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Diabetes among young Australians

DIABETES SERIES NO. 18

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Authoritative information and statistics
to promote better health and wellbeing

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Diabetes among young Australians

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Australian Institute of Health and Welfare
Board Chair
Dr Andrew Refshauge

Director
David Kalisch

Any enquiries about or comments on this publication should be directed to:
Communications, Media and Marketing Unit
Australian Institute of Health and Welfare
GPO Box 570
Canberra ACT 2601
Tel: (02) 6244 1032
Email: info@aihw.gov.au

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Please note that there is the potential for minor revisions of data in this report. Please check the online version at <www.aihw.gov.au> for any amendments.

Contents

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Abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ANDIAB	Australian National Diabetes Information Audit and Benchmarking
BGTS	blood glucose test strips
CSII	continuous subcutaneous insulin infusion
DCCT	Diabetes Control and Complications Trial
DoHA	Department of Health and Ageing
EDDC	Western Australia Emergency Department Data Collection
GP	general practitioner
IDF	International Diabetes Federation
IUs	International Units
JDRF	Juvenile Diabetes Research Foundation
NADC	National Association of Diabetes Centres
NCMD	National Centre for Monitoring Diabetes
NDSS	National Diabetes Services Scheme
NHMD	National Hospital Morbidity Database
NHMRC	National Health and Medical Research Council
NMD	National Mortality Database
PBS	Pharmaceutical Benefits Scheme
VEMD	Victorian Emergency Minimum Dataset

Symbols

—	nil or rounded to zero
. .	not applicable
n.a.	not available
n.p.	not publishable because of small numbers, confidentiality or poor data quality

Summary

This report explores how young Australians (aged 0–30 years) with diabetes are managing their condition, their use of health services, and the diabetes-related morbidity and mortality that they experience. The report findings are based on a range of data sources spanning the years 2001–2011.

In 2010, about 31,300 young Australians with diabetes were registered with the National Diabetes Services Scheme. Most (79%) had Type 1 diabetes. In 2007–09, 21,123 young Australians regularly obtained insulin through the Pharmaceutical Benefits Scheme, buying it 257,054 times. In the financial year 2009–10, there were 15,500 diabetes-related hospitalisations for this age group recorded in the National Hospital Morbidity Database.

Insulin pump use and blood glucose monitoring

- More than 7,300 people aged 0–30 (22% of people with Type 1 diabetes in this age group) used insulin pumps to treat their diabetes between 2004 and 2011. Insulin pump use was most common among people under 19.
- Only people with Type 1 diabetes using insulin pumps bought enough blood glucose test strips to meet recommended daily monitoring levels.
- People aged 19–24 bought blood glucose test strips at lower rates than other age groups, which suggests they are not managing their diabetes as well as others.

Health care sources

- Paediatricians and general practitioners (GPs) were the main providers (34 and 35% respectively) of insulin prescriptions for people under 19. GPs (70%) and endocrinologists (15%) were the main source of prescriptions for people aged 19–30.
- Young people with diabetes can have difficulty making the transition from paediatric to adult diabetes centres, and can experience poor health outcomes as a result.

Complications of diabetes and mortality

- Compared with other age groups, children aged 0–11 years had the highest rates of presentations for diabetes to hospital emergency departments in Victoria, New South Wales and Western Australia.
- People under 25 were hospitalised more often than those aged 25–30 for acute diabetes-related complications, such as ketoacidosis.
- The number of hospitalisations for ketoacidosis among people aged 0–24 increased over time from 2002–03 to 2009–10. These hospitalisations were associated with the presence of acute illnesses and a 'history of non-compliance with medical treatment', especially among people aged 12–24.
- Serious but preventable long-term complications of diabetes were already evident in some people aged 19–30, including nerve damage, foot ulcers, eye and kidney disease.
- Diabetes was the underlying cause of death of 88 people aged 0–30, and an associated cause of death for a further 76 in 2001–07. Most of these deaths occurred in people aged 25–30.

1 Introduction

The National Centre for Monitoring Diabetes has to date provided information mostly on all Australians with diabetes, and a focus on younger people has been relatively absent. In this report, we investigate issues that affect younger people with diabetes, by drawing on a range of data sources to provide an overview of diabetes in this group and insights into their diabetes experience.

Young people aged 0–30 face many physical, social and psychological changes as they mature and take up responsibility for their adult lives. A young person's health affects how they grow as a person and their long-term wellbeing and health outcomes (AIHW 2011d).

Childhood, adolescence and young adulthood are challenging times for a young person to experience a chronic disease like diabetes. The presence of this disease adds unique demands that need to be managed and requires a large amount of understanding. This is needed to effectively treat the disease, which is important to prevent or delay the onset of diabetes-related complications.

This report aims to explore the experience of young people living with diabetes in Australia. It seeks to describe from the national perspective their use of health services, self-care actions and morbidity (a level of illness). The results provide valuable baseline data, against which further study and more targeted research may be compared.

The report builds on other work by the Australian Institute of Health and Welfare (AIHW), including *Young Australians: their health and wellbeing 2011* (AIHW 2011d), *Cancer in young Australians* (AIHW 2011a) and *Diabetes and poor mental health and wellbeing* (AIHW 2011b).

The *Young Australians* report emphasises the importance of good health in this age group, because of this being the time when positive health and social behaviours are established. The *Cancer* report identified that young people with cancer have distinct medical, psychosocial and information needs, and that differences in access to and use of health care services are some of the factors that affect their health and wellbeing. The *Diabetes and mental health* report demonstrated that the rate of mental health problems in people with diabetes aged 0–29 was 3.4 times that of people without diabetes. Clearly then, the health and wellbeing of young adults with diabetes should be of much interest to policy makers, planners, service providers and the broader community.

Young people in Australia are affected mostly by Type 1 diabetes (see Box 1.1), but a smaller number are affected by Type 2 diabetes. As these young people mature, they must learn how to manage their disease for themselves and use the adult health care system.

These changes occur against the social and behavioural development of young adults. Similarly to children aged 0–11, people aged 12–18 are most likely to be at school and living at home. As developing adolescents, however, they are likely to be developing some level of independence. Those aged 19–24 are more likely to either be undertaking tertiary education or to have joined the workforce. The granting of adult privileges (ability to drive, eligibility to vote and to legally drink alcohol) and the potential for greater economic means may allow them to exercise more independence and possibly independent living arrangements. Differences in subsidies for insulin pumps and the transition from the use of paediatric to adult diabetes health services normally also occur across these nominal age groups.

Research has shown that many young people generally, and particularly those with diabetes, have difficulty in making the transition from paediatric to adult health services and can experience poor health outcomes as a result (Holmes-Walker et al. 2007).

This conclusion is underlined by the findings of the British National Diabetes Audit results on mortality in young people with diabetes (National Health Service Information Centre 2011). This work found that the mortality rate of males aged 5-34 with Type 1 diabetes was 4.2 times that of the same aged male general population, while that for females was 9.2 times that of the corresponding female population.

The focus of most health research on non-attendance must necessarily be on the health status of the non-attendees. However, it may well be that it is features of the health system that prevent or deter these people from using the health system.

Aims

This report therefore aims to investigate what is known about young people aged 0–30 with diabetes in Australia. It seeks to answer four broad questions:

- How are young people (aged 0–30) managing the treatment of their diabetes?
- Who provides health care for young people with diabetes?
- How much morbidity and mortality are young people with diabetes experiencing?
- How successful are young people in making the transition from paediatric health care to adult health care services, and what is the effect of this transition on their health?

National routinely collected datasets were analysed to answer the first three questions. There are no similar data that address the fourth question, and so the available research literature was analysed to answer this question.

Data sources and methods

This report explores possible differences in health care use, self-care actions and morbidity in young people with diabetes. Young people are defined here as people who are aged between 0 and 30. This age range has been divided into four groups, 0–11, 12–18, 19–24 and 25–30, to reflect their different social and behavioural situations.

Data from a range of sources were analysed to identify the health experience and health behaviour of young people (Table 1.1):

- Australian National Diabetes Information Audit and Benchmarking (ANDIAB) survey, for information on people who visit a diabetes centre
- Database of the National Diabetes Services Scheme (NDSS), for information on the quantities of consumables that the different age groups buy
- Pharmaceutical Benefits Scheme (PBS) database, which records all prescriptions for insulin that are filled by pharmacies.

These data sources relate mainly to the health maintenance behaviour of young people with diabetes. Other sources of data were also used that relate to the health outcomes (morbidity and mortality) of the diabetes population. These include:

- National Hospital Morbidity Database (NHMD), for information on all admissions to hospital

- National Mortality Database (NMD), for information on deaths and their contributing and underlying causes
- State-based databases of emergency department visits, which are maintained by the New South Wales, Victorian and Western Australian Health Departments (these are the data collections that identify patient diagnoses).

Each of these is described in more detail in Appendix A. The number of people living with diabetes in the different age groups was used to provide the background and denominator for these results. This information was obtained from the NDSS dataset.

Table 1.1 Data sources and diabetes population coverage

Dataset	Type of data analysed	Where analysed (chapter)	Diabetes population coverage
NDSS	People with diabetes	1	Type 1, Type 2, other and unknown diabetes.
PBS	Insulin prescriptions	3	Combined
NDSS	Sales of sharps[(a)], blood glucose test strips and urine testing strips	3	Type 1, Type 2, other and unknown diabetes.
ANDIAB	Diabetes centres	4	Type 1, Type 2, other and unknown diabetes.
NHMD	Hospitalisations	5	Type 1, Type 2, other and unknown diabetes.
Emergency department data (NSW, Vic and WA)	Emergency department presentations	5	Combined
NMD	Deaths	5	Type 1, Type 2, other and unknown diabetes.

(a) Syringe needles, pen needles and insulin pump products such as cannulas.

Report structure

The national health burden of diabetes in young people has been measured using population level data. The present introductory chapter outlines the number of young people affected by diabetes, the treatment they need and the health care services available to them.

Chapter 2, a review of the literature, identifies the particular challenges for adolescents in managing diabetes and the process of making the transition from paediatric to adult health care. The programs that are designed to make this process easier are described.

Chapter 3 explores the self-care that a person with diabetes uses when they are well and to maintain good health. Data on blood glucose monitoring and insulin use in particular are analysed. Chapter 4 analyses the health services that are used by young people with diabetes to maintain their health.

Data from Victoria are used in Chapter 5 to describe diabetes-associated presentations to hospital emergency departments. Admissions to hospital due to diabetes are analysed using AIHW's National Hospital Morbidity Database. Although rare, diabetes-related death does occur in young people, and so is also investigated.

The findings of this report are summarised and discussed in Chapter 6. We interpret the results that have been observed, and consider the factors that may affect them. Areas where further investigation is warranted are also identified.

Lastly, appendices are provided that contain further detail on datasets, analysis of emergency department visits in New South Wales and Western Australia that was repetitive, and tables of data that support figures in the report.

Diabetes

Diabetes is a disease in which the normal bodily processes that control a person's glucose levels no longer work correctly. There are several types of diabetes, the mechanisms for which are described in more detail in Box 1.1. In 1997, the Federal Government declared diabetes a National Health Priority because of the disease's significant impact on individuals and the health system as a whole, and its increasing level of occurrence.

Box 1.1: What is diabetes?

Diabetes mellitus (diabetes) is a chronic condition marked by high levels of glucose (sugar) in the blood. This condition is caused either by the inability to produce insulin (a hormone produced by the pancreas to control blood glucose levels), or the body cannot use insulin effectively, or both (World Health Organization 2006).

If left undiagnosed or poorly controlled, diabetes can lead to a range of complications including coronary heart disease, peripheral vascular disease, stroke, diabetic neuropathy (nerve disease), kidney failure, limb amputations and blindness (International Diabetes Federation 2006).

Type 1 diabetes is an auto-immune condition that usually first occurs in children or young people, although it can start at any age. It is marked by the almost complete inability to produce any insulin and those affected need insulin replacement for survival.

Type 2 diabetes is the most common form of diabetes. It occurs mostly in people aged 50 and over, and is still uncommon in childhood, although there are indications that it may be increasing among younger people. People with Type 2 diabetes produce insulin but may not produce enough of it or the body cannot use it effectively.

Gestational diabetes is a form of diabetes that may develop in women during pregnancy. It involves higher blood glucose levels appearing for the first time during pregnancy in women not previously diagnosed with other forms of diabetes. It is short-term and usually disappears after birth. This type of diabetes is excluded where possible from the analysis in this report.

Other types of diabetes can occur as a result of other conditions or syndromes, such as:

- genetic defects of beta-cell function in the pancreas and insulin action
- other diseases of the pancreas (including cystic fibrosis and cancer of the pancreas)
- endocrine disorders (for example, acromegaly and Cushing's Syndrome)
- drug- or chemical-induced diabetes (for example, steroid-induced diabetes)
- infections (for example, congenital rubella)
- uncommon but specific forms of immune-mediated diabetes mellitus
- other genetic syndromes sometimes associated with diabetes.

People can be affected by diabetes at any age. The two main types of diabetes (Type 1 and Type 2) have different ages at which they most commonly occur. Type 1 typically occurs in children, and beyond that, its incidence decreases with age. Type 2 diabetes, in contrast, mostly occurs in adults and increases with age. However, Type 2 does occur in teenagers, and so it is important where possible to identify the type because they have different health treatment requirements. Table 1.1, above, identifies which of the data sources distinguish the two types.

How many young people have diabetes?

Based on self-reports from the 2007–08 National Health Survey, 4% of the Australian population, an estimated 900,000 people, have diabetes. Most of these cases are Type 2 diabetes. In 2008, just over 5,700 of these were children aged 0–14 with Type 1 diabetes, the commonest form in this age group. This number is expected to increase a further 10% by 2013 (AIHW 2011c).

The best estimate of the number of diabetes cases in people aged 0–30 is obtained from the NDSS database. The NDSS subsidises the cost of syringes, pen needles, consumables for insulin infusion pumps, and diagnostic reagents (blood and urine testing strips) for people with diabetes.

At December 2010, around 31,300 people with diabetes aged 0–30 were registered with the NDSS. Women with gestational diabetes were excluded from this count. This number represents 0.3% of all Australians the same age, and 3.3% of all people with diabetes of any age registered on the NDSS.

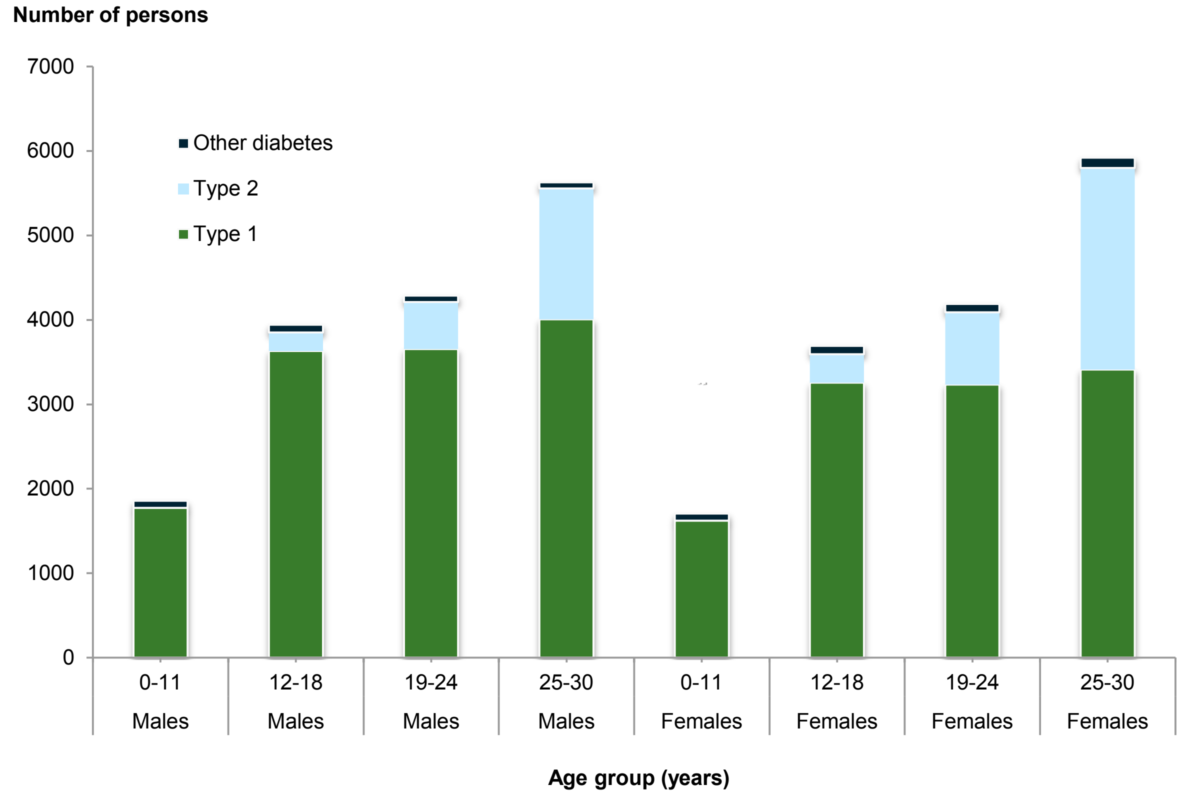
Although data for 2012 are available from the NDSS, the 2010 dataset is used in this report because it best matches in time the other data sources used in this report. The estimate is more likely to include, but is not limited to, people who use consumables such as syringes or pen needles to treat their diabetes. This captures almost all people with Type 1 diabetes and those who require insulin to treat their Type 2 diabetes. Whether a person has Type 1 or Type 2 diabetes can be medically difficult to determine in young adults. In reporting the numbers of each type from the NDSS dataset there is therefore a level of uncertainty about the actual numbers.

