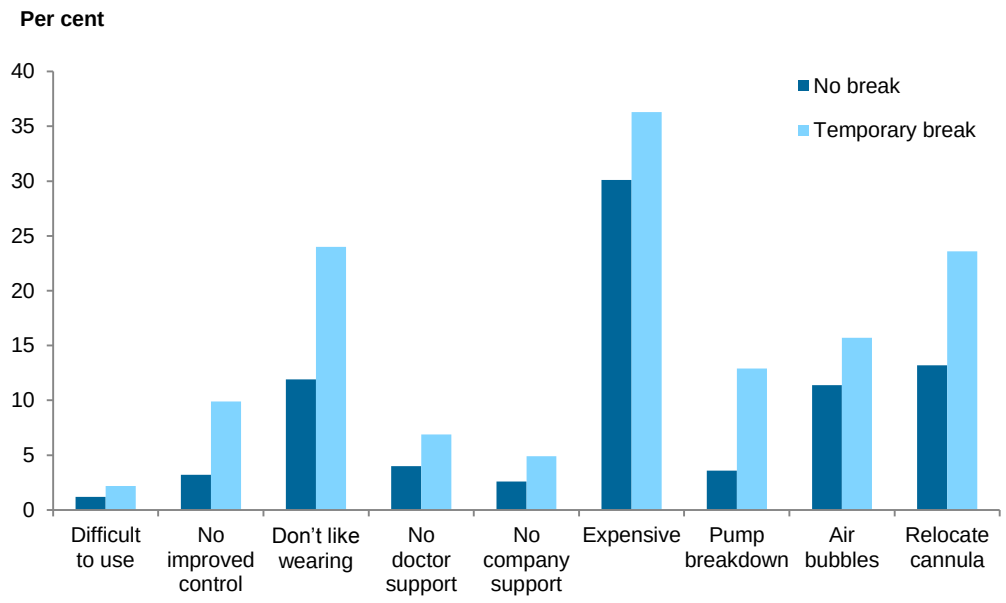
Note: Based on n = 1,816.

Source: AIHW Insulin Pump User Survey.

Figure 3.6: Distribution of age(s) at which insulin pump users took a temporary break from using an insulin pump by sex, Australia, 2011

Nineteen per cent of those who took a break from using their pump indicated that they had no significant problems with insulin pump therapy; this compares with 37% of those who did not take a temporary break. For all problems, there was a significant difference between those who had taken a break and those who had not had a break from using their insulin pump (Figure 3.7). For example, 24% of those who took a temporary break didn't like wearing an insulin pump, while 12% of those who didn't take a break felt this way.

The expense of consumables may have been a contributing factor for those that took a break from pump use—36% of those having a break believed consumables were too expensive compared with 30% of those who did not take a break. Pump breakdown may also have been a factor in the decision to take a break from pump use—of those taking a break, 13% had breakdown issues compared with 4% of those not taking a break. Additionally, relocating the cannula or tubing was cited as a problem for 24% of those taking a break and for 13% of those not taking a break.



Note: Based on n = 5,680.

Source: AIHW Insulin Pump User Survey.

Figure 3.7: Factors indicated by insulin pump users as a problem of using a pump by whether a temporary break had been taken, Australia, 2011

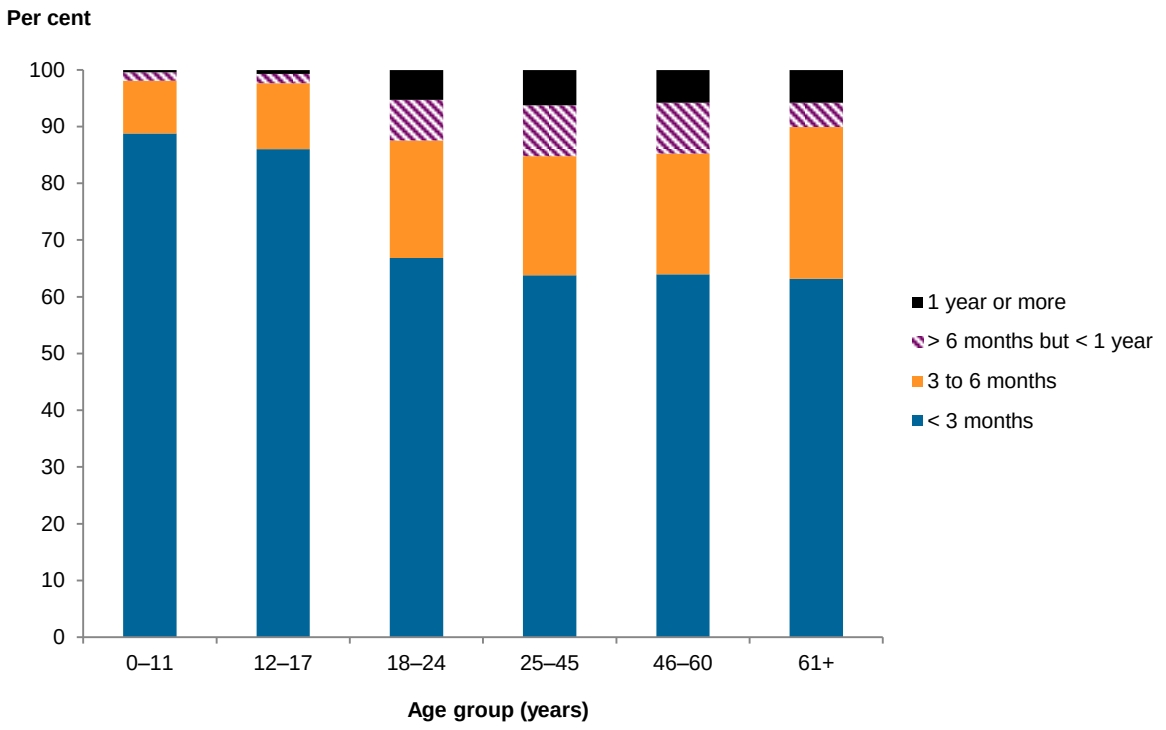
Time since last contact with diabetes health professional

Support from a professional is extremely important in the management of diabetes and close contact 'of patients and their families with the diabetes team has been associated with reduced hospital admissions, emergency room visits and improvement in glycaemic control' (Australian Healthcare Associates 2008). For this reason, insulin pump therapy is not recommended for people who are unwilling to maintain contact with their health-care professional (Medtronic 2012).

The majority of survey respondents had last had contact with a specialist diabetes doctor or diabetes educator (either by phone, internet or in a face-to-face consultation) within the 3 months before the survey—72% indicating this to be the case. Eighteen per cent last saw a specialist within 3–6 months, but for 10% of insulin pump users, it had been more than 6 months since they had had any contact with a specialist diabetes doctor or diabetes educator, with approximately two in every five of these people not having seen anyone for 1 year or more. The last contact is roughly indicative of the general frequency of contact with a health professional, but this may not be the case for everyone. For instance, someone who indicated that they last had contact with a specialist diabetes doctor or diabetes educator within the past 3 months may have had a much longer gap between that contact and the previous one.

Males and females did not vary in the time since they last saw a specialist diabetes doctor or diabetes educator; however, younger people were more likely to have had contact with a professional in the 3 months before the survey than older people. Over 85% of children

(under 17 years) had had contact with a specialist diabetes doctor or diabetes educator within this time compared with just over 60% of those aged over 18 (Figure 3.8). Less than 1% of those aged 11 and under had not seen a specialist for 1 year or more, compared with 6% of users over 25.



Note: Based on n = 5,646.

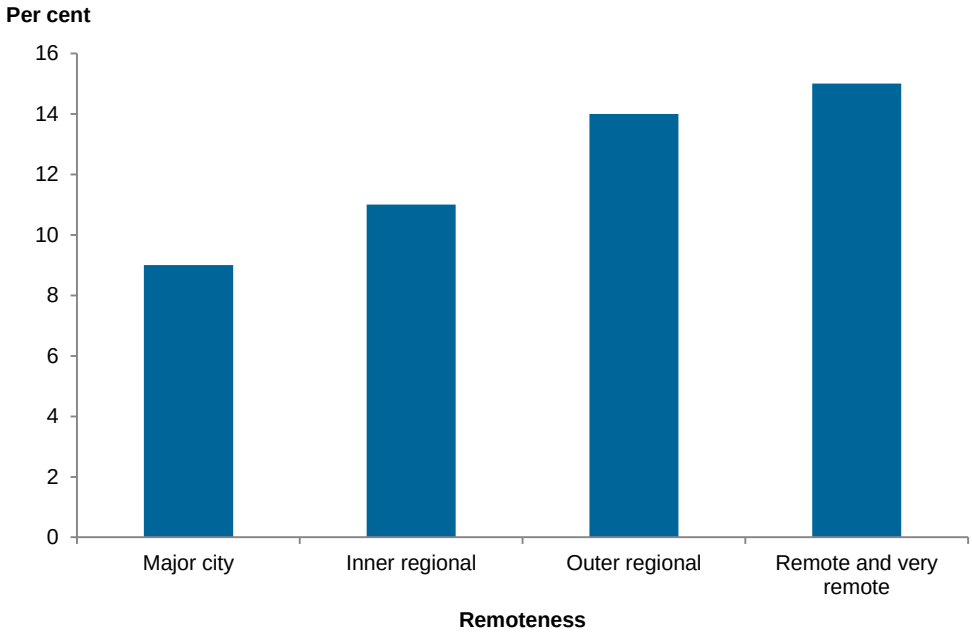
Source: AIHW Insulin Pump User Survey.

Figure 3.8: Time since last contact with specialist diabetes doctor or diabetes educator by age, Australia, 2011

Respondents who had not seen a health professional for 6 months or more were statistically significantly more likely to consider the relationship and support they had from professionals and pump company representatives as a problem. For respondents who had last seen a professional within the past 6 months, 4% thought that there was a lack of support from their doctor and 3% from the insulin pump company. For those who had not seen a doctor for more than 6 months, these figures were 11% and 6%, respectively. In terms of perceived benefits of using an insulin pump, those who had last seen a doctor more recently were significantly less likely to indicate that they felt better using a pump. This may suggest that those who were using their pumps successfully did not feel the need to consult as regularly. In this case, 51% of those who had seen a doctor within the past 6 months compared with 57% for whom it had been more than 6 months since they had seen a doctor indicated they felt better while using a pump.

In Australia, the initiation of insulin pump therapy is predominantly available in diabetes clinics in major metropolitan teaching hospitals (Victorian CSII Working Party 2009). Although the results were not conclusive, in part because of the small number of insulin

pump users in *Remote and very remote* areas, it appeared that those in more remote areas had less contact with a professional about their diabetes. As shown in Figure 3.9, 15% of those in *Remote and very remote areas* had last seen a specialist diabetes doctor or diabetes educator more than 6 months ago, compared with 9% of those living in *Major cities*.



(a) Remoteness was derived using the ABS ASGC.

Note: Based on n = 573.

Source: AIHW Insulin Pump User Survey.

Figure 3.9: Insulin pump users who had last had contact with specialist diabetes doctor or diabetes educator more than 6 months ago by remoteness[(a)], Australia, 2011

Pregnancy and insulin pump use

A total of 360 respondents indicated they first chose to use a pump because they were pregnant; this was 13% of women aged 16 and over at the time of the survey. Of these, 92% were current pump users (though it is not possible to say whether they were still pregnant or had continued on the pump after pregnancy), 6% were having a temporary break from the pump and 2% were not using one and did not intend to do so in the future.

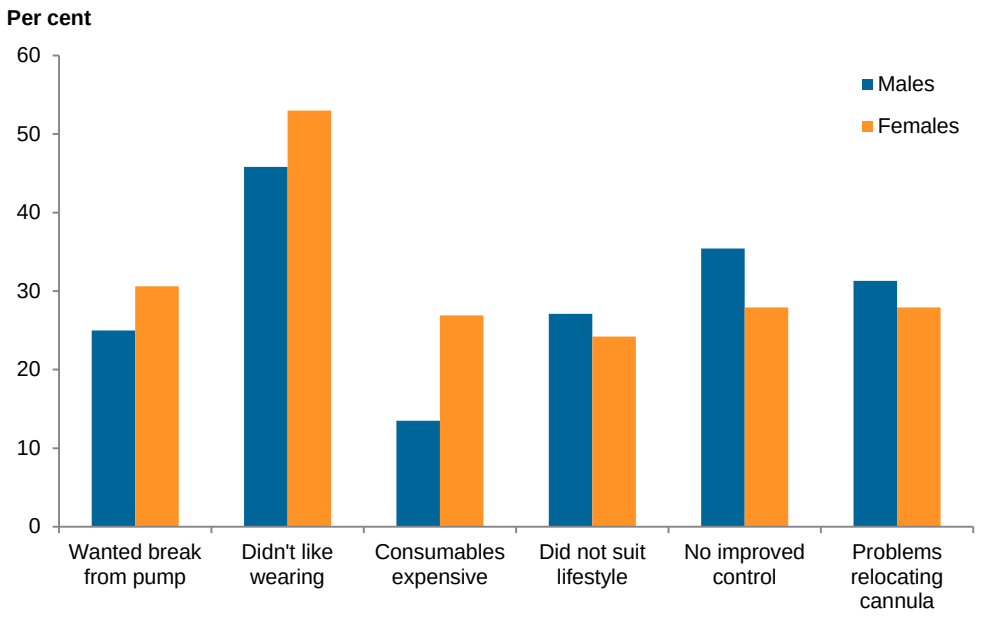
The majority of those who first chose an insulin pump for pregnancy reasons also chose the pump to better control their diabetes (78%), to prevent complications (59%), for lifestyle reasons and because it was recommended (both 52%).

Although CSII therapy may have originally been chosen for pregnancy reasons, the survey did not explore whether the insulin pump user had continued to use this type of treatment beyond pregnancy. For this reason, the responses to questions related to the benefits and problems of using an insulin pump may be more general and not specific to pregnancy. The main benefits of insulin pump therapy for this group were similar to those given by all

respondents to the survey except that diabetes control was considered to be a greater benefit than lifestyle. For the women who began using a pump for pregnancy reasons, almost all (92%) said it was to control their diabetes (86% of all pump users had selected this as a benefit). As with all users, the expense of pump consumables was the biggest issue, although this was a greater issue for this group, with 46% of women who began using a pump for pregnancy reasons indicating this to be the case, compared with 32% of all pump users.

Discontinuing insulin pump therapy

The discontinuation rate of insulin pump therapy is generally fairly low, with one study indicating it to be approximately 4% in children, adolescents and young adults (Hofer et al. 2010). It is thought that this is because the benefits of insulin pump therapy in terms of patient satisfaction and quality of life greatly outweigh the disadvantages. The AIHW survey results support this with 319 respondents indicating they were not currently using an insulin pump—5% of the total. However, this may be an underestimate because it is possible that people who were either having a temporary break or had permanently stopped using an insulin pump did not participate in the survey. Of non-current users, 58% were on a temporary break from using the pump and the remaining 42% indicated they had no intention of using a pump again in the future.



Note: Based on n = 315.

Source: AIHW Insulin Pump User Survey.

Figure 3.10: Factors indicated by those not currently using an insulin pump as a reason for stopping its use by sex, selected factors, Australia, 2011

Compared with those currently using an insulin pump, those who had stopped using a pump were slightly more likely to be female and were also more likely to be aged over 60. Among the non-current users, the most common reasons respondents gave for stopping insulin pump therapy was that they did not like wearing the pump (50%), they experienced

little or no improvement in diabetes control (30%), they had problems relocating the cannula or tubing (29%) and they wanted a break (29%) (Figure 3.10). The loss of financial assistance or subsidy was indicated as a factor in 3% of cases.

Although there appeared to be some differences in the reasons for stopping between children and young people compared with adults, these differences were not statistically significant for most factors. The only exception was in relation to the expense of pump consumables—of users under 18 years old, 9% gave this as a reason they stopped using the pump, compared with 28% of those aged 18 years and over.