Most people registered with the NDSS aged 30 and under have Type 1 diabetes (79%). The number rises with age; there were 3,397 people aged 0–11 with Type 1 diabetes, 6,888 people aged 12–18, 6,891 aged 19–24 and 7,419 aged 25–30 (Figure 1.1 and Table C.1). There were more males with Type 1 diabetes, especially in the older age groups.

The proportion of persons aged 0–30 with Type 2 diabetes was lower (19%), but also rose with age; 557 people aged 12–18 with Type 2 diabetes, 1,411 aged 19–24 and 3,938 aged 25–30. There were more females with Type 2 diabetes, especially in the older age groups.

Of people aged 0–11, almost all (93%) had Type 1 diabetes, but in people aged 25–30 only 64% had this type.

The number of people with other types of diabetes was low (724, 2.3%) and changed little across the age groups. For very few (0.1%) the type of diabetes was unknown.



Note: Cases where diabetes type is unknown are not shown here. See Table C.1.

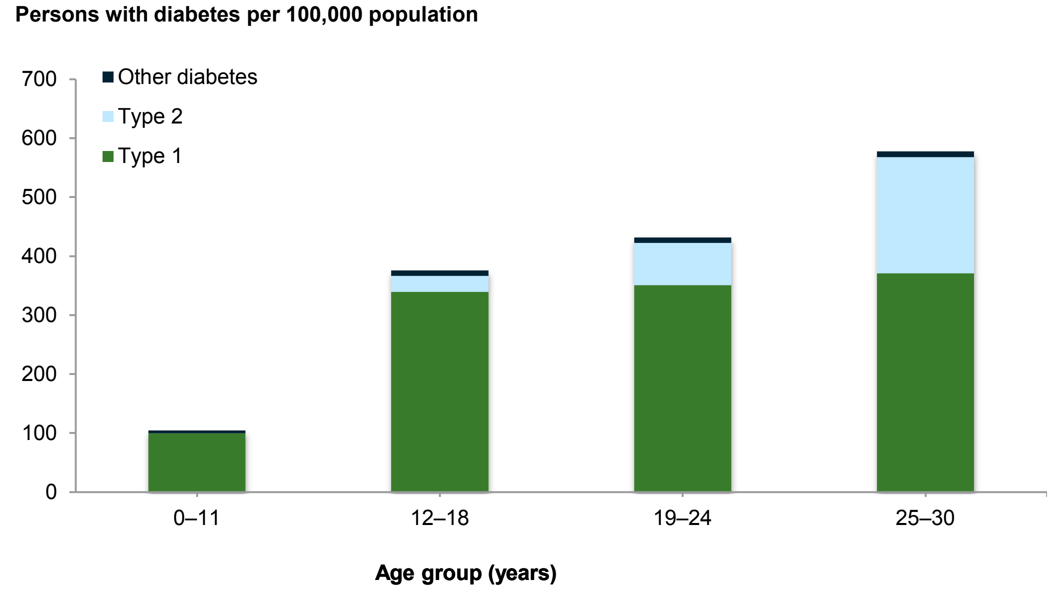
Source: AIHW analysis of NDSS data.

Figure 1.1: Males and females by diabetes type and age group, Australia, December 2010

The years of age included in these age groups are unequal and it is better to compare the figures as a rate in the Australian population. When the number of people with diabetes is compared against the total population, these data can be expressed as a rate. The rate of persons with Type 1 diabetes is highest in those aged 25–30 (371 per 100,000 persons) and is also high in those aged 12–18 (339 per 100,000) and 19–24 (351 per 100,000) compared with the rate of 100 per 100,000 in those aged 0–11 (Figure 1.2 and Table C.2).

The rate of Type 2 diabetes in the Australian population rises with age and is highest in those aged 25–30 (197 per 100,000) compared with the other age groups in this report (Figure 1.2).

The rate for other types of diabetes is lowest in those aged 0–11 (5 per 100,000) and is around 9 per 100,000 in the other age groups.



Note: Cases where diabetes type is unknown are not shown here. See Table C.2.

Source: AIHW analysis of NDSS data.

Figure 1.2: Rate of diabetes, by age group and diabetes type, Australia, December 2010

What treatment is needed for diabetes?

People with Type 1 diabetes require intensive constant treatment with insulin, the hormone that controls glucose levels in the blood. The treatment is highly individualised and needs to take into account numerous factors such as body weight, food intake and exercise. The monitoring of glucose levels, achieved with blood glucose test strips, is an essential part of the treatment process. The balance between insulin use and glucose levels can be upset by illness and other factors. One particular factor is the change in glucose metabolism that occurs with puberty, when the regular insulin treatment patterns developed in childhood are no longer as reliable as they were at controlling glucose levels.

The emphasis given to the treatment for Type 1 diabetes has changed greatly since the mid-1990s, when the clear benefits of tighter glucose control with more intensive insulin treatment in reducing complications were shown by researchers in the Diabetes Control and Complications Trial (DCCT) (The Diabetes Control and Complications Trial Research Group 1993). Further research since has confirmed the extended benefits of the tighter control of the original intervention (Polak et al. 2011; The Diabetes Control and Complications Trial/Epidemiology of Diabetes Interventions and Complications Research Group 2003).

Over this time, new forms of insulin and delivery methods, such as insulin pens and pumps, have also become more available and widely used. To achieve the tighter levels of control that are now recommended, people with diabetes need to master a great deal of information about how their blood glucose level varies over time, how it responds to eating and exercise, and how they can effectively use different kinds of insulin at different times.

The different forms of insulin that are available, and the way in which they are used, are summarised in Table 1.2.

Table 1.2: Insulin—information on the properties and actions of different forms

Insulin name used in this report	Insulin type	Brand name	PBS Item codes	Activity (hours)			Usual mode of use
				Onset	Time to peak	Duration	
Ultra-short acting (analogues) also known as Rapid							
Rapid	Insulin aspart	NovoRapid	8571D, 8435Y	0.1	1	3–4	Taken immediately before meals
Rapid	Insulin glulisine	Apidra, Apidra SoloStar	9224L, 1921D				
Rapid	Insulin lispro	Humalog	8084L, 8212F				
Short acting							
Short	Insulin neutral	Hypurin Neutral	1713E	0.5	2–3	5–6	Taken within 30 minutes before meal
		Actrapid	1531N, 1762R				
		Humulin R	1531N, 1762R				
Intermediate acting							
Intermediate	Insulin isophane	Hypurin Isophane	1711C	1–2	4–12	16–24	Taken once or twice daily
		Humulin NPH	1761Q, 1533Q				
		Protaphane	1533Q, 1761Q				
		Protaphane InnoLet	1761Q				
Long acting							
Long	Insulin detemir	Levemir	9040T	2–4	9	12–24	Taken once or twice daily
Long	Insulin glargine	Lantus, Lantus SoloStar	9039R	2		24	Taken once daily.
Pre-mixed combinations also known as Combination							
Combination	Insulin aspart + insulin aspart protamine suspension	NovoMix30	8609D	0.1	1	16–18	Taken once or twice daily
Combination	Insulin lispro + insulin lispro protamine suspension	Humalog Mix25	8390N	0.1	1	16–18	Taken once or twice daily
		Humalog Mix50	8874C				
Combination	Insulin neutral + insulin isophane (N.P.H.)	Humulin 30/70	1426C, 1763T	0.5	2–12	16–24	Taken once or twice daily
		Mixtard 30/70	1763T				
		Mixtard 50/50	1425B, 2062M				

The health service professionals who support people with diabetes to achieve the best glucose control are described in the next section.

An important part of the task of managing glucose levels is an awareness of current levels and how they have recently varied. Blood glucose monitoring strips are used to identify current glucose levels, and the most important indicator of past levels is the HbA1c test. This is described in Box 1.2.

Box 1.2: What is HbA1c?

When glucose circulates in the bloodstream, some of the glucose molecules combine with haemoglobin, the molecule that carries oxygen in the blood. This combined molecule is called glycated haemoglobin, or HbA1c. The level of HbA1c reflects the average amount of glucose in a person's blood over the previous 2–3 months, and is therefore useful as an indicator of how well people with diabetes are managing their disease.

It is measured in the laboratory and commonly expressed as a percentage. In current clinical practice, HbA1c concentrations are expressed both as a percentage and as mmol/mol.

Clinical guidelines state that children should aim to have HbA1c values below 7.5% (for adults the value is 7.0%). The attainment of lower values needs balancing against the increased risk of hypoglycaemia (low blood glucose). During hypoglycaemia, the brain can become starved of glucose and there is a risk of unconsciousness.

Health care services for diabetes

Clinical management guidelines recommend that people with Type 1 diabetes should be cared for by a multidisciplinary team (Craig et al. 2011). These most commonly operate in paediatric diabetes centres that are hospital outpatient services.

The teams most commonly include diabetes educators, endocrinologists, podiatrists, paediatricians, dieticians and psychologists or counsellors. Other health care professionals who care for people with diabetes include general practitioners (GPs), ophthalmologists, optometrists, pharmacists, exercise physiologists and dentists. According to the guidelines, the person with diabetes and their family should also be seen as important members of the team.

There are adult diabetes centres that have a similar range of health professional staff. Young people need to transition to using these services. The provision of specialist care distinguishes these centres from general practice.

People with diabetes, especially Type 1 diabetes, need to receive ongoing care from GPs and diabetes centres (paediatric or adult). Some people also choose to receive care from specialist endocrinologists in private practice (Figure 1.3). Referrals are required for people to access services from other sources of primary and secondary care. During episodes of acute illness caused by diabetes complications, people can get urgent health care from hospital emergency departments or they may be admitted to hospital.

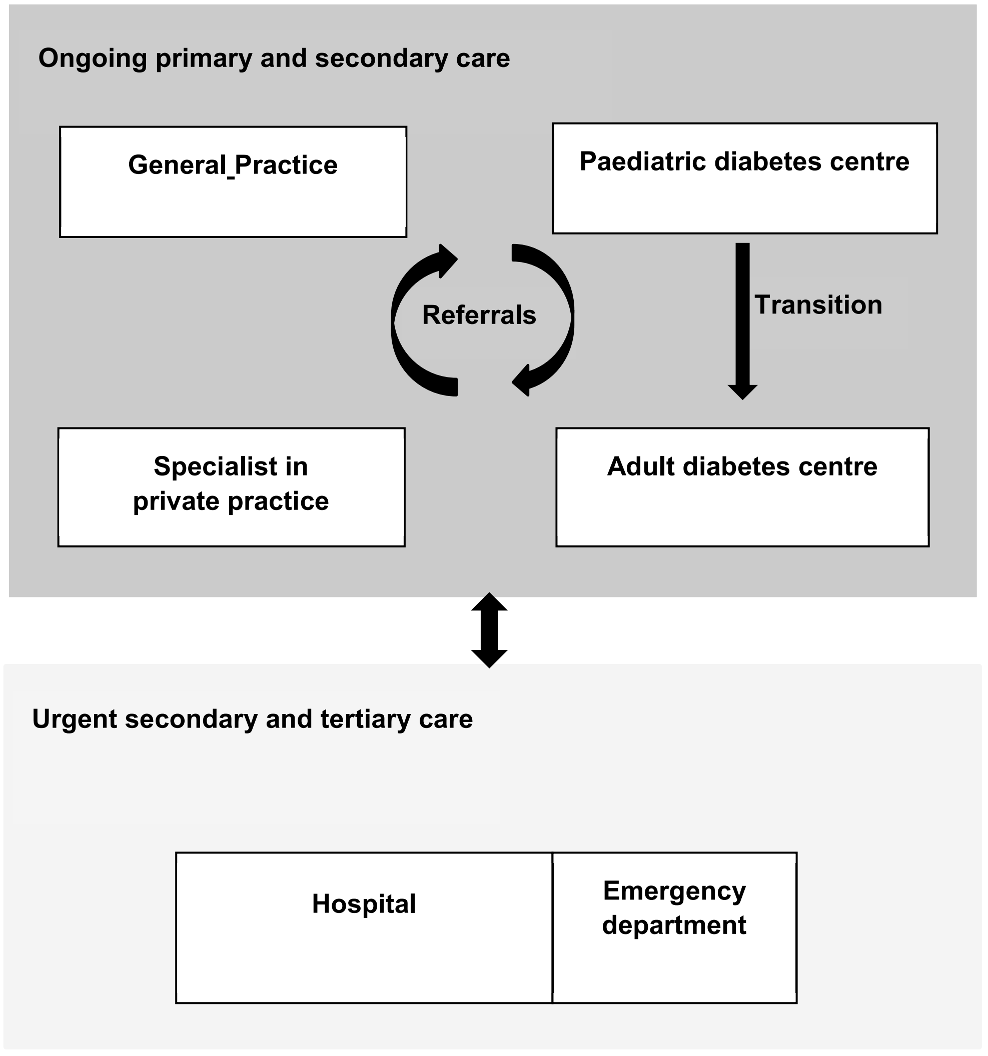


Figure 1.3: Diabetes health service providers within the health care system

2 Transition into adulthood and adult health care

A critical issue facing young people with a chronic disease, such as diabetes, is the need to assume responsibility for their own health. This includes managing their condition and making the transition from the paediatric to the adult health care system. How well people achieve these tasks has important implications for their health and wellbeing.

This chapter describes what is known about these issues from the literature, both internationally and in Australia, and the programs and measures in place to help people make this transition successfully. There is little information available and there are no data at a national level that would allow us to assess how well individuals are making these changes, or to relate them to their health outcomes.

Adolescence

Since the 1980s, a new view of health has emerged, which sees the health of young people, or adolescents, as being distinct from that of children or older adults (Alderman et al. 2003). Youth is a time of enormous development for young people, with change occurring across three main aspects of their lives—physical, psychological and social. The change across each of these dimensions is highly variable, and occurs at different times and pace for everyone.

The most visible changes are physical: the rapid growth in height and the onset of puberty. Change also occurs in the psychology of adolescents. This can include a higher level of self-conceptualisation, and new and different ways of thinking that are increasingly deep and abstract. The third area of change is in the social domain. Relationships with male and female peers alter radically, and how young people relate to their family also changes as they start looking towards more independence and self-sufficiency. These developments are desirable for the confident adoption of new adult roles and responsibilities.

The life skills that normally come with adulthood, which are required to successfully access and negotiate the adult health care system, include the ability to seek health care and advice when it is needed (including, for example, the making and keeping of appointments) and the behavioural skill of speaking for oneself in health care consultations (Johnson 1984). For children with a chronic condition, the need to manage their health care is present before they have developed these life skills. As children their parents bore this responsibility, but as they grow older the young adult at some stage will need to assume it.

Self-care in young people

The management of diabetes is a complex task, and to develop good habits of self-care, expert knowledge and much support is required. For children, this support is provided by their parents or carers as well as the staff of paediatric diabetes centres. As they grow older, they have to learn how to manage the disease for themselves and to develop their own habits of self-care. Part of this process includes integrating the support of experts on diabetes as they are found in diabetes centres.

The benefits of this model of care were first demonstrated in an English follow-up study in 1992. This showed that HbA1c levels in people attending the centre were significantly reduced, and that the admission rates for ketoacidosis and hypoglycaemia at the centre's associated hospital were also much reduced (Day et al. 1992).

The task of transitioning

Transitioning between the paediatric and the adult health care system has been identified as a challenge for young people with a chronic condition, and particularly for those with diabetes because of its disruption to the development of habits of good self-care. This section describes how these habits are disrupted and the health consequences of this disruption.

Regular attendance, three to four times annually, at a diabetes centre is now recommended in national guidelines for the clinical care of people with Type 1 diabetes, as the association of this attendance with better health outcomes has been clearly identified (Craig et al. 2011). For children attending paediatric centres, regular attendance is usually assured through parental organisation. For the young adult, however, making and attending appointments at an adult diabetes centre is increasingly their responsibility. A number of factors that affect their success at keeping appointments have been identified, but the issue remains that many young adults do not regularly attend a diabetes centre.

To demonstrate and quantify the rate of non-attendance, it is necessary to monitor the attendance of individuals over time, and to show that against either their own or the regular clinic attendance of other patients, these young adults have attended less regularly or not at all. This fact is further nuanced by the question of how long it is since the individual being monitored has been seen. Is a one month delay meaningful, or is the delay of a whole year at issue? In the research to be described, an important part of the evidence is that clear definitions of this criterion are provided.

What has been shown internationally?

Several studies have clearly demonstrated levels of non-attendance at diabetes clinics by young people with diabetes after transition.

A 2002 study by Oxford researchers measured attendance levels at diabetes clinics after the transition of study participants from paediatric to adult care. Attendance levels were monitored at least every three to four months and every six months (so that an individual who attended every three to four months will also have been recorded as attending every six months). The researchers demonstrated that the proportion of subjects attending at least every six months was markedly and significantly decreased after transition (Kipps et al. 2002) (Table 2.1). A notable result also was that in patients who failed to regularly attend a clinic post-transition, higher HbA1c levels had been observed two years *before* transition. Lastly, as part of the study, four different transition programs were also compared with the same methodology, from which a wide variation in attendance rates (21 to 79%) was also shown. This result gives support to the observation in the Introduction that health services need to be accessible.

Table 2.1: Rates of clinic attendance, Oxford 2002

Regularity of clinic attendance	2 years before transition	1 year before transition	1 year after transition	2 years after transition
		Per cent		
At least every 3-4 months	77	54	45	24
At least every 6 months	98	87	81	61

Source: Kipps et al. 2002.

A review of the literature on loss-to-follow up (the rate at which people do not attend a clinic appointment for an extended period, usually a year) found that the observed rates of non-attendance (defined in this study as not seen for more than a year) in English diabetes clinics ranged from 4 to 18%, and that the rate at one clinic in Ireland was more than 40% (Griffin 1998). This review also found that some people who had not attended a clinic were still receiving care from their general practitioner. In other studies referred to in this review, the health of people who saw only a GP was still poor compared with those who attended specialist diabetes clinics.

The focus of most research, however, has been on differences in morbidity rates between clinic attendees and non-attendees. The general finding has been that non-attendance at a clinic is associated with higher rates of diabetes-related complications. The disease outcomes that have been studied include rates of hospitalisation for diabetes ketoacidosis, HbA1c levels, and the presence of micro-albuminuria or retinal changes.

A North American study even found that young people who attended a clinic once or twice a year still had higher (worse) HbA1c levels than people who attended three or four times (Kaufman et al. 1999). Another study from England found that people attending a hospital clinic were three times less likely to be admitted to hospital for ketoacidosis than people who had not attended the clinic in the previous two years (Goyder et al. 1999).

One other notable study followed a cohort of young adults for 11 years, 75% of whom attended a diabetes clinic, while the rest were looked after by their GP or received no care (Bryden et al. 2003). The outcomes between those with no care or those who visited a GP were not compared. However, the overall results of the study were of concern and highlight the need for ongoing care for these patients: the proportion of all study participants with a serious complication increased from 3% at the start up to 37% at the end of the follow-up period. The proportion of patients with a psychiatric disorder was 28%. Twenty-six per cent of female patients had disordered eating habits, and 37% described misusing insulin in order to lose weight .

The findings of these studies need to be set within the wider perspective of non-attendance by patients within the broader health care system. Several studies provide useful insights. A recent editorial reported that rates of non-attendance at outpatient clinics in the United Kingdom varied from 5 to 34%. Waiting time was identified as the strongest predictor of non-attendance. Being male, a young adult and from a more deprived area were associated factors, and not owning a car or a telephone were also linked to non-attendance (Sharp & Hamilton 2001).

The second study, of failure to attend general practice appointments, focused on the use of appointment systems and how they can operate as a barrier to health care. The authors of this study write that: ‘Missed appointments reflect problems with the existing system of health care, whether from the patient's or the provider's perspective.' (George & Rubin 2003).

The third study provides a balanced account of the different sides of the issue, and also considered the impact of non-attendance on the patient's wellbeing. The investigators in this study identified 25 different predictors of non-attendance, and arranged them into environmental and patient factors, factors associated with the person's illness, and factors relating to the clinician or referring doctors. Although the study was set within a psychiatric outpatient service, the insight provided by the report into the causes of non-attendance are clearly relevant to the wider health system (Mitchell & Selmes 2007).

What has been shown in Australia?

A review of outcomes in Australia for children and adolescents with diabetes observed that a large body of outcome data has been produced following the Diabetes Control and Complications Trial (DCCT), and that reduced wellbeing, psychological health and maladaptation are significant problems but have been little recognised (Ambler et al. 2006; Northam et al. 2010). One of the studies also expressed the view that the improvements in metabolic control suggested by the DCCT trial would be best achieved through improved access to diabetes care teams at tertiary level (that is, larger) hospitals (Ambler et al. 2006). In light of this conclusion, the rate of attendance by young adults at diabetes clinics is important information.

In Australia, only one study that measured the efficacy of a new young adult diabetes clinic has shown explicitly that some young people are not progressing from paediatric care to adult diabetes health services (Holmes-Walker et al. 2007). The authors found that only 82% of those who had left paediatric care had attended an appointment with the adult service in the six months before the study audit. Twelve per cent had attended an appointment between 7 and 12 months previously, while 6% had not attended for more than 12 months. For the program's efficacy, this study demonstrated a clear reduction in the number of cases of diabetic ketoacidosis resulting in admission to hospital. Improved HbA1c levels were also demonstrated in the patients who had attended the young adult clinic two or more times, compared with the values observed for patients' first attendance at the new clinic.

Note that what can be known about the health and wellbeing of young people with diabetes can only be gained from their contact with the health system. The health status of young people who have not attended a diabetes clinic is therefore unknown.

Why is transition difficult?

The effective use of adult health services is a life skill that has to be learnt. People with diabetes need to learn this from a young age. The magnitude of this task is emphasised by the numerous differences between the paediatric and adult health care settings, and their contrasting cultures. The major difference between the two settings is in the expected roles of the patient (Table 2.2). In the paediatric system the patient is part of the family team, whereas in the adult system, the patient is expected to be an informed and autonomous individual. There is a formal element to this in that hospitals require adults to provide informed consent to receive treatment. This aspect, and a number of others that add to the magnitude of the task are summarised in Table 2.2.

Table 2.2: Generalised characteristics of paediatric and adult diabetes health care

	Health service setting	
Factor	**Paediatric**	**Adult**
Primary ‘patient’ role	Families and individuals as part of care team	Autonomous individual and support network as part of care team
Responsibility for making and keeping appointments	Little required, as family supports	Self
Role of family	Central	Peripheral
Responsibility for self-care	Strong family involvement	Independent self
Location of ancillary and specialist services	Co-located	Fragmented, geographically separate
General focus of care	Supporting normal growth & development	Management of illness (problem solving and resolution)

A number of studies have sought to better understand why young people might not attend diabetes clinics. Some of these have focused on barriers to care, while others have emphasised mismatches between the aims of the young adult in seeking health care and what the health providers offer.

Diabetes Australia, in its survey of young people with diabetes, found that major barriers to care for young adults were long waiting lists to see a specialist or general practitioner of their choice, getting time off work or study to attend an appointment, lack of transport, and the cost of the care (Diabetes Australia 2006). A Canadian study also found that time constraints, waiting times and the hospital environment (sterile, impersonal) prevented or deterred young people from attending (Scott et al. 2005).

A more wide-ranging review contrasts the distinct needs and cultures of the paediatric and adult health care systems, and suggests that a system of care that is more responsive to the needs of young people with diabetes is required (Weissberg-Benchell et al. 2007). A report by Gilbert and Millard, referred to in the 2011 NHMRC Clinical Guidelines (Craig et al. 2011), suggests that people with diabetes were most interested to learn about diet, sources of support (online and from peers), and about the adjustment of insulin doses with physical activity. In contrast, the diabetes health professionals who were surveyed thought that young people needed most to be informed about professional counselling and mental health care, legal and employment issues, and to be provided with information about contraception and alcohol and other drugs.

Transition programs in Australia

The peak consumer and advocacy organisation Diabetes Australia has recognised the importance of transition through its national policy platform. It advocates having transition care plans and improvements in access to health services for all young people with diabetes aged 15–24 (Diabetes Australia 2010). The National Diabetes Services Scheme sends a ‘transition pack’, comprising a birthday card and information on transition for parents, to people with diabetes aged 12–21 each year on their birthday.

Other initiatives that aim to keep young people in touch with the health system are now being implemented at the jurisdictional level.

The *Sweet* program was developed in 2006 in Queensland, where an estimated 30% of clients of the paediatric services clinic at Mater Children's Hospital were being lost each year to follow-up (Lang 2011). The program aims to improve the engagement of young people with diabetes with the health system, by effectively transitioning them to adult care services, and to ensure that they are being screened for complications according to national and international guidelines.

In New South Wales, the *Diabetes Transition Support Program* is based at Westmead Hospital. It began in 2001 and focuses on people aged 15–25. A recent audit found that age at transition was unrelated to a person's measured HbA1c value at their first visit to the hospital's adult diabetes centre. However, a gap of more than six months between their last visit to the paediatric centre and their first visit to the adult centre resulted in significantly higher (worse) HbA1c levels than did those whose first visit was sooner (Farrell & Holmes-Walker 2011).

In Western Australia, almost all children with diabetes attend the diabetes centre at the Princess Margaret Hospital for Children. This was confirmed by Dr Wendy Davis in an email on 19 January 2012 (Davis 2012). Young adults, as part of their transitioning process, are referred to their nearest adult clinic. For those moving from Princess Margaret Hospital to adult centres, educators from these centres attend the paediatric centre to meet the patient before their transition. Young adult clinics are also run at the Fremantle and Rockingham General Hospitals to facilitate the transition process.

In Victoria, the Monash Medical Centre provides a Young Adult Diabetes Service. This is closely integrated with the Centre's paediatric service, and a planned transfer from this to the co-located young adult service occurs around the age of 15. To improve accessibility for young adults, the service provides evening clinics twice a month. In addition to the co-located presence of a multidisciplinary team of health care providers, a clinical nurse coordinator provides appointment reminders for patients. Four long-term and regularly employed clerical staff also provide a familiar and consistent welcome to the clinic (Rodda et al. 2012).

3 Blood glucose monitoring and control

Background

Insulin is essential for the regulation of blood glucose levels, and a complete lack of this hormone quickly leads to death. This was the inevitable outcome for people with Type 1 diabetes before 1922, when insulin was discovered by Canadian researchers. Since then, people with Type 1 diabetes have been able to enjoy full and active lives. For people with Type 2, the problem of high blood glucose levels can at first be treated with oral anti-hyperglycaemic (blood glucose lowering) drugs. As the disease progresses, people with Type 2 diabetes may have to start using insulin. Women with gestational diabetes may also have to use insulin during their pregnancy. The amount of insulin needed by a person is affected by many factors, including their levels of physical activity, what they eat and body weight.

Insulin is delivered into the body by sub-cutaneous (under-the-skin) injection. There are three methods of insulin delivery: by syringe, pen or insulin pump. This last method is also referred to as continuous sub-cutaneous insulin infusion (CSII). An insulin pen is a discrete syringe-like device that enables insulin doses to be easily modified and given unobtrusively. The little needles for insulin pens are provided by the NDSS, and so the pattern of their use across the age groups is analysed in this part of the report. This information complements the PBS data on insulin purchases, which are analysed in the second part of this chapter.

In order to best control blood glucose, it is necessary to know its level and how this changes with meals and exercise and other factors. Monitoring devices and glucose test strips are used by people to measure and monitor their glucose levels, and thus to determine the amount of insulin they need to use.

The issue with glucose monitoring is how often people are testing their levels to adjust their treatment regime and inform their course of action. How many test strips they buy from the NDSS each month can indicate how often or closely they are doing this. It is also possible to buy strips to test blood glucose levels in the urine, and these are analysed separately.

Insulin pump use

An increasing proportion of people with diabetes are using an insulin pump (AIHW 2012b). The number of people aged 0–30 buying insulin pump products between January 2004 and July 2011 was 7,333. This corresponds to 22% of the people with Type 1 diabetes in the same age group in the NDSS data set (Table 3.1). People aged 18 and under at the time of their first purchase of any NDSS product were more likely to be using a pump than people who were older, with 38% of those aged 0–11 and 21% of those aged 12–18 buying pump products. The rate for the two older age groups was lower at 14% of people aged 19–24 and 15% of people aged 25–30.

Since 2008, eligible people under 18 can receive subsidies for up to 80% of the cost of buying insulin pumps from the Australian Government and the Juvenile Diabetes Research Foundation. This may be a contributing factor to the rising use of pumps in people under 18.

The National Centre for Monitoring Diabetes (NCMD) has also reported in more detail on the experiences of people who use insulin pumps (AIHW 2012b).

Table 3.1: People buying insulin pump consumables, by age group, Australia, January 2004–June 2011

	Age group (years at first purchase)				
	0–11	12–18	19–24	25–30	0–30
Number buying insulin pump consumables	3,210	1,912	1,053	1,158	**7,333**
Proportion of age group buying insulin pump consumables (%)	38	21	14	15	**22**

Source: AIHW analysis of NDSS data.

Blood glucose monitoring

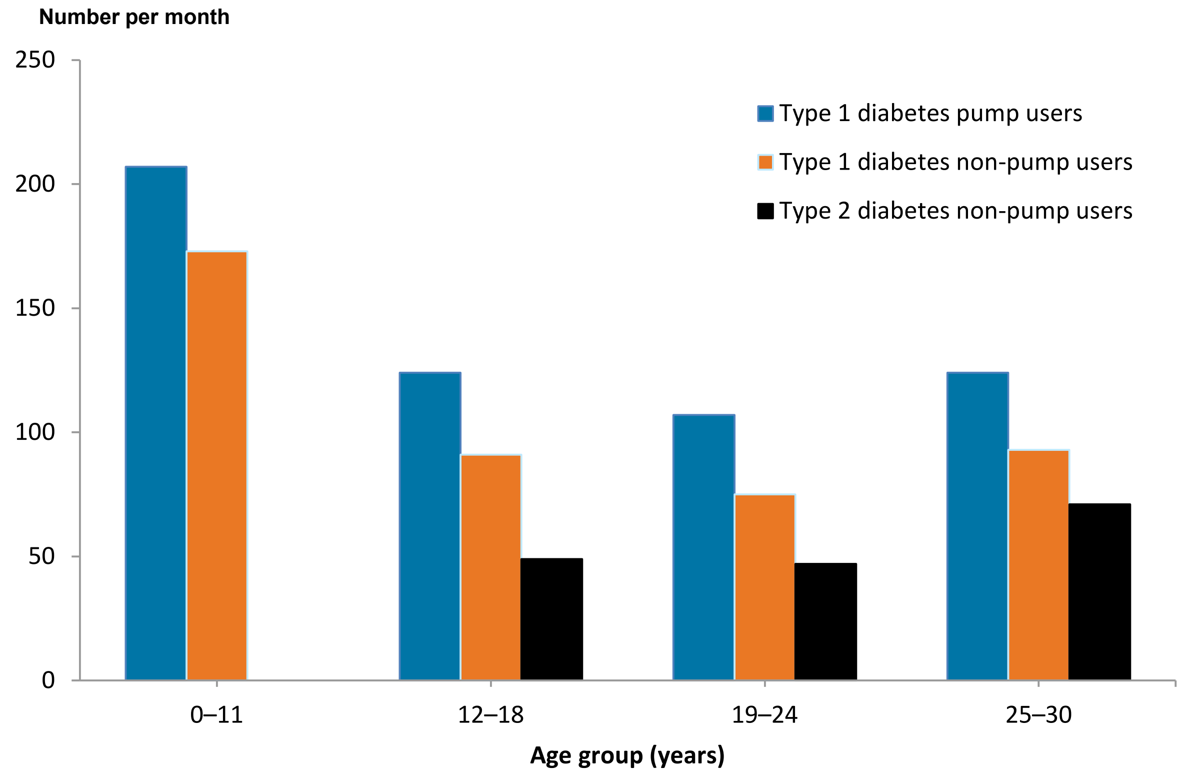
NDSS data on purchases of blood glucose test strips (BGTSs) and other consumables were analysed according to diabetes type and whether insulin pumps are used. This is because these groups have a different focus on how they monitor their glucose levels.

People aged 0–30 with Type 1 diabetes who used a pump had a higher rate of buying BGTSs per month (158 BGTSs), than did people with Type 1 diabetes not using a pump (105 BGTSs) or those with Type 2 diabetes (63 BGTSs) (tables 3.2, 3.3 and 3.4).

Children aged 0–11 bought more BGTSs per month than people in the other age groups. Those aged 12–18 had the next highest rate of buying BGTSs, followed by those aged 25–30. People aged 19–24 had the lowest rate of buying BGTSs per month (Figure 3.1).