Almost half of those people who were not currently using an insulin pump also provided additional comments about their reasons for not currently using. For those who were on a temporary break, there were a number of themes that came up as 'other' reasons. By far the most frequently stated other reason was problems with the site of the cannula, including bruising, bleeding and infections around the site and difficulties and pain with relocating it. As one respondent commented, 'My sites take [a] long time to heal so after a year or so I have to rest ...'. Respondents indicated that their temporary break was partly because of the lack of knowledge and experience of professionals, with one person stating that they 'Lived in [the] country. Pump strange to health practitioners'. Others said that their stoppage had actually been at the recommendation of their doctor or diabetes educator. Lifestyle issues were also given as reasons for taking a temporary break; these included undertaking water sports, holidays and travel.

For those who were no longer using an insulin pump and had no intention to do so in the future, the reasons for stopping pump use included health issues, pump breakdown, generally dislike of using the pump, and finding no benefits from pump use. A small number of respondents had no further need for an insulin pump as they had received a pancreas, kidney or islet cell transplant.

4 Summary and discussion

As of June 2011, there were 10,510 insulin pump users in Australia, representing 10% of all those with Type 1 diabetes. This represented a substantial growth in the number of insulin pump users since 2004—from 2004 to 2010, the number of new pump users increased by over 30%. The introduction of subsidies in 2004 (for insulin pump consumables) and 2008 (for insulin pumps themselves) probably made a significant contribution to this increase. The growth in pump use was also accompanied by a reduction in the amount of time from diagnosis of Type 1 diabetes to commencing continuous subcutaneous insulin infusion therapy, with 18% of those diagnosed with Type 1 diabetes in 2008 beginning an insulin pump within 2 years.

Insulin pump users had demographic characteristics that differed quite considerably from all people with Type 1 diabetes—pump users were much younger and with a higher proportion of females. The median age of insulin pump users was 27, while the median age for those with Type 1 diabetes was 55. Females made up 61% of pump users but only 45% of those with Type 1 diabetes.

Those using insulin pumps were proportionally more likely to be located in the Australian Capital Territory, Western Australia or Tasmania, in metropolitan areas and to some extent, in the least socioeconomically disadvantaged areas. However, in younger age groups, subsidies and other forms of assistance to people from more disadvantaged areas may have levelled out the relationship with socioeconomic status, thereby giving all families greater access to pump therapy.

With insulin pumps costing up to $9,000 each and the cost of consumables to pump users averaging $28 per month, commencing continuous subcutaneous insulin infusion therapy is not a cheap form of treatment. (The comparative average monthly expenditure on consumables for non-pump users was $6). It is, however, difficult to know how many people are prohibited from using a pump due to the cost or their ineligibility for subsidies, but at least 7% of insulin pump users did not obtain any funding for the purchase of their pump. Of those who did receive financial assistance, almost all obtained a rebate on private health insurance, with private health insurance data showing 1,319 hospital separations for patients being fitted with an insulin pump in 2010. This equated to approximately 80% of pump users.

One particular financial hurdle relates to the continuation of pump use. The majority of pump users maintain private health cover and can therefore replace pumps after a given time period if required. There is, however, a proportionally lower rate of pump use among those of lower socioeconomic status, which might reflect the difficulties they face in obtaining a pump without private health cover and, in the case of those who used an insulin pump subsidy to obtain their pump when they were under 18, obtaining a replacement pump once they are no longer eligible for the subsidy.

Results of the Insulin Pump User Survey, which had a 59% response rate, showed that the choice to use continuous subcutaneous insulin infusion therapy was influenced mainly by the need for better diabetes management (88%), lifestyle flexibility (67%) and the prevention of long-term health problems (66%); however, age influenced which factor was the most important. Diabetes management and the prevention of long-term complications was more important for those aged under 12 than for those in other age groups, possibly reflecting the concerns of the parents and/or carers who likely completed the survey on behalf of their

children. Lifestyle reasons were most important to 18–24 year olds and insulin pump users aged over 60 were most likely to have been recommended to use a pump by a doctor or diabetes educator than other pump users.

Many studies have found that the drop-out from insulin pump use is minimal, with the analysis showing 5% of survey respondents not currently using a pump (a proportion of these considered they were taking a temporary break, rather than stopped using permanently). The responses to the survey about the benefits would support why this is so. Survey responses on the benefits of insulin pump therapy compared with the problems showed that the benefits far outweighed any issues that people had with insulin pump therapy and less than 2% of users said they didn't experience any benefits.

The largest benefits pump users identified were that insulin pump therapy fitted their lifestyle (86%), that they achieved better diabetes management (83%) and that relocating the cannula was better than having several daily injections (76%). Although males and females had similar views on the benefits overall, males considered the improvements in management and being able to eat different foods a greater benefit than females, while females rated the discretion pumps afforded and that they were conducive to their lifestyle more highly than males. These benefits also varied by age, with attitudes related to specific life stages related to the importance placed on different factors. For instance, being able to eat a variety of foods and considering the pump to fit into their lifestyle were considered greater benefits to those aged under 25 compared with those aged 25 and over.

On the whole, insulin pump users did not consider there to be too many issues with using an insulin pump, though the biggest problem was the expense of insulin pump consumables, as indicated by approximately one in three pump users. However, in spite of the expense, one respondent stated that, 'pump consumables are expensive, but worth it for the benefits', again highlighting the positive outcomes people had with continuous subcutaneous insulin infusion therapy.

Another issue highlighted, and related to cost, was that consumables for the continuous glucose monitor are not subsidised at all. Although some pumps that have continuous glucose monitoring capability are covered by private health insurers, the consumables (sensors) required for continuous glucose monitoring are not covered by the National Diabetes Services Scheme. Sensors used to monitor interstitial glucose levels cost approximately $75 each and need to be replaced every few days.

Almost one-quarter of pump users had attended hospital, either an emergency department or been admitted for diabetes management, while using an insulin pump. Females were more likely to have visited hospital than males, as were those aged 18–24 compared with other age groups. In particular, and of greatest concern, were females aged 18–24 who were almost twice as likely to attend hospital as males the same age.

Insulin pump users commonly took breaks from their therapy, returning to multiple daily injections for a period of time—approximately one in four were found to have taken at least one break during their time using a pump. Compared with those not having any breaks, those who had taken a temporary break were more likely to indicate problems with their insulin pump and, although they were also more likely to consider that they had no support from specialists, had similar contact patterns with health professionals to pump users who had not taken any breaks.

Being willing to have regular ongoing contact with a specialist is a key criterion in the selection of suitability for pump use and important for ensuring the long-term health of

insulin pump users. The recommended level of support is 3–6 months with both a credentialled diabetes educator and specialist physician. On the whole, the majority of insulin pump users appeared to have complied with this; when asked how long it had been since they had last had contact with a specialist diabetes doctor or diabetes educator, 90% had seen a professional within the last 6 months. However, older people were less likely to have complied with recommendations, with, for example, 6% of those aged over 25, compared with 1% of 0–11 year olds, not having seen a specialist for 1 year or more.

In spite of the financial costs, this report has demonstrated the many perceived benefits that insulin pump therapy has for people with Type 1 diabetes in Australia and for most people the pump provides greater independence and freedom to live a 'normal' life.

Appendix A: Survey methodology

The objectives of the survey were to gain an understanding of the experiences of insulin pump users and what motivations they have for starting, interrupting and ceasing insulin pump use. The survey covered the following areas:

- the background of insulin pump users, including age, sex, how long they had had diabetes, how long they had been using a pump and how they funded their insulin pump
- factors that influenced the choice to use an insulin pump
- the benefits and problems of using an insulin pump, including whether users had required hospitalisation or visited an emergency department for diabetes control issues while using their pump
- information about the breaks users had taken from using a pump
- the contact users had with a specialist diabetes doctor or diabetes educator.