This same pattern was observed in those with Type 1 diabetes with and without a pump and to a lesser extent in those with Type 2 diabetes (results shown below). For example, people with Type 1 diabetes with a pump aged 0–11 bought 207 BGTSs per month, compared with those aged 12–18 who bought 124 per month, and those aged 19–24 (107) and 25–30 (124 BGTSs).

The BGTS results presented here are based on the NDSS data. It is also possible for people to buy these strips through the PBS. Without linking the two data sources it is not possible to determine if the variations in buying rates observed here are being compensated for by purchases through the PBS, or whether the observed differences in buying rates across age groups represent a real effect.



Source: AIHW analysis of NDSS data.

Figure 3.1: Average monthly purchase rates of blood glucose test strips (BGTSs) through the NDSS, by age group, Australia, January 2004–July 2011.

Consumables obtained by people with Type 1 diabetes using an insulin pump

Overall, on average each month a person with Type 1 diabetes using an insulin pump obtained 158 BGTSs, 43 needles, 4.7 insulin reservoirs and 5.4 cannulae for insulin pumps, and 2.5 urine test strips for glucose (Table 3.2).

Table 3.2: Average monthly purchase rates of consumables by users of insulin pumps with Type 1 diabetes, Australia, January 2004–July 2011

	Age group (at first purchase)				
Item	**0–11**	**12–18**	**19–24**	**25–30**	**0–30**
	Number per month per person				
Blood glucose test strips	207	124	107	124	**158**
Needles	51	39	29	43	**43**
Insulin pump reservoirs	5.1	4.7	3.5	4.1	**4.7**
Cannulae	6.0	5.2	4.1	5.3	**5.4**
Urine test strips	2.4	1.9	1.8	6.0	**2.5**

Note: Needles or syringes could not be distinguished.

Source: AIHW analysis of NDSS data.

All these rates varied across age groups. The monthly purchase rates for most items were highest for people aged 0–11 (Table 3.2), while the lowest were for those aged 19–24. The number obtained each month by the 19–24 group (107 BGTSs) was half that of the 0–11 age group (207), and 16% less than for the 25–30 age group (124). The use of urine test strips was higher in the 25–30 age group (6.0 strips) than in the 0–11 age group (2.4 strips).

Consumables obtained by people with Type 1 diabetes not using an insulin pump

On average, young adults with Type 1 diabetes not using a pump obtained 105 BGTSs, 64 needles or syringes, and 2.8 urine test strips each month (Table 3.3). Again, children aged 0–11 had the highest monthly purchase rates, at 173 BGTSs, 93 needles or syringes, and 2.9 urine test strips each month. The lowest rates were again consistently observed in those aged 19–24, with monthly purchases of 75 BGTSs, 46 needles or syringes, and 1.8 urine test strips. The age group-specific purchase rates for BGTSs are shown in Figure 3.1, together with the rates for the pump users and people with Type 2 diabetes.

Table 3.3: Average monthly purchase rates of consumables by people with Type 1 diabetes NOT using insulin pumps, Australia, January 2004–July 2011

	Age group (years at first purchase)				
Item	**0–11**	**12–18**	**19–24**	**25–30**	**0–30**
			Number per month per person		
Blood glucose test strips (BGTSs)	173	91	75	93	**105**
Needles	93	66	46	54	**64**
Urine test strips	2.9	2.1	1.8	6.7	**2.8**

Note: Needles and syringes cannot be distinguished in this data set.

Source: AIHW analysis of NDSS data.

Consumables obtained by people with Type 2 diabetes not using a pump

The average number of consumables bought by people with Type 2 diabetes not on an insulin pump is shown in Table 3.4. Data for the 0–11 age group are not shown because of the small number of people with Type 2 diabetes in this age group. The pattern of monthly purchases of BGTSs and needles or syringes is smaller, but the quantities of urine test strips are higher than those for people with Type 1 diabetes.

Overall, people aged 0–30 with Type 2 diabetes obtained 63 BGTSs, 44 needles or syringes, and 8.2 urine test strips each month. The use of urine test strips was lower in the 19–24 age group (4.6 test strips) compared with the rate of 13.7 for the 25–30 age group (Table 3.4).

Table 3.4: Average monthly purchase rates of consumables by people with Type 2 diabetes NOT using insulin pumps, Australia, January 2004–July 2011

	Age group (years at first purchase)			
Item	**12–18**	**19–24**	**25–30**	**0–30**
	Number per month per person			
Blood glucose test strips (BGTSs)	49	47	71	**63**
Needles or syringes	34	35	49	**44**
Urine test strips	2.8	4.6	13.7	**8.2**

Note: Needles and syringes cannot be distinguished in this dataset.

Source: AIHW analysis of NDSS data.

Blood glucose control with insulin

The use of exogenous (injected) insulin is essential to survival for people with Type 1 diabetes, who make up most of the young population with diabetes. The filling of a prescription for insulin by a person specifically indicates two pieces of information. The first is that they have diabetes (not necessarily Type 1), and the second is that their need for insulin will, with one qualification, continue. This qualification is that people with gestational diabetes usually need to use insulin only for the course of their pregnancy. Otherwise, once a person is using insulin, the continued use of it can be expected with a high degree of certainty.

How much and which form of it a person actually uses, however, is less certain. This is because the amount of insulin dispensed has to be greater than the quantity required (otherwise, the amount would be insufficient). The amount required depends mostly on the person’s level of activity and amount and type of food that they eat. Different forms of insulin (rapid, fast, combined) are also used in combination or at different times to further tailor an individual’s blood glucose control. Nonetheless some regularity in supply should be apparent, and this can be indicated by the number of prescriptions an individual fills over time.

Box 3.1: Analysis method for PBS and NDSS data sets

The PBS prescription data and NDSS consumable data can be analysed at both the population and the individual level.

Population level analysis

All of the prescription or consumable records are considered together, and the results relate to the population with diabetes as a whole. Thus, we might say that 84,000 prescriptions for insulin were filled in a year, and that a proportion of this quantity was for a specific type of insulin. From this non-personal point of view, we can explore how these data vary across age groups or according to other factors of interest.

Individual level analysis

Contrasting this, the second level of analysis is based on the prescription and consumable records that are linked to a single person. Here we are more interested to know about the number of prescriptions that the 'average' person with diabetes has obtained, or how many glucose test strips the 'average' person has used in a month. For these calculations, the entire period for which any product data for an individual are present is used to determine monthly consumption rates. This is in contrast to other work by the NCMD, which has used only the period for which a specific product was obtained, to calculate the consumption rate for that product.

Statistical measures

Mean

The mean is the sum of observations divided by the number of observations. This statistic is used to describe the usual amount of products bought by people in the NDSS and PBS datasets.

Median

The median is used in situations where the average might be 'misleading' in that it is not representative of the observations as a whole. An example is where most people have a low value of some parameter but one or two people have extreme values that widely skew the average value away from the most typical value. In contrast, the median is the middle point of a series of ordered observations. This report uses the median number of scripts filled, to summarise the PBS dataset.

Interquartile range

In the same way that a median divides a set of ordered observations into halves, quartiles are the observations that divide a dataset into four equal parts. The interquartile range, the difference between the values of the upper and lower quartiles, is used to give an idea of the spread of data values. This report has used this statistic to describe the variation in the number of prescriptions filled.

95th percentile

The 95th percentile, which is used with the ANDIAB HbA1c data, is the value of the observation that separates the top 5% of observations from the other values of the distribution.

How many people are supplied with insulin?

For the three-year period 2007–2009, a total of 21,123 people aged 0–30 regularly obtained insulin (that is, four or more times over the period) with a prescription through the PBS. The number of people in each age group is shown in Table 3.5.

There were more males than females in all the age groups and, overall, males accounted for 53% of the cohort. Around 95% of people aged 0–30 bought insulin for use in an insulin pen injecting device at least once during the study period.

Table 3.5: Characteristics of people and amount of insulin supplied, by age group, Australia, 2007–09

	Age group (years)				
	0–11	12–18	19–24	25–30	0–30
Number of persons	3,503	6,289	5,906	5,425	**21,123**
Males	1,799	3,300	3,112	2,885	**11,096**
Females	1,704	2,989	2,794	2,540	**10,027**
Males (%)	51	52	53	53	**53**
Pen users[a] (%)	93	96	96	96	**95**
Median number of prescriptions filled per person	12	13	11	9	**11**
Interquartile range	9–15	10–17	9–14	6–12	**8–15**

(a) Bought insulin for delivery using a pen needle at least once in 3 years.

Source: AIHW analysis of PBS data.

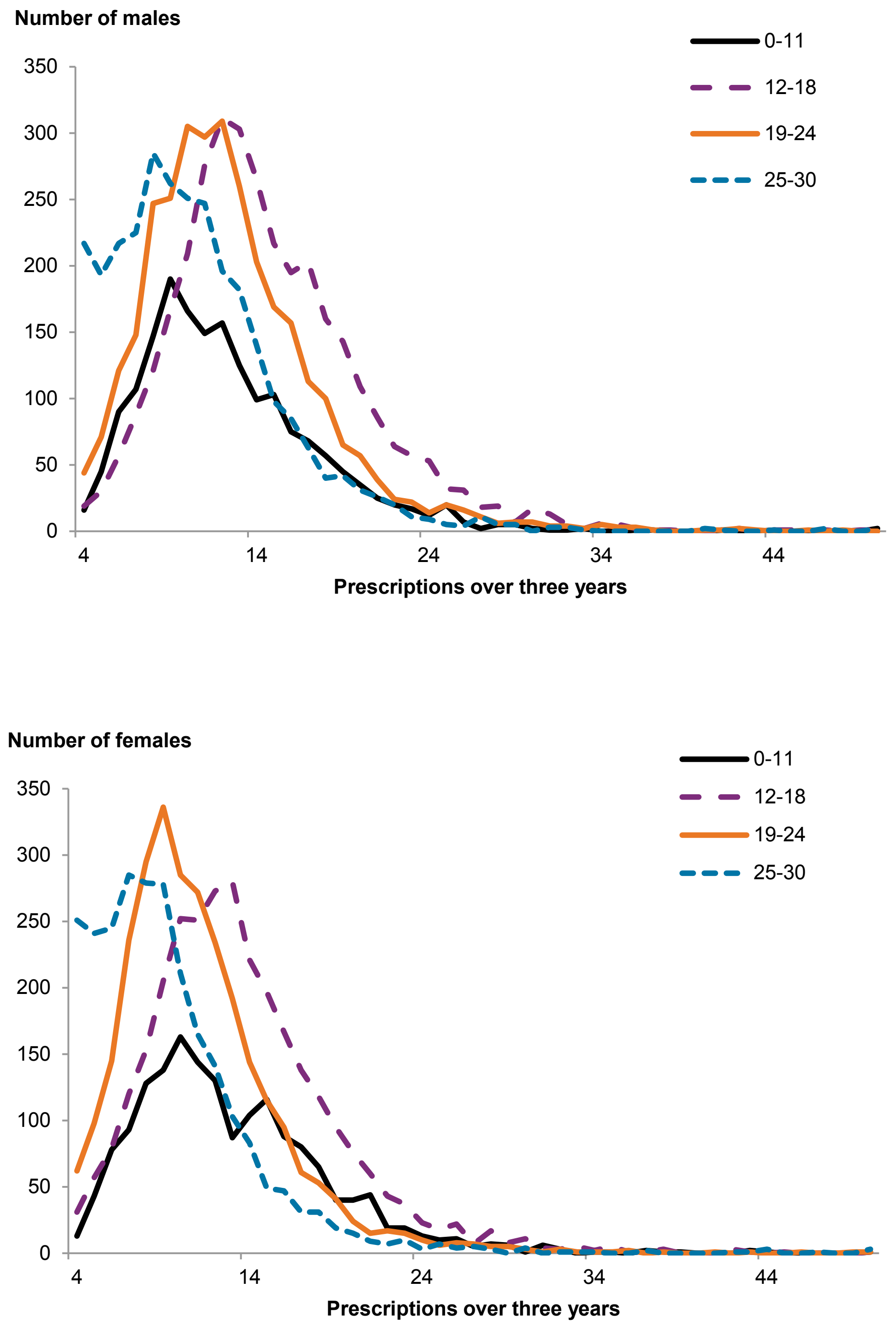
How many prescriptions for insulin were filled?

The total number of regularly filled insulin prescriptions for people aged 0–30 in the three-year period 2007–2009 was 257,054, a rate of 85,685 per year. The number filled per person during the period varied from 4 (the minimum selected) to more than 50. The median number of prescriptions filled per person during the period was 11, and half the number of people who filled prescriptions did so between 8 and 15 times (Table 3.5).

The effect of gender on these statistics is shown in Figure 3.2 where the male and female-specific patterns across the different age groups are shown. This separation by gender allows the possible effect of purchases by females with gestational diabetes to be observed. However, the limitation of the dataset to people obtaining four or more prescriptions should already have removed nearly all of these records.

The highest number of insulin prescriptions filled per person was observed for both males and females aged 12–18, the median values for which were 13 prescriptions for males (interquartile range 10–17) and 12 prescriptions for females (interquartile range 9-15).

For both sexes, the increased height of the curves indicates a larger number of people aged 12–18 and 19–24 taking the amount plotted, compared with the number of people aged 0–11. The position more to the right of the curve for people aged 12–18 indicates a larger number of prescriptions filled per person in that age group. Correspondingly, the leftwards position of the curves for the 19–24 and 25–30 age groups indicates a generally lower number of prescriptions filled per person.



Source: AIHW analysis of PBS data.

Figure 3.2: Number of insulin prescriptions supplied over three years for males (a) and females (b) by age group, Australia, 2007–09

However, the number of people who filled only four prescriptions was also largest in the 25–30 age group. It is likely that many of these records represent different types of users and behaviours, including:

- people who are newly diagnosed with diabetes, who have only been prescribed insulin four times since diagnosis
- people who are poorly compliant, who are using reduced doses, or who are skipping insulin treatments
- people with Type 2 diabetes, whose use of insulin is part of a combined regime with oral anti-hyperglycaemic drugs, and who are therefore using smaller amounts
- people being present in the dataset for varying amounts of time. This includes some who may have 'aged out' of the cohort, if they were aged 30 in 2007, the first year of the study period.

What kind of insulin is obtained?

Insulin is available in several different forms that act for different lengths of time (Table 1.2, above). People with diabetes often use more than a single form in a regime to provide an initial and fast amount of glucose control, such as before eating, and then for an extended period of control, between meals or overnight. They can do this using pre-mixed insulins (Combination) or by mixing the different insulin forms themselves just before injecting. Although this last behaviour is now unusual, some people still practise it because of the flexibility in insulin control that it provides.

A reserve supply of fast or rapid insulin is also kept at home by some people for use on 'sick-days', a time when blood glucose levels can rapidly change and need to be quickly controlled. Lastly, while people may have obtained these different forms of insulin, it is not possible to know whether they have actually been used, either together or alone. Expert opinion from the National Diabetes Data Working Group suggests, however, that where two types of insulin have been dispensed, both forms of the insulin are being used.

In the analysis that follows (Table 3.6), the proportions of people using only a particular insulin type are presented. The higher proportions using only rapid insulin, compared with the other forms, can be related to the use of this form of insulin in pumps. Also, the proportion of people using only Combination insulin increased, from 0.1% in the 0–11 age group up to 4.3% in the 25–30 age group. Otherwise, the proportions are mostly very low, which indicates that the majority of people aged 0–30 with diabetes are using more than one type of insulin.

Table 3.6: Proportion of cohort only buying single forms of insulin in three years, Australia, 2007–09

	Age group (years)				
Insulin types	**0–11**	**12–18**	**19–24**	**25–30**	**0–30**
			Per cent		
Rapid (R)	5.8	5.5	4.5	3.9	**4.9**
Short (S)	0.0	0.0	0.1	0.2	**0.1**
Long (L)	0.1	0.1	0.2	0.4	**0.2**
Intermediate (I)	0.1	0.1	0.1	0.3	**0.2**
Combination (Z)	0.1	1.3	3.3	4.3	**2.4**

Source: AIHW analysis of PBS data.

The proportion of people being dispensed a particular form of insulin, without reference to the other forms they may also be obtaining, is shown in Table 3.7.

Table 3.7: Proportion of cohort buying particular forms of insulin, Australia, 2007–09

	Age group (years)				
Insulin types	**0–11**	**12–18**	**19–24**	**25–30**	**0–30**
			Number		
Rapid (R)	2,297	5,862	5,312	4,609	**19,080**
Short (S)	1,494	1,787	906	991	**5,178**
Long (L)	2,640	5,179	4,477	3,692	**15,988**
Intermediate (I)	2,234	2,484	2,270	2,436	**9,424**
Combination (Z)	199	777	693	671	**2,340**
			Per cent		
Rapid (R)	94.1	93.2	89.9	85.0	**90.3**
Short (S)	42.6	28.4	15.3	18.2	**24.5**
Long (L)	75.4	82.4	75.8	68.1	**75.7**
Intermediate (I)	63.8	39.5	38.4	44.9	**44.6**
Combination (Z)	5.7	12.4	11.7	12.4	**11.1**

Source: AIHW analysis of PBS data.

Prescriptions for rapid insulin were supplied for 90% of people aged 0-30 in 2007–09 (Table 3.7). The supply rates for the other forms were: short (25%); long (76%); intermediate (45%) and Combination (pre-mixed short and intermediate) (11%). However, these values also varied across the age groups.

Among people aged 0–11, 94% filled prescriptions for rapid insulin. This value decreased across the older age groups, and for those aged 25–30 the value was 85%. The prescription rate for long insulin varied from 68% for people aged 25–30, up to 82% for people aged 12–18. Prescriptions for Combination insulin were least commonly filled by those aged 0–11 (6%), while the proportion in the other age groups was higher: for those aged 12–18 and 19–24 the rate was 12%.

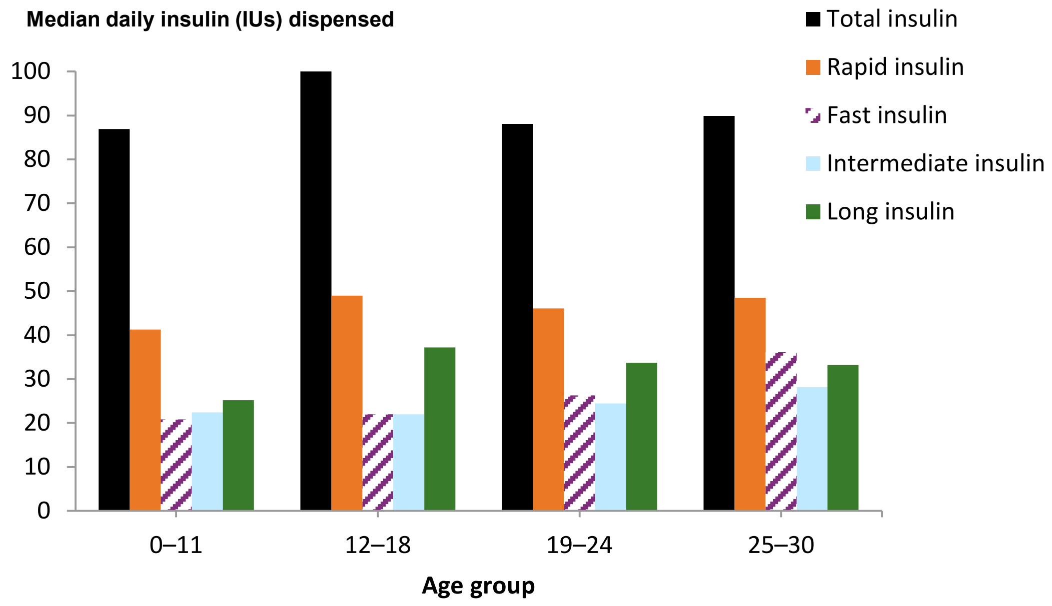
What doses of insulin are being dispensed?

The second way in which the insulin data were explored was by analysing the amounts of insulin dispensed per person. This analysis has the advantage that it takes into account the differing periods of time that people were present in the PBS dataset. To remove the influence of extreme values, median statistics (see Box 3.1) are the primary statistic used in the analysis.

The median amount of total insulin dispensed per person aged 0–30 was 92 international units (IUs) per day (Figure 3.3). The value was highest (101 IUs per day) in those aged 12–18, while the values for the other age groups were under 90 IUs per day.

Compared with the older age groups, people in the 0–11 age group were dispensed smaller amounts of rapid (41 IUs per day) and long insulin (25 IUs per day). The older age groups were dispensed more than 46 IUs of rapid insulin and 33 IUs of long insulin per day.

The amount of short (fast) insulin dispensed increased across the age groups, from 21 IUs in the 0–11 age group up to 36 IUs per day in the 25–30 age group.



Source: AIHW analysis of PBS data.

Figure 3.3: Median daily amount of insulin dispensed, by insulin type and age group, Australia, 2007–09

What combinations of insulin are being dispensed?

As shown in Table 3.6, only a small number of people had prescriptions filled for single types of insulin. Just over a thousand people (n=1,025, 4.9%) had prescriptions filled for rapid insulin by itself, and half that number (n=518, 2.4%) had prescriptions only for Combination insulin.

Where an individual has prescriptions filled for more than one type of insulin, it cannot be known whether the different forms are being used at the same time, or whether they were in the process of changing their treatment regime. The results presented in Table 3.8 are at least documenting the insulin types that have been bought by young adults with diabetes, and provide some suggestion as to the pattern of insulin regimes being used.

The combination of two insulin types (rapid and long) was the pattern most frequently observed in the study population, which was recorded for 7,363 people (35%). Results for the most commonly observed combinations of insulin types are shown in Table 3.8, and for all the possible combinations in Figure 3.4.

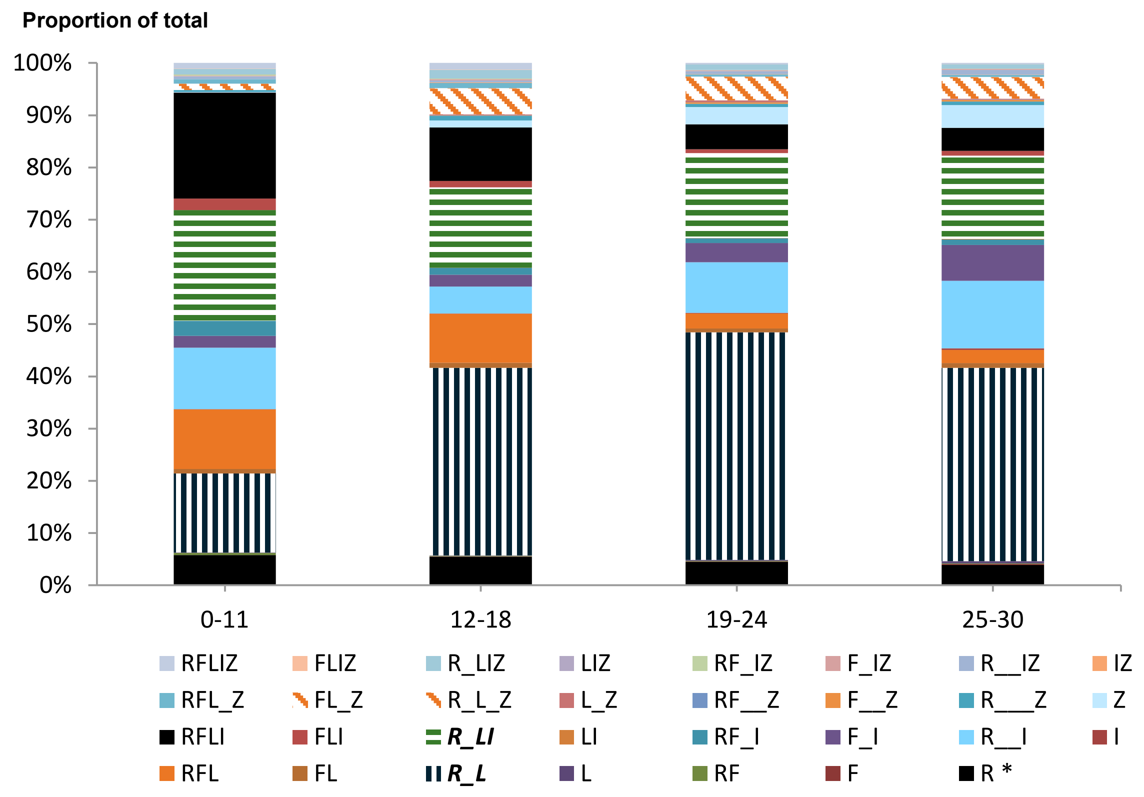
Table 3.8: Proportion of cohort buying combinations of different insulin types, Australia, 2007–09

	Age group (years)				
Insulin types	**0–11**	**12–18**	**19–24**	**25–30**	**0–30**
			Number		
Rapid and long (RL)	531	2,255	2,571	2,006	**7,363**
Rapid and intermediate (RI)	412	323	572	703	**2,010**
Rapid, long and intermediate (RLI)	744	968	958	866	**3,536**
			Per cent		
Rapid and long (RL)	15.2	35.9	43.5	37.0	**34.9**
Rapid and intermediate (RI)	11.8	5.1	9.7	13.0	**9.5**
Rapid, long and intermediate (RLI)	21.2	15.4	16.2	16.0	**16.7**

Source: AIHW analysis of PBS data.

For people aged 0–11, the most common combination of insulin types was the rapid, long and intermediate pattern, observed for 21% (Table 3.8 and Fig. 3.4), while 15% had the rapid and long insulin pattern, and 12% the rapid and intermediate insulin pattern. In contrast, the pattern most observed for those aged 12–18 was the combination of rapid and long insulin (36%). In the 19–24 age group, this combination was observed in 43%.

A final feature of these data is the presence of small numbers of people who have prescription records for long insulin only (Table 3.6), without prescription records for other insulin types. The number of people with this pattern increased with age. In those aged 0–11, less than five people were observed, while in those aged 25–30, 55 (0.4%) were observed using this type of insulin. In view of this pattern, it is possible that these people have Type 2 diabetes, and that the increased usage with age reflects the increased occurrence of Type 2 diabetes with age. This interpretation is supported by published expert advice that refers to the use of long insulin by people with Type 2 diabetes (Wong & Yue 2004).



Note: R=rapid; F=short; L=long; I=intermediate; Z=Combination.

Source: AIHW analysis of PBS data.

Figure 3.4: Proportion of cohort buying insulin types over time by age group, Australia, 2007–09

Who prescribes insulin?

Pharmacists normally dispense insulin with a doctor's prescription. For each supply of insulin reported to the PBS, information about the specialty of the prescribing doctor is also notified. This provides important evidence about the type of doctors who are caring for people with diabetes (Table 3.9).

GPs, the largest group of prescribers, wrote 54% of prescriptions for people aged 0–30. Paediatricians (14% of prescriptions) and endocrinologists (16%) were the other main prescribing doctors. This pattern varied markedly across the age groups.

For people aged 0–11, paediatricians were the primary source (39%) of insulin prescriptions, (Table 3.9 and Figure 3.5). GPs (29%) were the next most important source. For those aged 12–18, 32% of prescriptions came from a paediatrician, while the proportion written by GPs increased to 38%.

For people aged 19–24, 67% of prescriptions were written by a GP, while just 2% were written by paediatricians. For those aged 25–30, the proportion written by a paediatrician was less than 1%. GPs wrote 72% of the prescriptions for people in this age group.

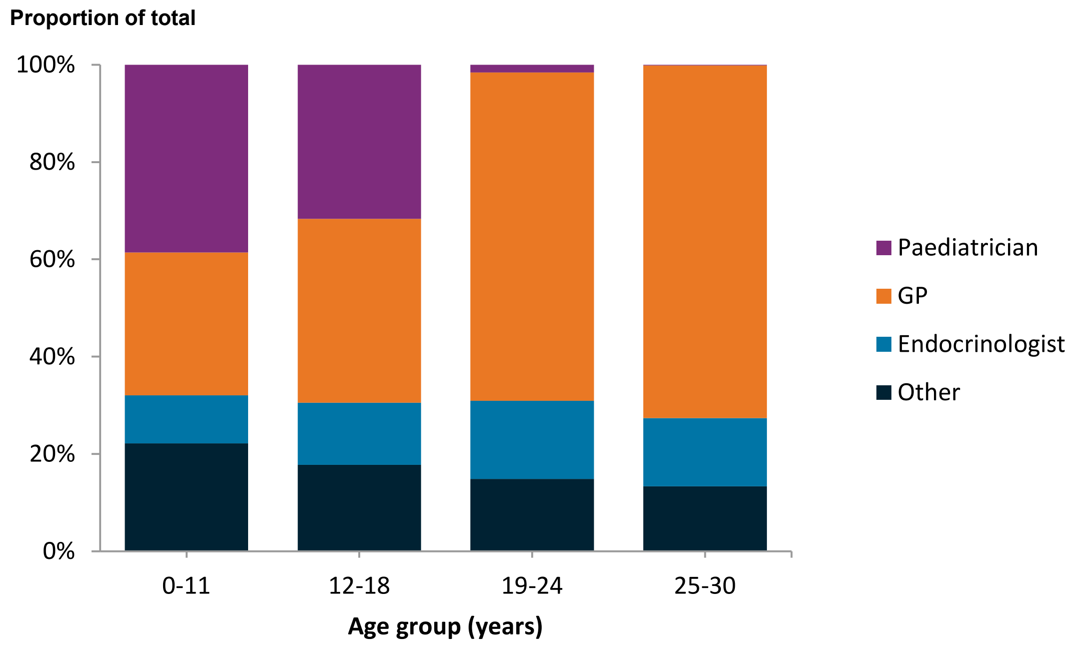
Endocrinologists and other specialist doctors together wrote about 30% of the prescriptions. This amount changed little across the four age groups (Figure 3.5). Specialists may be giving directions to GPs on what to prescribe to patients but this cannot be shown with this dataset. Therefore this result may underestimate the level of care provided by specialists.

Health care providers in the 'other' category were from a wide range of specialists, such as cardiologists, psychiatrists or surgeons.

Table 3.9: Specialty of prescribing doctor by patient age group, Australia, 2007–09

	Age group (years)				
Medical specialty	0–11	12–18	19–24	25–30	0–30
			Number of insulin prescriptions		
Paediatrician	12,117	26,609	1,133	109	**39,968**
GP	9,219	31,732	47,395	49,354	**137,700**
Endocrinologist	3,101	10,704	11,296	9,554	**34,655**
Other	6,975	14,926	10,425	9,111	**41,437**
Total	**31,412**	**83,971**	**70,249**	**68,128**	**253,760**
			Per cent		
Paediatrician	38.6	31.7	1.6	0.2	**15.8**
GP	29.3	37.8	67.5	72.4	**54.3**
Endocrinologist	9.9	12.7	16.1	14.0	**13.7**
Other	22.2	17.8	14.8	13.4	**16.3**
Total	**100.0**	**100.0**	**100.0**	**100.0**	**100.0**

Source: AIHW analysis of PBS data.



Source: AIHW analysis of PBS data.

Figure 3.5: Proportion of insulin prescriptions provided by medical specialty, Australia, 2007–09

4 Use of health care services

General practice

General practitioners (GPs) are often the first point of contact for Australians with a health problem. As demonstrated in Figure 3.5, they provide most of the prescriptions for insulin to people aged 0–30. However, younger persons with Type 1 diabetes are typically supported in the management of their diabetes by a multi-disciplinary team based in a diabetes centre. GPs may be associated with such a team, but by definition they are not located at diabetes centres.

Diabetes centres

Diabetes centres are specialist centres that bring together a range of health care providers to work as a team to care for people with diabetes. The provision of more specialist care distinguishes these centres from general medical practice.

In Australia there are 66 diabetes centres, which are located in major cities and towns (National Association of Diabetes Centres). In some states or territories, a person with diabetes might have to travel some way to attend one of these clinics.

The National Association of Diabetes Centres (NADC) regularly surveys the clinical activity of its diabetes centre members. Data relating to more than 8,500 people who attended a centre in 2009 were included in the 2009 Australian National Diabetes Information Audit and Benchmarking (ANDIAB) survey. This survey does not contain data from all diabetes centres, but it is based on data obtained from most of the major centres and all the states and territories. More information is provided in Appendix A.

Who attended diabetes centres?

In the ANDIAB survey, 3,167 people were surveyed who were aged 30 or less: 2,509 (79%) were aged 0–18 and 658 (21%) were 19–30. These two age ranges are analysed separately (Tables 4.1 and 4.2) because they are reported by different diabetes centres (paediatric or adult) and on different forms representing different datasets of information.

Of those aged 0–18 attending diabetes centres, 65% were aged 12–18 (Table 4.1). There were slightly more males than females: 52% of people aged 0–11 and 51% in the 12–18 group. Almost all attendees in these age groups had Type 1 diabetes: 99% of those aged 0–11 and 97% of people aged 12–18. People with Type 2 diabetes were less than 1% of those aged 0–11, but this increased to 2.3% of those aged 12–18. Other types of diabetes were also recorded but these were minimal (less than 0.5%).

Almost everyone aged 0–18 attended paediatric centres: 99% of those aged 0–11 and 96% of those aged 12–18.