Survey instrument

The survey instrument (see 'Appendix B: Insulin Pump User Survey') was developed in consultation with the National Diabetes Data Working Group (NDDWG). The NDDWG is a multidisciplinary committee that includes representatives from Australian Government, consumers and general practice and diabetes-related professionals. The NDDWG provides advice and guidance to the work of the National Centre for Monitoring Diabetes at the AIHW.

The survey and data collection methods were approved by the AIHW Ethics committee.

Selection of survey participants

Those in scope for the survey consisted of registrants on the NDSS who were also eligible to purchase IPCs and had given consent to be contacted for research purposes—around 90% of insulin pump users had provided this consent. In total, there were 9,618 people eligible to participate in the survey. The purchase of IPCs from the NDSS is only possible where registrants have been assessed against a set of criteria that have been endorsed by the Department of Health and Ageing (DoHA). The assessment must be authorised by an endocrinologist, credentialed diabetes educator or specialist physician.

Nearly all participants on the scheme and who participated in this study have Type 1 diabetes, though people with Type 2 and gestational diabetes can be eligible in certain circumstances and may therefore have received and completed a survey. Additionally, some people registered for the insulin pump scheme may not have followed through by purchasing and using an insulin pump and, although a survey would have been sent to them, weren't eligible to complete it.

Survey mail-out

To maintain privacy, the contact information of survey participants was not given to the AIHW. Instead, they were contacted by Diabetes Australia (DA), which maintains the list of

registrants to the NDSS. The AIHW and DA independently passed to a mailing house the survey materials and distribution list, respectively.

The survey pack sent to participants included a reply-paid envelope that was addressed to the AIHW. Because the questionnaire itself did not contain any identifying information, the responses could not be traced to individuals.

The first mail-out was on 7 October 2011. Each participant was sent a cover letter, introducing them to the survey, the survey instrument itself and a reply-paid envelope. On 24 October 2011, a reminder was sent to all participants; this pack included a reminder letter, the survey instrument and a reply paid envelope. Because the AIHW could not identify respondents, the second reminder mail-out was distributed to all participants.

Survey hotline

The AIHW established a toll-free survey hotline during the survey. This allowed survey participants to seek information on the purpose of the survey, how to complete the questionnaire, or to advise if they did not wish to take part in the survey.

Response rate and non-respondents

In total, of the 9,618 who were sent a survey form and discounting those that were not used for the reasons outlined below, there were 5,680 completed survey forms used in the analysis, giving a response rate of 59%.

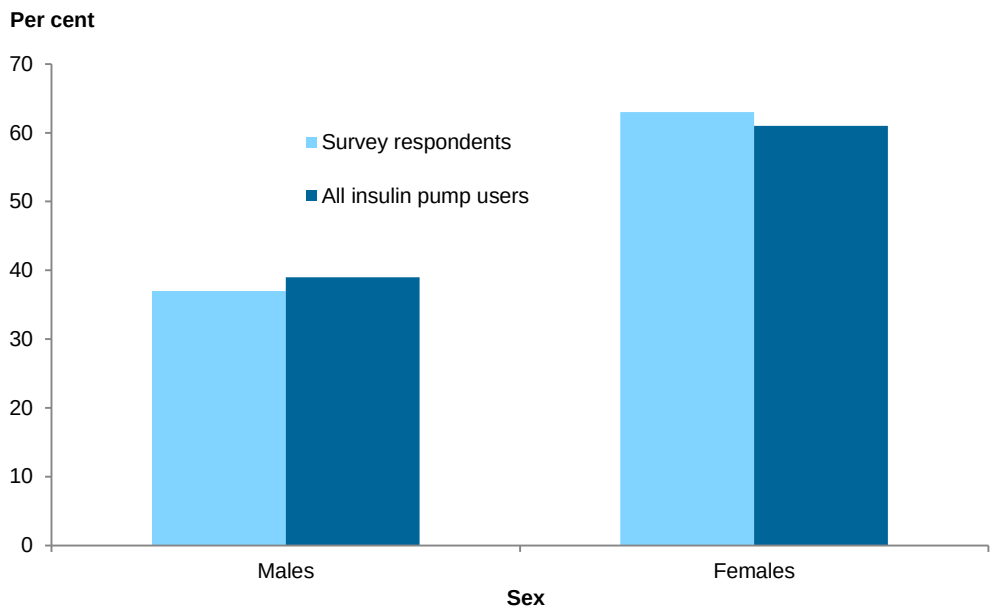
Reasons for non-analysis of the Insulin Pump User Survey:

- duplicate survey form
- respondent deceased
- respondent indicated they had never had or used a pump
- respondent lived overseas
- survey form returned to AIHW after the final cut-off date of 20 December 2011.

Representativeness of the sample to all pump users

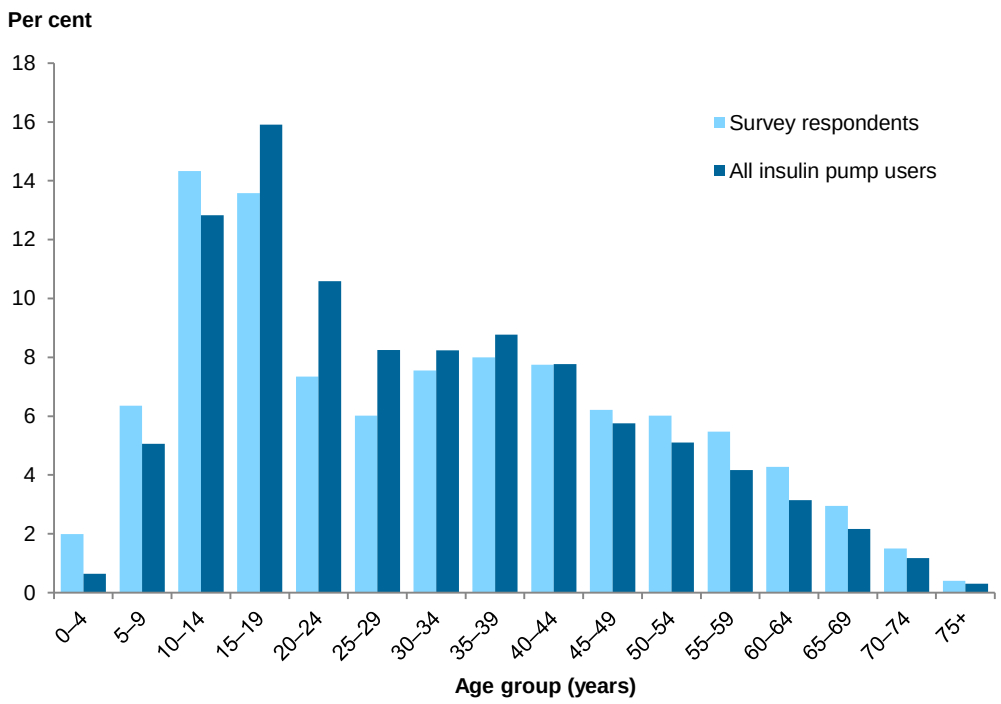
Survey respondents were a relatively representative sample of all NDSS registrants who were insulin pump users for the key demographic variables of sex, age, state or territory of current residence and region. For the key demographic variables sex (Figure A1), the state or territory of current residence (Figure A3) and remoteness (Figure A4), the sample of insulin pump users was very similar to all pump users in the NDSS. However, for age (Figure A2), the distribution varied slightly. 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 difference in age distributions between the survey respondents and all insulin pump users showed that the difference in the results were minimal. However, where the analyses are not presented by age group, the results should consider any impact that under-representation of those 15 to 29 may have had.