Table 4.1: Children aged 0–18 attending diabetes specialist centres, ANDIAB survey, 2009

	Age group (years)			
	0–11	12–18	0–11	12–18
	Number of people		Per cent of age group	
People in age group	885	1,624		
Male	458	825	51.8	50.8
Female	427	792	48.2	49.2
Missing	0.0	7	0.0	0.4
Type 1 diabetes	880	1,581	99.4	97.4
Type 2 diabetes	n.p.	37	n.p.	2.3
Other diabetes type	n.p.	n.p.	n.p.	n.p.
First visit	22	44	2.5	2.7
Attended paediatric centre	881	1,565	99.5	96.4
Attended adult centre	4	59	0.5	3.6

Source: AIHW analysis of ANDIAB 2009.

For people aged 19-30 who attended a diabetes centre, 66% were 19–24 (Table 4.2). There were fewer males than females: 46% of those aged 19–24 and 35% of those aged 25–30 were male.

The proportion of people with different diabetes types changed markedly across the age groups. In those aged 19–24, 89% had Type 1 diabetes while in those aged 25–30 this proportion had reduced to 74%. People with Type 2 diabetes accounted for 6% of those aged 19–24, and 9% of those aged 25–30. Of people aged 25–30, the proportion of attendees diagnosed with other types of diabetes was 14%.

It was the first visit for 8% of people aged 19–24 and 13% of people aged 25–30.

Attendance at a paediatric centre by people older than 18 appears to have ceased by age 25: only 81 people aged 19–24 (19%) attended a paediatric centre, while no-one aged 25–30 did.

Table 4.2: Adults aged 19–30 attending diabetes specialist centres, ANDIAB survey, 2009

	Age group (years)			
	19–24	25–30	19–24	25–30
	Number of people		Per cent of age group	
People	437	221	66.4	33.4
Male	200	78	45.8	35.3
Female	218	140	49.9	63.3
Missing	19	3	4.3	1.4
Type 1 diabetes	390	163	89.2	73.8
Type 2 diabetes	27	19	6.2	8.6
Other diabetes type	9	30	2.1	13.6
First visit	35	29	8.0	13.1
Attended paediatric centre	81	0	18.5	0.0
Attended adult centre	356	221	81.5	100.0

Source: AIHW analysis of ANDIAB 2009.

How well were glucose levels controlled?

Levels of glycated haemoglobin (HbA1c) reflect a person's blood glucose concentrations over the course of months (Box 1.2). This gives one indication of how their diabetes is being managed over a longer time. Table 4.3 shows the proportions of people in the different age groups whose HbA1c value was higher than the targets recommended by clinicians (for people aged 0–18 the target value is 7.5%, for those aged 19 or older it is 7.0%). For the two younger age groups, this proportion was 73%. For those aged 19–24 the value increased to 80%, and for those aged 25–30 it was 71%.

Values of the median and 95th percentiles for the different age groups are also shown in Table 4.3 to provide more insight into the distribution of HbA1c values for each age group.

The median HbA1c value varied little between the groups. For people aged 0–11 it was 8.1%, compared with 8.3% in those aged 12–18, 8.2% in those aged 19–24 and 7.8% in those aged 25–30.

The 95th percentile is the value of the HbA1c statistic for which 95% of values in the dataset were lower (conversely, 5% of the population had values that were higher than this HbA1c value). For children aged 0–11, the value of the 95th percentile was 10.1%. The value for those aged 12–18 was higher (11.6%) and in those aged 19–24 higher again (12.8%). For those aged 25–30, the value was 11.9%, lower than the previous group but not lower than the first group mentioned.

The proportion of people not meeting the target HbA1c level was highest in those aged 19–24. The 95th percentile HbA1c value was also the highest in this age group compared with other age groups. In combination with the observed median HbA1c values, these results suggest that the variability in HbA1c values is widest in those aged 19-24.

There were numbers of missing values for the HbA1c data. Across the age groups, the proportion of these ranged from 11% up to 31%. The latter value was for the 19–24 age group.

Table 4.3: HbA1c results for people attending specialist diabetes centres, by age group, 2009

	Age group (years)			
Statistic	**0–11**	**12–18**	**19–24**	**25–30**
Number exceeding recommended HbA1c level[(a)]	550	1,057	240	120
Per cent exceeding recommended HbA1c level (%)[(a)]	72.6	72.9	80.0	71.4
Median HbA1c value (%)	8.1	8.3	8.2	7.8
HbA1c 95th percentile value (%)	10.1	11.6	12.8	11.9
Number of missing values	127	174	137	53
Per cent of values missing	14.4	10.7	31.4	24.0

(a) For people aged 18 or under the cut-off value is 7.5%, and for those over 18 it is 7.0%.

Source: AIHW analysis of ANDIAB 2009.

5 Diabetes-related morbidity and mortality

Hospital emergency department services

On arriving at an emergency department, all patients are classified into a triage category according to how urgently they need medical attention. The triage category of Resuscitation means the person needs immediate medical attention, whereas the definition Emergency cases need to be treated within 10 minutes of arrival. Other categories include Urgent (ideally treated within 30 minutes), Semi-Urgent (1 hour) and Non-Urgent (2 hours). Following treatment in an emergency department some people are discharged and return to their residence. Others require further treatment and may be admitted to the hospital attached to the emergency department or another hospital.

Data from New South Wales, Victoria and Western Australia are used in this report to measure the use of emergency department services by young people with diabetes. These states are the only ones that record diagnosis information.

How many people presented to emergency departments for diabetes?

Basic information on emergency department presentations for diabetes is shown in Table 5.1. To compare rates across the states, however, the method of data collection needs also to be appreciated. In New South Wales, data are collected from around 81–83% of emergency departments in the state, whereas in Victoria 100% of departments provide data. In Western Australia, only about 50% of emergency department admissions are ICD-10 coded, but those that are represent admissions to nine of the ten metropolitan hospitals, and thus the major teaching (the largest and most important) hospitals in the state.

Table 5.1: Rate of visits for diabetes as a principal diagnosis, by data coverage and state, people aged 0–30, 2005-06 to 2009-10

	NSW	Vic	WA
Average annual number of diabetes presentations	1,323	1,286	321
Rate of diabetes presentations in 5 years (per 1,000 population)	0.5	0.6	0.3
Proportion of emergency departments in state providing data	81–83%[(a)]	100%	12%[(b)]
Period of data studied	2005–06 to 2009–10 (5 years)	2005–06 to 2009–10 (5 years)	2005–06 to 2009–10 (5 years)

(a) 81% from 2005–06 to 2007–08 and 83% from 2008–09 to 2009–10.

(b) These 10 include 9 of the 10 metropolitan hospitals and one rural hospital.

Notes: AIHW analysis of emergency department presentations for diabetes as a principal diagnosis (ICD-10-AM E10–E14 and ICD-9 250).

Source: New South Wales based Emergency Department Information System; Victorian Emergency Minimum Dataset (VEMD); and Western Australia Emergency Department Data Collection.

Data from New South Wales and Western Australia therefore cannot be compared directly with the Victorian data. At the broadest level, however, the rate of visits for diabetes across the three states shown in Table 5.1 are consistent. For this reason, and to provide indicative information on what the national picture might look like, the data from Victoria are analysed in this chapter. Results from New South Wales and Western Australia are shown in Appendix B.

Attendance rates across the age groups in Victoria

In Victoria, presentations for diabetes represent only a small proportion (0.1%) of all emergency department presentations for all conditions by people of all ages (6.7 million in 5 years).

When comparing diabetes presentations for people aged 30 or under, the highest proportions of presentations were for people in the 12–18 age group (34%) (Table 5.2). Presentations by 0–11 year olds represented around 25% and a similar proportion (26%) were for 19–24 year olds. Around 16% of presentations were for 25–30 year olds.

These age groups are of different sizes. There are different numbers of people with diabetes in the community who access these services. For these reasons, it is important to compare the rate of presentations per person with diabetes in Victoria.

The overall average annual rate of emergency department presentations for people aged 0–30 was 16.9 presentations per 100 people with diabetes in Victoria.

Children aged 0–11 had the highest average annual rate (34.2 presentations per 100 people with diabetes) of emergency department presentations (Figure 5.1). This compares with 22.3 for those aged 12–18, 16.1 for those aged 19–24 and 7.6 for those aged 25–30.

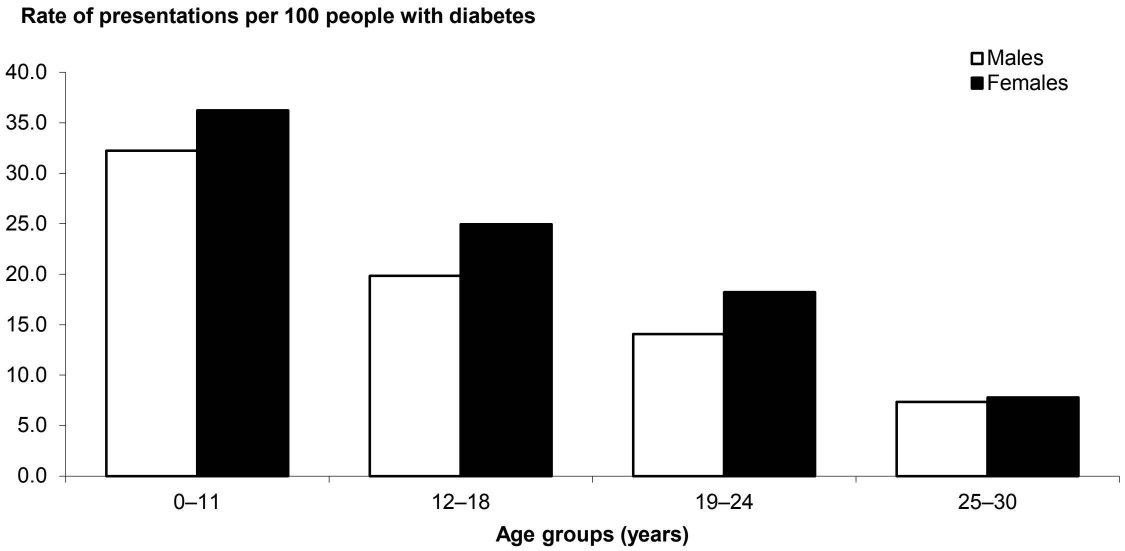
Table 5.2: Average annual emergency department diabetes presentations by people aged 0–30, Victoria, 2005–06 to 2009–10

	Emergency department presentations		
Age group (years)	**Average number**	**Per cent**	**Rate per 100 persons with diabetes**
0–11	319	24.8	34.2
12–18	433	33.7	22.3
19–24	330	25.7	16.1
25–30	204	15.8	7.6
0–30	**1,286**	**100**	**16.9**

Note: Presentations with a principal diagnosis of diabetes (ICD-10 code E10–E14).

Source: AIHW analysis of Victorian Emergency Minimum Dataset (VEMD).

The rates of presentation were higher for females than for males in all age groups except for people aged 25–30 (Figure 5.1). Females aged 0–11 had an average annual rate of 36 per 100 people with diabetes compared with 32 in males. Females aged 12–18 had an average annual rate of 25 per 100 people with diabetes compared with 20 in males.



Note: Presentations with a principal diagnosis of diabetes (ICD-10 code E10–E14).

Source: AIHW analysis of Victorian Emergency Minimum Dataset (VEMD) and National Diabetes Services Scheme.

Figure 5.1: Average annual rate of presentations to an emergency department for diabetes, by age group and sex, Victoria, 2005–06 to 2009–10

How many diabetes presentations arrived by ambulance?

Ambulances respond to requests for medical attention at any location. If a person requires further medical attention, they are transported by the ambulance to the emergency department. This can indicate severity or urgency of the condition but ambulances can also be used by people without other means of transport.

The proportion of diabetes presentations that arrived by ambulance varied by age group and was smallest in people aged 0–11 (14%). In comparison, 24% of presentations by those aged 12–18 arrived by ambulance and this was only slightly higher for those aged 19–24 (26%) and those aged 25–30 (28%).

The proportion of diabetes presentations that arrived by ambulance was higher in Western Australia and New South Wales than in Victoria; especially in adults aged 25–30 (Appendix B).

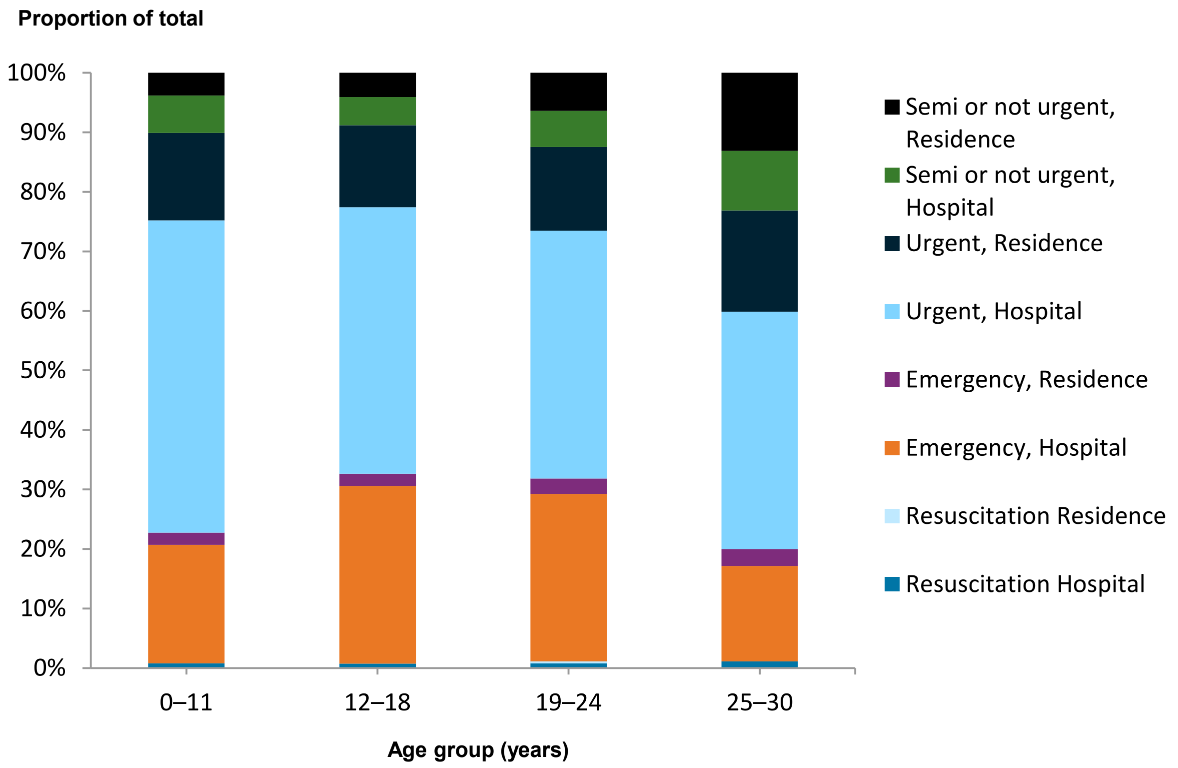
Triage category and departure

This report compares the pathway from clinical severity to the type of departures or outcomes for diabetes presentations made by people in different age groups.

The number of deaths following a presentation for diabetes was too low to reliably report this statistic for any of the states. However, another outcome of treatment that can be reported is the number of departures for further treatment in hospital or to a place of residence.

Around 1% of diabetes presentations in Victoria were assigned the triage category Resuscitation. Almost all of these presentations departed the emergency department for further hospital treatment.

A big difference between the age groups was the higher proportion of diabetes presentations by people aged 12–18 (31%) and 19–24 (29%) assigned the triage category Emergency and then departed to hospital (Figure 5.2). This is compared with 22% of diabetes presentations by those aged 0–11 and 17% of diabetes presentations by those aged 25–30. The proportion of Emergency presentations that then returned to residence was similar in all age groups and ranged from 2% to 3%.



Notes

1. Hospital departure includes the following categories: Wards, Short Stay Unit, Transfer out of this Hospital to another Hospital, Transfer to another Hospital, Emergency Medical Unit, Medical Assessment and Planning Unit, Intensive Care Unit, Another hospital campus, Coronary Care Unit and Mental Health Observation/Assessment Unit.
2. Residence includes: Aged Care residency, Home, Left at own risk after treatment started, Correctional/Custodial Facility.
3. Presentations involving a death in the emergency department are not included.

Source: AIHW analysis of Victorian Emergency Minimum Dataset (VEMD).

Figure 5.2: Proportion of diabetes presentations given a triage category and who 'departed' to hospital or their place of residence, Victoria, 2005–06 to 2009–10

The majority of emergency department presentations for diabetes were Urgent. The proportion of Urgent presentations was highest in those aged 0–11. Around 58% of presentations for people in this age group were classified as Urgent and required treatment in a hospital and a further 16% were Urgent and could return to their residence (Figure 5.2). Of presentations by people aged 12–18, 47% were Urgent and departed to a hospital, and 15% were Urgent and returned to their residence.

Many Semi-urgent or Non-Urgent presentations for diabetes required further hospital treatment despite the low triage category. Semi- and Non-Urgent presentations were more common for people in the 25–30 age group (11% needed hospitalisation and 14% returned to residence) than in the other age groups (Figure 5.2).