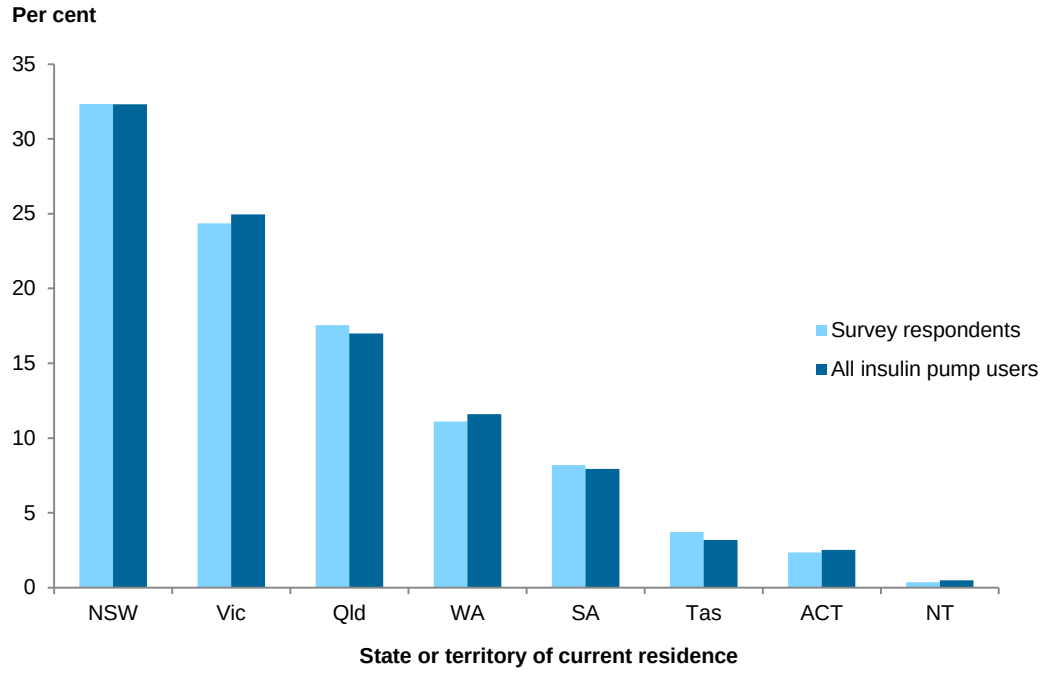
Sources: AIHW analysis of NDSS data and AIHW Insulin Pump User Survey.

Figure A1: Insulin pump users registered on the National Diabetes Services Scheme and respondents to the Insulin Pump User Survey by sex



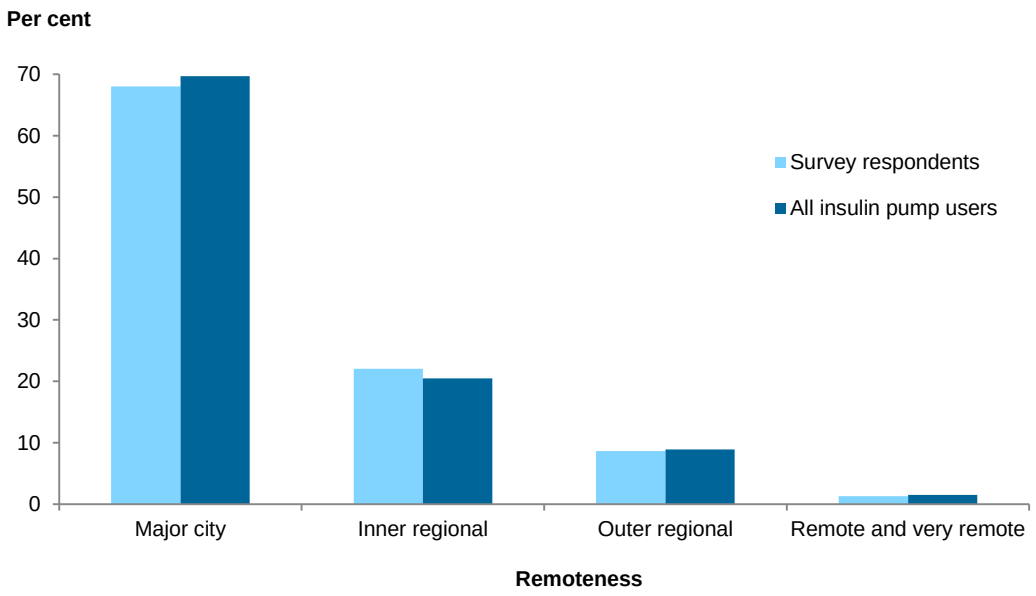
Sources: AIHW analysis of NDSS data and AIHW Insulin Pump User Survey.

Figure A2: Insulin pump users registered on the National Diabetes Services Scheme and respondents to the Insulin Pump User Survey by age



Sources: AIHW analysis of NDSS data and AIHW Insulin Pump User Survey.

Figure A3: Insulin pump users registered on the National Diabetes Services Scheme and respondents to the Insulin Pump User Survey by state or territory of current residence



(a) Remoteness was derived using the ABS ASGC.

Sources: AIHW analysis of NDSS data and AIHW Insulin Pump User Survey.

Figure A4: Insulin pump users registered on the National Diabetes Services Scheme and respondents to the Insulin Pump User Survey by remoteness[(a)]

Appendix B: Insulin Pump User Survey

The Insulin Pump User Survey is designed to help us understand what motivates people when making choices about using insulin pumps to treat their diabetes. Your contribution will help us build an accurate picture of pump usage in Australia and highlight the benefits and difficulties of using an insulin pump. Your answers are confidential and no identifying information is collected. Participation in the survey is voluntary.

The questions below are about the insulin pump user. If you are the carer, please answer for the pump user. When you have finished, please post the completed questionnaire in the reply paid envelope provided. If you have any questions you can contact us via email <pumpsurvey@aihw.gov.au> or phone 1800 466 155.

1. What is your (the insulin pump user) sex? *Please tick one box only*

   (1) ☐ Male (2) ☐ Female

2. In what year were you (the insulin pump user) born?

   Year

3. What is your current home postcode?

   Postcode

4. At what age were you (the insulin pump user) **first diagnosed** with diabetes?

   Age

5. At what age did you (the insulin pump user) **first begin** using an insulin pump?

   Age

6. What was your home postcode when you (the insulin pump user) **first started using** an insulin pump?

   Postcode

7. Are you **currently** using an insulin pump? *Please tick one box only*

(1) ☐ I am currently using an insulin pump

(2) ☐ I am not currently using an insulin pump as I am having a temporary break

(3) ☐ I am not currently using an insulin pump and do not intend to use one again in future

8. If you are currently using an insulin pump, please tell us the brand and model of this insulin pump.

Brand: _____

Model: _____

9. Did you receive funding from any of the following sources towards the purchase of your **current or last** insulin pump?

(1) ☐ No, I paid for the entire cost of the pump myself

(2) ☐ No, I am using a pump on loan from the pump company

Yes… *Please tick all that apply*

(3) ☐ Commonwealth Government subsidy

(4) ☐ Private Health Insurance rebate

(5) ☐ Juvenile Diabetes Research Fund grant

(6) ☐ Not sure

10. Why did you (the insulin pump user) **first choose** to use an insulin pump? *Please tick all that apply*

(1) ☐ To better control my diabetes (to reduce hypoglycaemic [low blood sugar] or hyperglycaemic [high blood sugar] events)

(2) ☐ To prevent long-term health complications (such as heart disease, kidney disease and blindness)

(3) ☐ To improve awareness of low blood sugar events

(4) ☐ Due to pregnancy

(5) ☐ For lifestyle reasons (e.g. flexibility with meals times or food quantities or to be able to sleep in)

(6) ☐ Recommended by doctor or diabetes educator

(7) ☐ Don't know

(8) ☐ Other (*please specify*)

_____

11. Thinking about when you have used an insulin pump, what **benefits** have you experienced? *Please tick all that apply*

(1) ☐ I have not had any benefits
(2) ☐ Better control of my diabetes
(3) ☐ Being able to eat different types of food
(4) ☐ Fits in with lifestyle (e.g. flexibility with meals times or food quantities or to be able to sleep in)
(5) ☐ Relocating the cannula/tubing every few days is better than several injections each day
(6) ☐ I feel better
(7) ☐ More discreet when administering insulin in public
(8) ☐ More convenient
(9) ☐ Low blood sugar awareness has improved
(10) ☐ Other (*please specify*)

_____

12. Thinking about when you have used an insulin pump, what significant **problems** have you had? *Please tick all that apply*

(1) ☐ I have not had any significant problems
(2) ☐ The pump has been difficult to use
(3) ☐ The pump has given me little or no improvement in diabetes control
(4) ☐ I don't like wearing a pump
(5) ☐ I have had inadequate support from my specialist diabetes doctor/diabetes educator
(6) ☐ I have had inadequate support from the pump company/company representatives
(7) ☐ Pump consumables are too expensive
(8) ☐ My pump keeps breaking down
(9) ☐ I have had problems with air bubbles affecting insulin delivery
(10) ☐ I have had problems with relocating the cannula/tubing
(11) ☐ Other (*please specify*)

_____

13. Have you had to go to an Emergency Department or been admitted to hospital specifically for your diabetes management **while using a pump**? *Please tick one box only*

(1) ☐ Yes (2) ☐ No

14. How long ago did you last have contact with a specialist diabetes doctor or diabetes educator (either by phone, internet or in face-to-face consultation)? *Please tick one box only*

(1) ☐ Less than 3 months
(2) ☐ 3 to 6 months
(3) ☐ More than 6 months but less than 1 year
(4) ☐ 1 year or more

15. Since starting to use an insulin pump, how many **temporary breaks** have you taken from using the pump (that is, gone back to injecting insulin with a syringe, even for a short period)? *Please tick one box only*

If you are currently having a temporary break from your pump, please count this as a break.

(1) ☐ Never had a break
(2) ☐ One break
(3) ☐ Two breaks
(4) ☐ Three breaks or more

16. If you have had a temporary break, what age/s were you when you took a break from using a pump?

If you are currently having a temporary break from your pump, please note your current age.

	Age
First break:	☐☐
Second break:	☐☐
Third break:	☐☐

17. If you are **not currently** using an insulin pump (either permanently or temporarily), what were the reasons you stopped using it? *Please tick all that apply*

(1) ☐ I wanted a break from counting carbohydrates
(2) ☐ I wanted a break from using the pump
(3) ☐ I didn't like wearing the pump
(4) ☐ I had a change in routine
(5) ☐ The pump was faulty
(6) ☐ Pump consumables were too expensive
(7) ☐ It did not suit my lifestyle
(8) ☐ The pump has been difficult to use
(9) ☐ The pump has given me little or no improvement in diabetes control
(10) ☐ I had inadequate support from my specialist diabetes doctor/diabetes educator

(11) ☐ I had inadequate support from the pump company/company representatives

(12) ☐ I had problems with relocating the cannula/tubing

(13) ☐ I no longer received a financial assistance/subsidy for my pump

(14) ☐ I was no longer pregnant

(15) ☐ Other (*please specify*)

_____

Thank you for completing the Insulin Pump User Survey

Appendix C: Summary tables

Table A1: Characteristics of insulin pump users and people with Type 1 diabetes by sex, Australia, 1 January 2004–30 June 2011

	Insulin pump users			All people with Type 1 diabetes		
	Males	Females	Total	Males	Females	Total
Age (years)						
0–4	42	30	**72**	162	122	**284**
5–9	265	278	**543**	809	814	**1,623**
10–14	642	710	**1,352**	1,908	1,798	**3,706**
15–19	782	887	**1,669**	2,873	2,484	**5,357**
20–24	456	653	**1,109**	3,070	2,684	**5,754**
25–29	257	608	**865**	3,293	2,805	**6,098**
30–34	221	644	**865**	3,361	2,745	**6,106**
35–39	256	664	**920**	3,717	2,949	**6,667**
40– 44	259	556	**815**	3,984	3,261	**7,245**
45–49	209	394	**603**	3,974	3,477	**7,451**
50–54	215	321	**536**	4,116	3,525	**7,641**
55–59	181	257	**438**	4,217	3,279	**7,496**
60–64	144	185	**329**	4,902	3,551	**8,453**
65–69	110	118	**228**	4,849	3,662	**8,511**
70–74	59	64	**123**	4,437	3,834	**8,271**
75–79	11	21	**32**	3,882	3,875	**7,757**
80–84	3	6	**9**	2,957	3,308	**6,265**
85–89	2	—	**2**	1,604	2,184	**3,788**
90–94	—	—	**—**	549	938	**1,487**
95+	—	—	**—**	197	343	**540**
Total	*4,114*	*6,396*	***10,510***	*58,806*	*51,564*	***110,371***
State or territory of current residence						
NSW	1,421	1,979	**3,400**	20,727	18,887	**39,614**
Vic	931	1,685	**2,616**	14,315	12,698	**27,013**
Qld	677	1,115	**1,792**	10,491	8,902	**19,393**
WA	482	734	**1,216**	5,697	4,582	**10,280**
SA	325	508	**833**	4,696	4,067	**8,763**
Tas	137	198	**335**	1,569	1,385	**2,954**
ACT	119	145	**264**	946	767	**1,713**
NT	20	31	**51**	404	333	**737**
Total	*4,112*	*6,395*	***10,507***	*58,845*	*51,621*	***110,467***

(continued)

Table A1 (continued): Characteristics of insulin pump users and people with Type 1 diabetes by sex, Australia, 1 January 2004–30 June 2011

	Insulin pump users			All people with Type 1 diabetes		
	Males	**Females**	**Total**	**Males**	**Females**	**Total**
Remoteness[(a)]						
Major cities	2,875	4,447	**7,322**	40,002	*35,425*	**75,427**
Inner regional	840	1,318	**2,158**	*12,588*	*10,980*	**23,568**
Outer regional	346	554	**900**	*5,361*	*4,457*	**9,818**
Remote and very remote	51	76	**127**	*894*	*759*	**1,653**
Total	*4,112*	*6,395*	***10,507***	*58,845*	*51,621*	***110,467***
Socioeconomic status group[(b)]						
1 Lowest SES	492	853	**1,345**	12,284	11,688	**23,972**
2	766	1,214	**1,980**	12,835	11,387	**24,222**
3	815	1,277	**2,092**	11,830	10,367	**22,197**
4	865	1,377	**2,242**	10,947	9,241	**20,188**
5 Highest SES	1,137	1,634	**2,771**	10,614	8,667	**19,281**
Total	*4,075*	*6,355*	***10,430***	*58,510*	*51,350*	***109,861***

(a) Remoteness was derived using the ABS ASGC.

(b) Socioeconomic status was derived using the ABS IRSD.

Note: Totals vary due to missing data on some variables.

Source: AIHW analysis of NDSS data.

Table A2: Respondents to the Insulin Pump User Survey by age and sex, Australia, 2011

	Males		Females		Total	
Age (years)	**Number**	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
0–4	50	2.4	63	1.8	**113**	**2.0**
5–9	171	8.1	189	5.3	**360**	**6.4**
10–14	383	18.2	429	12.1	**812**	**14.3**
15–19	350	16.6	419	11.8	**769**	**13.6**
20–24	144	6.8	272	7.7	**416**	**7.3**
25–29	74	3.5	266	7.5	**340**	**6.0**
30–34	99	4.7	329	9.3	**428**	**7.6**
35–39	111	5.3	342	9.6	**453**	**8.0**
40–44	119	5.7	320	9.0	**439**	**7.8**
45–49	103	4.9	249	7.0	**352**	**6.2**
50–54	121	5.8	220	6.2	**341**	**6.0**
55–59	125	5.9	185	5.2	**310**	**5.5**
60–64	112	5.3	130	3.7	**242**	**4.3**
65–69	81	3.9	86	2.4	**167**	**2.9**
70–74	49	2.3	36	1.0	**85**	**1.5**
75–79	9	0.4	14	0.4	**23**	**0.4**
80–84	3	0.1	5	0.1	**8**	**0.1**
85–89	2	0.1	0	0.0	**2**	**0.0**
95+	0	0.0	3	0.1	**3**	**0.1**
Total	**2,106**	**100**	**3,557**	**100**	**5,663**	**100**

Source: AIHW analysis of Insulin Pump User Survey.