Admitted patient hospital services

How many hospitalisations for diabetes in Australia were there?

For young people, hospital care is often needed at the time of diagnosis of Type 1 diabetes and the commencement of insulin pump therapy. For all types of diabetes, admission to hospital may also be needed during episodes of acute complications such as ketoacidosis and hypoglycaemia. Some long-term complications for diabetes are also treated in hospital for people aged 30 or under, such as for kidney, eye and neurological complications.

In this section, data for 2009–10 from the whole of Australia are analysed. There were 8,386 hospitalisations with a principal diagnosis of diabetes for people aged 30 or under. Of these, 93.4% were for Type 1 diabetes, 5.2% for Type 2 diabetes, 0.6% for other types of diabetes and 0.8% for diabetes type unknown. Slightly more of these hospitalisations were for females (54%) compared with males (46%).

Diabetes was an additional diagnosis for a further 7,086 hospitalisations in 2009–10. A large proportion of these were for Type 1 diabetes (68.8%) compared with 21.9% for Type 2 diabetes, 8.7% for other type of diabetes and 0.6% where the type is unknown.

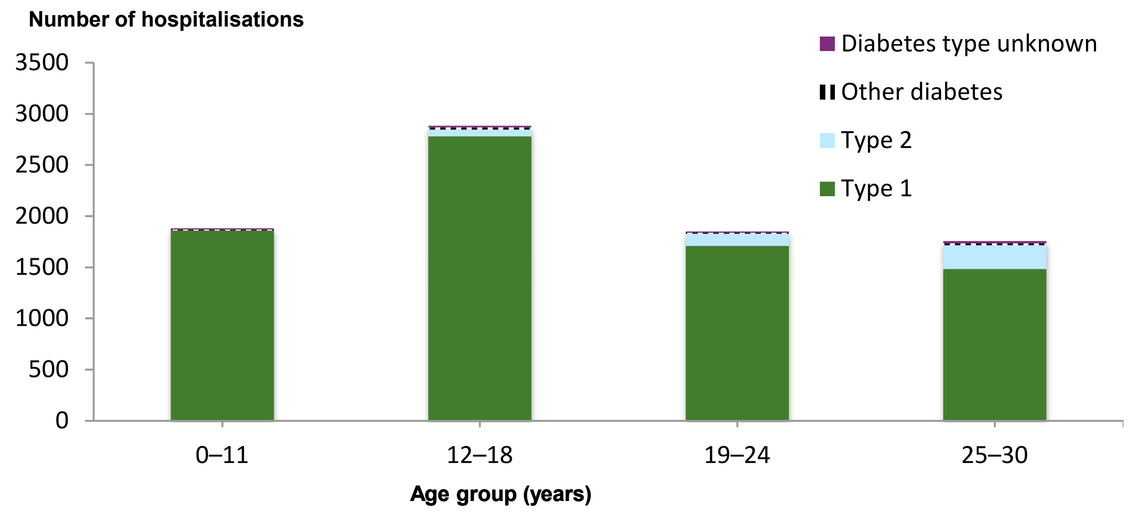
Young people are over-represented in diabetes-related hospitalisations. People aged 30 or under account for 4.3% of all diabetes hospitalisations. However, people in this age group represent only 3.3% of all people with diabetes registered with the NDSS.

How do the age groups compare?

Most of the hospitalisations by people aged 30 and under were for Type 1 diabetes. Of the 8,386 hospitalisations with a principal diagnosis of diabetes, the largest number was for Type 1 diabetes by people aged 12–18 (2,780) (Figure 5.3). People in other age groups also had a large number of hospitalisations for Type 1 diabetes: 0–11 (1,861), 19–24 (1,710) and 25–30 (1,485).

This compares with 118 and 231 hospitalisations for Type 2 diabetes by people aged 19–24 and 25–30 respectively. There were 23 or fewer hospitalisations for other or unknown types of diabetes in each age group.

These age groups are of different sizes. There are different proportions of people with diabetes in the community that access these services. For these reasons it is important to compare the rate of presentations per person with diabetes in Australia.



Note: Diabetes hospitalisations are classified according to the ICD-10AM code (Type 1 E10, Type 2 E11, other E13 and unknown E14).

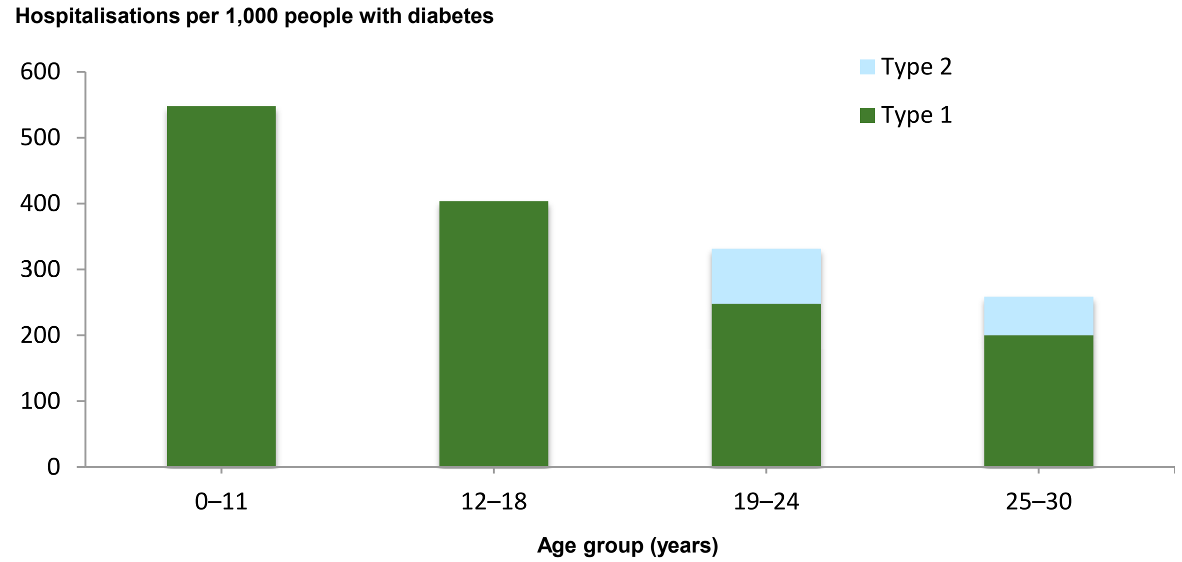
Source: AIHW analysis of National Hospital Morbidity Database .

Figure 5.3: Number of hospitalisations with diabetes as a principal diagnosis, by type of diabetes and age group, Australia, 2009–10

What is the rate of hospitalisation by age groups?

The rate of diabetes hospitalisations for Type 1 diabetes was much higher than for Type 2 (Figure 5.4). The rate of Type 1 diabetes hospitalisations was highest for people aged 0–11 (548 per 1,000 persons), when compared with people aged 12–18 (404 per 1,000), 19–24 (248 per 1,000) and 25–30 (200 per 1,000).

In some cases, the hospitalisation rates for people with Type 2 or other and unknown type of diabetes could not be reliably reported due to the low numbers of admissions. For people aged 19–24, the rate of Type 2 diabetes hospitalisations was 84 per 1,000 persons with diabetes, which was slightly higher than in those aged 25–30 (59 per 1,000).



Note: Diabetes hospitalisations are classified according to the ICD-10AM code (E10-E11).

Source: AIHW analysis of National Hospital Morbidity Database and National Diabetes Services Scheme (December 2009).

Figure 5.4: Rate of hospitalisations with diabetes as a principal diagnosis, by diabetes type and age group, Australia, 2009–10

What causes Type 1 diabetes hospitalisations?

To further examine Type 1 diabetes hospitalisations, they have been divided into three groups:

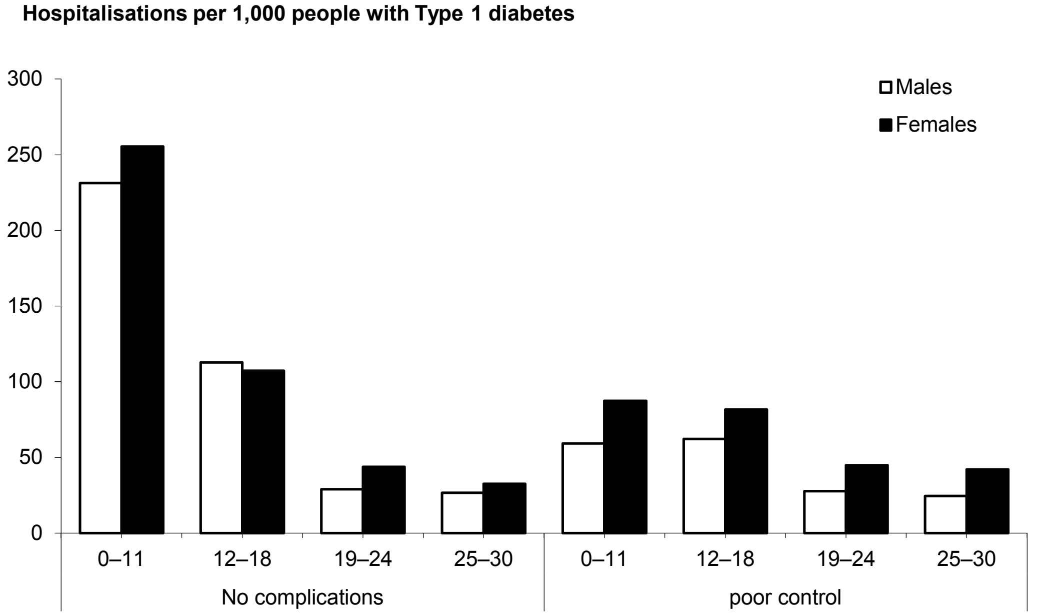
- hospitalisations with no complications or poor control,
- hospitalisations for acute complications including hypoglycaemia or ketoacidosis,
- hospitalisations for long-term complications (for example renal, eye, neurological and circulatory complications).

The number of hospitalisations for Type 2 diabetes by people aged 0–30 was too small to repeat this analysis.

Type 1 diabetes with no complications or poor control

The rate of hospitalisations without complications was similar for males and females but it varied by age and was highest in people aged 0–11 (231 per 1,000 males with Type 1 diabetes and 256 per 1,000 females) (Figure 5.5). This dropped to 113 per 1,000 males and 107 per 1,000 females aged 12–18 and was lower still in people aged 19–30.

The rates of hospitalisations for diabetes with poor control were higher in females than in males, and for people aged 0–11 and 12–18 compared with those aged 19–30.



Note: Diabetes hospitalisations are classified according to the ICD-10AM code (no complications E10.9, poor control E10.65).

Source: AIHW analysis of National Hospital Morbidity Database and National Diabetes Services Scheme (December 2009).

Figure 5.5: Rate of hospitalisations for a principal diagnosis of Type 1 diabetes with no complications or poor control, by age group and sex, Australia, 2009–10

Insulin pump procedures in Type 1 diabetes hospitalisations

Insulin pump procedures are only recorded in the National Hospital Morbidity Database in hospitalisations that last a single day. It is not possible to distinguish between procedures to fit a pump device for the first time or to add insulin to an existing pump. By comparing single day hospitalisations, we have analysed the causes for hospitalisations when pumps are fitted.

Hospitalisations with no complications or poor control were the most common type of Type 1 diabetes hospitalisation to have a pump procedure recorded (Table 5.3). This did not vary greatly by age group.

Table 5.3: Proportion of single day admissions with pump procedures for Type 1 diabetes, by diagnosis and age group, Australia, 2009–10

	Age group (years)			
Principal diagnosis	**0–11**	**12–18**	**19–24**	**25–30**
		Per cent		
No complications	39.1	35.7	45.1	38.7
Poor control	21.4	19.2	25.3	26.7
Other	0.9	0.6	0.2	0.8

Note: Diabetes hospitalisations are classified according to the ICD-10AM code (other E10 (excluding E10.9, 10.65), no complications E10.9, poor control E10.65, insulin pump procedures 96200-06 (1206) and 96209-06).

Source: AIHW analysis of National Hospital Morbidity Database and National Diabetes Services Scheme (December 2009).

Acute complications of Type 1 diabetes

Acute complications of diabetes can be life-threatening if not treated urgently. Diabetic ketoacidosis and hypoglycaemia are the two most common complications (Box 5.1, below).

Acute illnesses like colds and flu that are associated with fever, vomiting and diarrhoea need to be managed carefully so they do not result in hypoglycaemia or ketoacidosis. People with diabetes are advised to have an action plan in place to deal with acute illness. The action plan describes how to monitor blood glucose and ketone levels, change insulin doses, and how and when to seek medical advice. In these circumstances, medical advice may be needed urgently, 24 hours a day.

National guidelines for the care of children and adolescents with Type 1 diabetes report that the risk of ketoacidosis in people with established Type 1 diabetes ranges up to about 10% per patient per year (Craig et al. 2011). People who have higher risks of ketoacidosis include:

- those with poor glycaemic control or who have experienced previous episodes of ketoacidosis
- peripubertal and adolescent girls
- children with psychiatric disorders, including eating disorders
- children with difficult or unstable family circumstances, and
- children with limited access to medical services.

The risk of ketoacidosis is also increased in people who omit insulin or use CSII (because only rapid insulin is used). Interruption of insulin delivery for any reason rapidly leads to insulin deficiency and in turn ketoacidosis.

Box 5.1: Ketoacidosis

Ketoacidosis is a condition caused by very high blood glucose levels and the accumulation in the blood of substances called ketones. Without enough insulin, the body’s cells cannot use glucose for energy. To compensate for this the body begins to burn fat for energy instead. This leads to the accumulation of ketones in the blood, which in turn also appear in the urine.

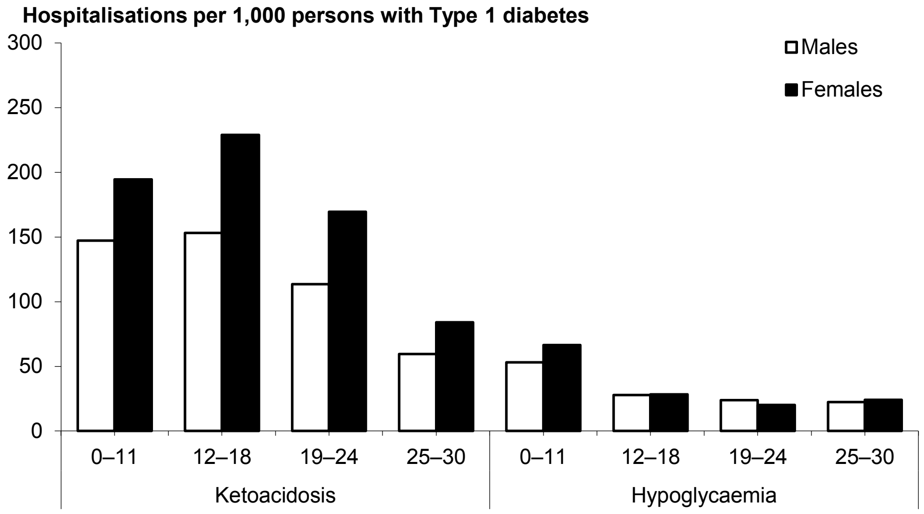
The rate of hospitalisations for ketoacidosis varied by age group (Figure 5.6). They occurred at a higher rate in people aged 0–11 (170 per 1,000 persons with Type 1 diabetes), 12–18 (189 per 1,000) and 19–24 (140 per 1,000) than for people aged 25–30 (71 per 1,000).

The rate of hospitalisations for ketoacidosis was higher for females than it was for males. This is most evident in people aged 12–18, where females had a rate of 229 hospitalisations for 1,000 females with Type 1 diabetes compared with the rate of 153 per 1,000 males.

The rate of these hospitalisations was much lower for people aged 25–30 (60 per 1,000 males with Type 1 diabetes and 84 per 1,000 females) when compared with the other age groups.

Hospitalisations for hypoglyceamia did not vary as much by sex and were most common in those aged 0–11 (53 per 1,000 males and 67 per 1,000 females) with Type 1 diabetes.

Hospitalisations for other acute complications including lactic acidosis and hyperosmolarity were much less common and occurred at a rate of 1–3 per 1,000 persons with diabetes in each age group.