Table A3: Factors indicated by insulin pump users as reasons for first choosing to use a pump by sex, Australia, 2011

	Males		Females		Total	
	Number	**Per cent**	**Number**	**Per cent**	**Number**	**Per cent**
To better control my diabetes	1,876	88.9	3,114	87.5	**4,990**	**87.9**
To prevent long-term health complications**	1,474	69.8	2,278	64.0	**3,752**	**66.1**
To improve awareness of low blood sugar events*	499	23.6	758	21.3	**1,257**	**22.2**
Due to pregnancy	. .	. .	360	13.0	**360**	**6.3**
For lifestyle reasons**	1,460	69.2	2,335	65.6	**3,795**	**66.9**
Recommended by doctor or diabetes educator**	1,308	62.0	2,066	58.0	**3,374**	**59.5**

Note: **p < 0.01, *p < 0.05 for the chi-square test of significance for differences between males and females.

Source: AIHW analysis of Insulin Pump User Survey.

Table A4: Factors indicated by insulin pump users as a benefit of using a pump by sex, Australia, 2011

	Males		Females		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
Better control of my diabetes**	1,773	84.0	2,914	81.9	**4,687**	**82.6**
Being able to eat different types of food**	1,401	66.4	2,208	62.0	**3,609**	**63.6**
Fits in with lifestyle**	1,780	84.3	3,073	86.3	**4,853**	**85.6**
Relocating the cannula/tubing every few days is better than several injections each day	1,610	76.3	2,674	75.1	**4,284**	**75.5**
I feel better	1,067	50.5	1,844	51.8	**2,911**	**51.3**
More discreet when administering insulin in public**	1,246	59.0	2,234	62.8	**3,480**	**61.4**
More convenient	1,505	71.3	2,545	71.5	**4,050**	**71.4**
Low blood sugar awareness has improved	633	30.0	1,012	28.4	**1,645**	**29.0**

Notes

1. **p < 0.01 for the chi-square test of significance for differences between males and females.
2. Where benefits were indicated in addition to no benefits, the response to 'I have not had any benefits' was disregarded.

Source: AIHW analysis of Insulin Pump User Survey.

Table A5: Factors indicated by insulin pump users as a problem of using a pump by sex, Australia, 2011

	Males		Females		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
The pump has been difficult to use	23	1.1	58	1.6	**81**	**1.4**
The pump has given me little or no improvement in diabetes control	96	4.6	173	4.9	**269**	**4.7**
I don't like wearing a pump**	222	10.5	612	17.2	**835**	**14.7**
I have had inadequate support from my specialist diabetes doctor/diabetes educator**	75	3.6	188	5.3	**263**	**4.7**
I have had inadequate support from the pump company/company representatives	62	2.9	116	3.3	**178**	**3.4**
Pump consumables are too expensive**	618	29.3	1,170	32.9	**1,788**	**31.5**
My pump keeps breaking down**	82	3.9	246	6.9	**328**	**5.8**
I have had problems with air bubbles affecting insulin delivery	242	11.5	461	13.0	**703**	**12.4**
I have had problems with relocating the cannula/tubing	334	15.8	552	15.5	**886**	**15.6**

Notes

1. **p < 0.01 for the chi-square test of significance for differences between males and females.
2. In approximately 10% of cases people indicated no significant problems as well as particular problem/s with using an insulin pump.

Source: AIHW Insulin Pump User Survey.

Table A6: Factors indicated by insulin pump users as a problem of using a pump by age, Australia, 2011

	0–11 years	12–17 years	18–24 years	25–45 years	46–60 years	61+ years	Total
				Number			
The pump has been difficult to use	9	17	12	18	14	12	**82**
The pump has given me little or no improvement in diabetes control**	22	58	39	80	35	35	**269**
I don't like wearing a pump**	71	164	145	300	118	36	**834**
I have had inadequate support from my specialist diabetes doctor/diabetes educator**	34	25	35	99	45	26	**264**
I have had inadequate support from the pump company/company representatives**	15	16	18	69	39	21	**178**
Pump consumables are too expensive**	187	240	222	673	329	134	**1,785**
My pump keeps breaking down**	26	75	59	115	35	17	**327**
I have had problems with air bubbles affecting insulin delivery**	144	158	85	183	84	46	**700**
I have had problems with relocating the cannula/tubing**	130	180	157	244	113	60	**884**
				Per cent			
The pump has been difficult to use	1.2	1.6	1.8	1.1	1.4	2.5	**1.45**
The pump has given me little or no improvement in diabetes control**	2.9	5.6	5.8	4.7	3.5	7.2	**4.8**
I don't like wearing a pump**	9.4	15.7	21.7	17.5	11.9	7.4	**14.7**
I have had inadequate support from my specialist diabetes doctor/diabetes educator**	4.5	2.4	5.2	5.8	4.5	5.3	**4.7**
I have had inadequate support from the pump company/company representatives**	2.0	1.5	2.7	4.0	3.9	4.3	**3.1**
Pump consumables are too expensive**	24.7	23.0	33.2	39.3	33.1	27.9	**31.5**
My pump keeps breaking down**	3.4	7.2	8.8	6.7	3.5	3.5	**5.8**
I have had problems with air bubbles affecting insulin delivery**	19.0	15.1	12.7	10.7	8.5	9.7	**12.4**
I have had problems with relocating the cannula/tubing**	17.2	17.2	23.5	14.2	11.4	12.3	**15.6**

Notes

1. **$p < 0.01$ for the chi-square test of significance for differences between age groups.
2. In approximately 10% of cases people indicated no significant problems as well as particular problem/s with using an insulin pump.

Source: AIHW Insulin Pump User Survey.

Table A7: Factors indicated by insulin pump users as a problem of using a pump by whether hospital attended for diabetes management, Australia, 2011

	Hospital visit		No hospital visit		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
The pump has been difficult to use**	33	2.5	48	1.1	**81**	**1.4**
The pump has given me little or no improvement in diabetes control**	85	6.6	183	4.2	**268**	**4.8**
I don't like wearing a pump*	218	16.8	612	14.1	**830**	**14.7**
I have had inadequate support from my specialist diabetes doctor/diabetes educator**	82	6.3	182	4.2	**264**	**4.7**
I have had inadequate support from the pump company/company representatives**	70	5.4	108	2.5	**178**	**3.2**
Pump consumables are too expensive**	461	35.5	1,325	30.5	**1,786**	**31.6**
My pump keeps breaking down**	131	35.5	197	30.5	**328**	**5.8**
I have had problems with air bubbles affecting insulin delivery**	223	17.2	480	11.0	**703**	**12.5**
I have had problems with relocating the cannula/tubing**	283	21.8	601	13.8	**884**	**15.7**

Note: **p < 0.01, *p < 0.05 for the chi-square test of significance for differences between those who did and did not attend hospital.

Source: AIHW Insulin Pump User Survey.

Table A8: Factors indicated by insulin pump users as a problem of using a pump by whether a temporary break had been taken, Australia, 2011

	No break		Temporary break		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
The pump has been difficult to use**	53	1.2	29	2.2	**82**	**1.4**
The pump has given me little or no improvement in diabetes control**	139	3.2	130	9.9	**269**	**4.7**
I don't like wearing a pump*	521	11.9	314	24.0	**835**	**14.7**
I have had inadequate support from my specialist diabetes doctor/diabetes educator**	174	4.0	90	6.9	**264**	**4.7**
I have had inadequate support from the pump company/company representatives**	114	2.6	64	4.9	**178**	**3.1**
Pump consumables are too expensive**	1,314	30.1	476	36.3	**1,790**	**31.5**
My pump keeps breaking down**	159	3.6	169	12.9	**328**	**5.8**
I have had problems with air bubbles affecting insulin delivery**	499	11.4	206	15.7	**705**	**12.4**
I have had problems with relocating the cannula/tubing**	577	13.2	309	23.6	**886**	**15.6**

Note: **p < 0.01, *p < 0.05 for the chi-square test of significance for differences between those that took a temporary break and those who did not.

Source: AIHW Insulin Pump User Survey.

Table A9: Factors indicated by those not currently using an insulin pump as a reason for stopping its use by sex, Australia, 2011

	Males		Females		Total	
	Number	Per cent	Number	Per cent	Number	Per cent
I wanted a break from counting carbohydrates	8	8.3	13	5.9	**21**	**6.6**
I wanted a break from using the pump	24	25.0	67	30.6	**91**	**28.5**
I didn't like wearing the pump	44	45.8	116	53.0	**160**	**50.2**
I had a change in routine	3	3.1	16	7.3	**19**	**6.0**
The pump was faulty	15	15.6	34	15.5	**49**	**15.4**
Pump consumables were too expensive**	13	13.5	59	26.9	**72**	**22.6**
It did not suit my lifestyle	26	27.1	53	24.2	**79**	**24.8**
The pump has been difficult to use	8	8.3	36	16.4	**44**	**13.8**
The pump has given me little or no improvement in diabetes control	34	35.4	61	27.9	**95**	**29.8**
I had inadequate support from my specialist diabetes doctor/diabetes educator*	4	4.2	28	12.8	**32**	**10.0**
I had inadequate support from the pump company/company representatives	3	3.1	12	5.5	**15**	**4.7**
I had problems with relocating the cannula/tubing	30	31.3	61	27.9	**91**	**28.5**
I no longer received a financial assistance/subsidy for my pump	5	5.2	4	1.8	**9**	**2.8**
I was no longer pregnant	. .	. .	14	6.4	**14**	**4.4**

Note: **p < 0.01, *p < 0.05 for the chi-square test of significance for differences between age groups.

Source: AIHW Insulin Pump User Survey.

Appendix D: Methods

Age

Age calculations

The reference date for age calculations for NDSS registrants was 30 June 2011.

In the survey data age was estimated from year of birth.

Age categories

The presentation of analyses by age uses different age breakdowns throughout the report. The choice of categories depended on two factors:

- the appropriateness of the groupings for the reporting and interpretation of the results
- the total number of records in each category.

For example, many of the results from the survey are presented in age groups that align to broad life stages because the analysis showed that the results could be best interpreted this way. In instances where the number in categories were small, such as analysis of non-current pump users or breakdowns by remoteness, wider age groups were used to ensure categories were large enough to reduce any potential ambiguities in the results.

Geographic classifications

Geographic location was classified according to the Australian Bureau of Statistics (ABS) Australian Standard Geographical Classification Remoteness Structure, which groups geographic areas into categories. These categories are based on 2006 Census Collection Districts and defined using the Accessibility/Remoteness Index for Australia (ARIA). ARIA is a measure of the remoteness of a location from the services provided by large towns or cities. Accessibility is judged purely on distance to one of the metropolitan centres, so it provides a relative indication of how difficult it might be for residents to access certain services such as health care and education.

The categories are used in this publication are:

- *Major cities*
- *Inner regional*
- *Outer regional*
- *Remote and very remote*.

It should be noted that newer participant postcodes may not map to the 2006 Census-based concordances and were not included in relevant tables. Further, some postcodes may have changed remoteness area since the 2006 Census; however, they will still be included under the area they were assigned in 2006.

Socioeconomic classification

Socioeconomic classifications were based on the ABS Index of Relative Socioeconomic Disadvantage (IRSD). Geographic areas are assigned a score based on attributes such as low

income, low educational attainment, high unemployment and jobs in relatively unskilled occupations. It does not refer to the socioeconomic situation of a particular individual, but instead refers to the area in which a person lives. A low score means an area has more low-income families, people with little training and high unemployment, and may be considered disadvantaged relative to other areas with higher scores. Areas with high index scores may be considered less disadvantaged relative to other areas.

Geographic areas may be excluded where no score is determined due to low populations or high levels of non-response in the underlying census. Additionally, newer participant postcodes may not map to these 2006 Census-based concordances and were also excluded. Lastly, some postcodes may have changed SES group since the 2006 Census; however, they will still be included under the area they were assigned in 2006.

In this report, a participant's socioeconomic status was classified using the participant's residential postcode according to the IRSD for 2006. Five socioeconomic groups, based on the level of the index, were used for analysis where group 1 represents the most disadvantaged fifth of the population and group 5 the least disadvantaged.

Chi-square test of significance

Where results presented in this publication indicate a statistical difference between groups or categories in the survey data, for example between males and females or differences in age group, a chi-square test of significance has been used at the 95% confidence level to determine that the differences found are large enough not to have occurred merely by chance (with 95% certainly).

The chi-square test is a non-parametric test that establishes the independence, or otherwise, between two nominal variables. Chi-square requires no assumption about the exact shape of the population distribution. It is a measurement of how expectations compare with the actual results.

Appendix E: Data Quality Statement

Insulin Pump User Survey

Summary of key data quality issues

- 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 data set may have included duplicate responses. With no identifying information on the survey form, the AIHW was 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.

Glossary

basal dose: a continuous low level dose of insulin, required to keep blood glucose levels within the normal range as the liver releases glucose into the blood.

blood glucose: the main sugar that the body makes from the food in the diet. Glucose is carried through the bloodstream to provide energy to all cells in the body. Cells cannot use glucose without the help of insulin.

bolus dose: a faster-acting insulin that provides the boost of insulin needed to stop the rise in blood glucose levels that occurs after meals.

chi-square: a non-parametric test that establishes the independence or otherwise between two nominal variables.

diabetes: a chronic condition in which the body cannot properly use its main energy source: the sugar glucose. This is due to either the pancreas not producing enough of the hormone insulin, or the body being unable to effectively use the insulin produced. Insulin helps glucose enter the body's cells from the bloodstream and then be processed by them. Diabetes is marked by an abnormal build-up of glucose in the blood, and can have serious short- and long-term effects on many of the body's systems, especially the blood vessels and nerves.

insulin: a hormone produced by the pancreas. Its main action is to enable body cells to absorb glucose from the blood and use it for energy.

insulin pump: a device worn close to the body that delivers insulin subcutaneously.

HbA1c (glycosylated haemoglobin): a measure of long-term blood glucose control. Higher levels of HbA1c indicate poorer control of glucose levels.

hypoglycaemia (low blood glucose): a common and dangerous condition for many people with type 1 diabetes. It can be caused by eating less than usual, taking more exercise than normal or too much insulin administered.

hyperglycaemia (high blood glucose): occurs when the body has too much food or glucose, or too little insulin. It can be caused by a clog in insulin pump tubing, missing an insulin dose, eating more than usual, stress or less exercise than normal.

ketoacidosis: when the body cannot turn glucose into energy (due to insufficient insulin) it uses its own fats for energy. When these fats are broken down they release acids known as ketones, which can accumulate in dangerous levels in the blood and urine, causing diabetes ketoacidosis. This condition is potentially life threatening if not treated.

National Diabetes Service Scheme (NDSS): started in 1987, is an initiative of the Australian Government, administered by Diabetes Australia. The NDSS delivers diabetes-related products at subsidised prices and provides information and support services to people with diabetes.

nephropathy: a severe complication of diabetes that results from high blood sugar levels damaging the blood-filtering capillaries in the kidneys.

neuropathy: a complication of diabetes that results in damage to the nerves.

retinopathy: a complication of diabetes that causes damage to the capillaries of the retina in the eye.

statistical significance: variation or difference in observed values or rates may only reflect a random variation or difference. Statistical significance assesses whether differences in values of rates are statistically significant—that is, that they are not due to chance alone.

Type 1 diabetes: marked by the inability to produce insulin. People with Type 1 diabetes need insulin replacement for survival. Most cases are caused by an autoimmune condition that destroys the pancreatic cells which produce insulin.

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Insulin pump use in Australia explores the number, characteristics and experiences of insulin pump users using information from the National Diabetes Services Scheme and the first national survey of insulin pump users, conducted by the Australian Institute of Health and Welfare.

In 2011, the proportion of Australians with Type 1 diabetes using an insulin pump was approximately 10%, representing an increase over previous years. Pump use was more common among females and people under 25 years, and for most pump users the benefits of pump use outweighed the problems.