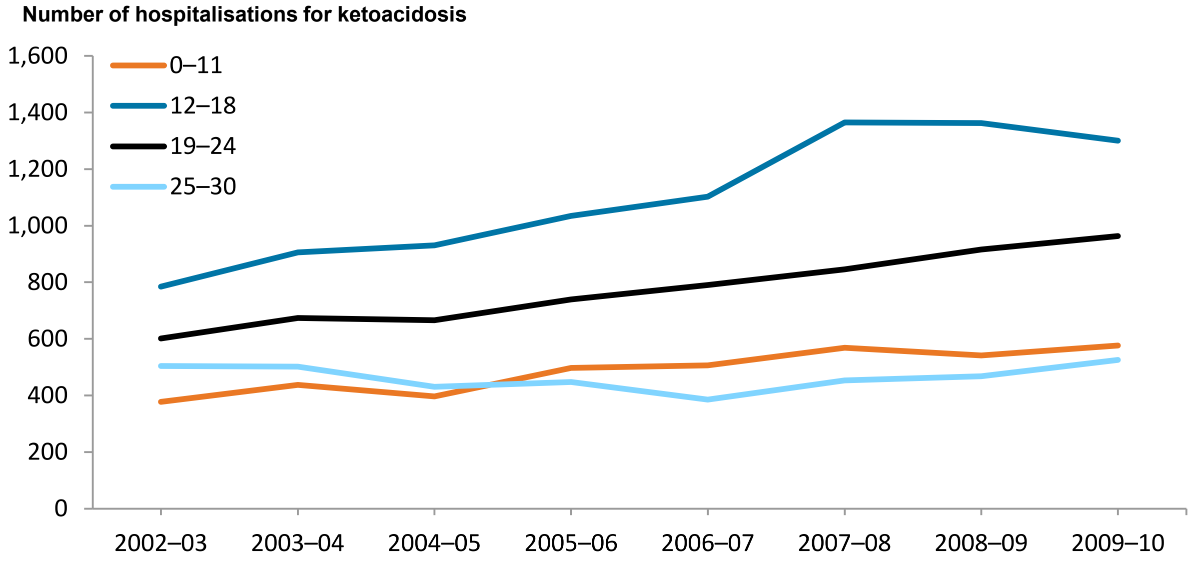


Note: Diabetes hospitalisations are classified according to the ICD-10AM code (ketoacidosis E10.11, E10.12, E10.15 E10.16 and hypoglycaemia E10.64).

Source: AIHW analysis of National Hospital Morbidity Database and National Diabetes Services Scheme (December 2009).

Figure 5.6: Rate of hospitalisations for a principal diagnosis of Type 1 diabetes with ketoacidosis or hypoglycaemia, by age group, Australia, 2009–10

The number of hospitalisations for ketoacidosis has increased from 2002–03 to 2009–10 in all age groups (Figure 5.7).



Note: Diabetes hospitalisations are classified according to the ICD-10AM code (E10.11, E10.12, E10.15 and E10.16).

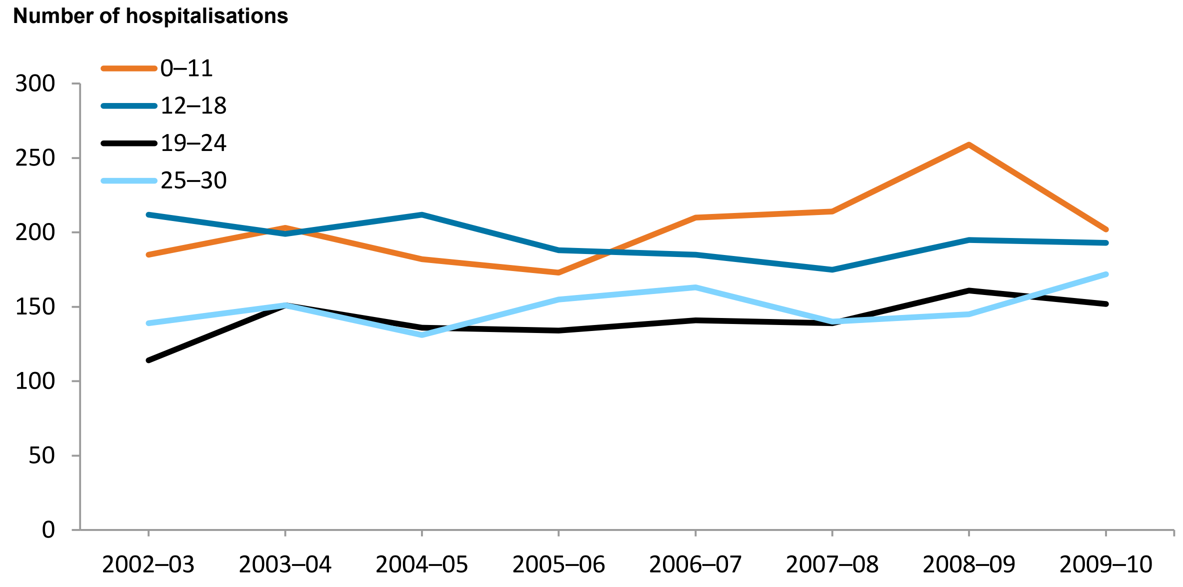
Source: AIHW analysis of National Hospital Morbidity Database.

Figure 5.7: Number of hospitalisations for a principal diagnosis of Type 1 diabetes with ketoacidosis, by age group, Australia, 2002–03 to 2009–10

There were 785 hospitalisations for ketoacidosis in 2002–03 for people aged 12–18; in 2009–10 this increased to 1,301 hospitalisations. Similar results are seen in all of the age groups. For those aged 0–11, the number increased from 377 hospitalisations to 577 and for those aged 19–24 it increased from 602 to 963. For people aged 25–30, the increase was not as great as it was for the other age groups and the number was more variable from year to year: from 2002–03 to 2009–10, it increased from 504 to 526 hospitalisations.

Some of this trend in increased hospitalisations is due to the increase in diabetes prevalence but a parallel increase in the trend for hypoglycaemia hospitalisations that would be expected to occur was not observed (Figure 5.8). It is not possible to control for this, however, because no annual data are available on the age-specific prevalence of diabetes during this time. There were no changes in the relevant ICD codes used in hospital statistics during this time either.

The trend in hospitalisations for hypoglycaemia was different to that of ketoacidosis hospitalisations (Figure 5.8). There are fewer hospitalisations for Type 1 diabetes with hypoglycaemia than ketoacidosis. From 2002–03 to 2009–10, the number of hypoglycaemia hospitalisations increased slightly for those aged 19–24 and 25–30 but fell for people aged 12–18. Compared with the trend in ketoacidosis hospitalisations, the increase observed in some age groups was not as large and the figures are more variable from year to year. Some of the increase may be due to more people with diabetes in the population.



Note: Diabetes hospitalisations are classified according to the ICD-10AM code (E10.64).

Source: AIHW analysis of National Hospital Morbidity Database.

Figure 5.8: Number of hospitalisations for a principal diagnosis of Type 1 diabetes with hypoglycaemia, by age group, Australia, 2002–03 to 2009–10

To further investigate the reasons for the increasing number of hospitalisations for ketoacidosis, the other diagnoses recorded (additional diagnoses) have been examined. One of the most common additional diagnoses was a personal history of non-compliance with medical treatment and regime (ICD-10AM code Z91.1). Over time, there were increasing numbers of these hospitalisations especially for people aged 12–18 and to a lesser extent those aged 19–24. There was no such increase over time for the other age groups with this additional diagnosis.

The second main group of additional diagnoses were those indicating acute illnesses. Some of the commonly recorded codes were those for viral intestinal infection, gastroenteritis, dehydration, potassium deficiency, acute upper respiratory infection, constipation, abdominal pain, nausea, vomiting and urinary tract infection. Although it is possible to have more than one of these additional diagnoses, the number of hospitalisations with at least one of these additional diagnoses has been increasing between 2002–03 and 2009–10 in all age groups.

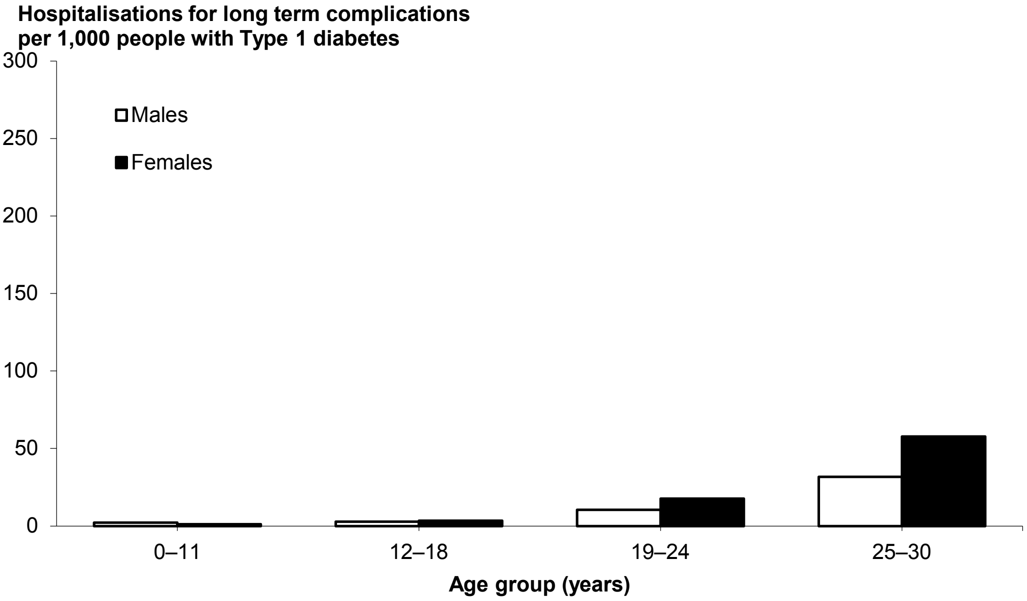
Lastly, the number of people with the additional diagnosis of 'Tobacco use' increased, especially for those aged 19–24.

There was also a large number of about 350 other diagnoses that were recorded for people with a principal diagnosis of ketoacidosis; it is possible for any of these to be associated with admissions for other reasons.

It is unlikely that the recent occurrence of the fitting of an insulin pump device in hospital explains these figures either, as a very small proportion of hospitalisations for ketoacidosis have a pump procedure recorded when they are single day admissions (Table 5.3). Secondly, failure of a medical device was very rare as an additional diagnosis for hospital admissions with a principal diagnosis of ketoacidosis.

Long-term complications of Type 1 diabetes

Too much glucose in the blood over a long period can lead to the occurrence of other conditions such as kidney disease and cardiovascular disease. These conditions are usually referred to as long-term complications of diabetes as they take years to occur.



Note: Diabetes hospitalisations are classified according to the ICD-10AM code (E10.2-E10.5, E10.7 E10.8, E10.61-63 and E10.69). The 0–300 scale on the y-axis has been retained to facilitate comparison with Figures 5.5 and 5.6.

Source: AIHW analysis of National Hospital Morbidity Database and National Diabetes Services Scheme (December 2009).

Figure 5.9: Rate of hospitalisations for a principal diagnosis of long-term complications of Type 1 diabetes, by age group, Australia, 2009–10

Hospitalisations for long-term complications of diabetes were rare and occurred at a rate of fewer then 4 per 1,000 persons with Type 1 diabetes for the age groups 0–11 and 12–18 (Figure 5.9). (To facilitate comparison with Figures 5.5 and 5.6 this figure uses the 0–300 scale on the y-axis.) They were highest in females aged 25–30 with Type 1 diabetes (58 per 1,000 females) and males aged 25–30 (32 per 1,000 males) (Figure 5.9). The rate in females aged 19–24 was 18 hospitalisations per 1,000, and was higher than in males (10 hospitalisations per 1,000).

The most common types of long-term complications causing hospitalisation included diabetic autonomic neuropathy, foot ulcer, proliferative retinopathy and established diabetic nephropathy.

Mortality

Seven years of national mortality data were combined for analysis to compensate for the small number of deaths that occur in the age groups being studied. From 2001–07, there were 88 deaths where diabetes was recorded as the underlying cause of death in people aged 0–30. In each year, the number of these deaths ranged from 10 to 14. Thirty-five of the deaths were for people identified as having Type 1 diabetes, three as Type 2, with the rest (50 deaths) being recorded as diabetes type unknown.

The deaths were evenly divided across gender, with 45 (51%) males and 43 (49%) females. There were fewer than 5 deaths among children (0–11), and fewer than 15 deaths in those aged 12–18. In those aged 19–24 there were 24 deaths, and in those aged 25–30 there were 47 deaths.

The rate of death from diabetes in Australia was highest in those aged 25–30 (4.1 per million Australian population) (Table 5.4). Among people with diabetes, the rate for this age group was 0.6 deaths per 1,000 people with diabetes.

For these deaths, the associated (or contributing) causes of death were also analysed. For 22 of the deaths a cardiovascular cause was identified, and for fewer than 10 deaths a kidney-related cause was identified. For fewer than 15 deaths, choking or anoxic brain damage were also identified as contributing causes. Drug use was also an associated cause for these diabetes deaths, which occurred mostly in those aged 25–30.

Table 5.4: Average annual rate of deaths due to diabetes as an underlying cause of death, Australia, 2001–07

Age group (years)	Deaths per million Australian population per year	Deaths per 1,000 persons with diabetes per year
0–18	0.5	0.2
19–24	2.0	0.4
25–30	4.1	0.6
0–30	**1.5**	**0.4**

Note: 2004 Australian estimated resident population used as denominator.

Source: AIHW analysis of National Mortality Database, and National Diabetes Services Scheme.

In 2001–2007, there were a further 76 deaths in people aged 0–30 where diabetes was recorded as an associated cause of death in people aged 0–30. More deaths, 41 (54%), occurred in males than females. In total, this represented an annual rate of 1 death per million population aged 0–30 in Australia, or 0.3 per 1,000 persons with diabetes.

For these deaths, the largest category of underlying causes was cardiovascular disease (14, or 18%), and seven of these were due to ischaemic heart disease or cardiomyopathy. Cystic fibrosis was recorded as the underlying cause of death for a further 11 deaths (14%), and cancer was the next most common category of deaths (9, or 12%). There were 9 deaths (12%) due to an external cause (car accident, drowning or poisoning by drugs).

6 Synthesis of findings

This report has explored how young people (aged 0–30) with diabetes are managing their condition, their use of health services, and the diabetes-related morbidity and mortality that they experience. The study results provide useful baseline data and a clearer understanding of the problems faced by young people with diabetes.

In 2010, there were about 31,300 people aged 0–30 with diabetes in Australia. Most had Type 1 diabetes (79%). The proportion of those with Type 2 (19%) increased with age. The study population was separated into the following age groups for comparison: 0–11, 12–18, 19–24 and 25–30 years.

How do young people manage the treatment of their diabetes?

To understand how young people are managing their diabetes, NDSS data were used to calculate purchase rates of blood glucose test strips and other consumables (urine testing strips, needles and insulin reservoirs).

The highest consumers of these products were people aged 0–11.

People aged 19–24 were the lowest purchasers of blood glucose test strips, but they bought other products such as needles, reservoirs and urine test strips at a similar rate to people aged 25–30.

The higher level of blood glucose monitoring in children aged 0–11 can be attributed to the high level of parental involvement in the child's diabetes care. This involvement decreases as the person aged 12–18 manages this task more and spends an increasing amount of time away from the family's direct care. For people aged 19–24, the level of independence is greater again if not complete, and they are likely to have assumed most of the responsibility for their own care.

People using an insulin pump had the highest purchase rates of blood glucose test strips, compared with others with Type 1 or Type 2 diabetes. Only people with Type 1 diabetes on insulin pumps in all age groups bought enough blood glucose test strips to allow monitoring four times a day, the minimum recommended in clinical guidelines.

Among those not using insulin pumps, only children aged 0–11 accessed a large enough supply of these strips to allow monitoring more than 4 times a day, while the other age groups could monitor their glucose levels a maximum of 2–3 times a day based on their purchase rate of strips.

Insulin pump use was more common in people aged 18 and under. Possible reasons for this are the subsidies available for eligible people under 18 to buy a pump, and greater availability of resources for initiating pump therapy in paediatric centres. The National Centre for Monitoring Diabetes at the AIHW has prepared a separate report of insulin pump use in Australia.

Insulin supply was also analysed through the PBS dataset and the results compared by age group. For the three-year period 2007–09, nationwide 21,123 people aged 0–30 regularly obtained insulin and filled 257,054 prescriptions.

The median amount of all insulin types supplied per person was 92 IUs per day. This contrasts with the result of 58 IUs bought per day per person observed in another study (Morris et al. 1997). For the present study, the amount of insulin that is subsequently used, not used and wasted, or kept in case of emergency is not known.

The amount and type of insulin bought showed few clear results. The most prominent of these was the larger amount of all insulin dispensed to people aged 12–18. This is most likely due to the physiological changes of adolescence occurring in this age group. Differences in the amounts purchased of the different insulin types between the youngest age group and the older age groups were also observed, as was a consistent increase across the age groups for the purchased amount of short insulin.

Apart from the changes in physiology mentioned, these variations may best be explained by the introduction of new insulin types to the market over time, people buying to use what they are used to, and occasionally changing habits as their needs and opportunities change.

Who provides health care for young people with diabetes?

Analysis of the PBS dataset showed a large change in the specialisation of the prescribing doctor. Paediatricians were the primary sources of insulin prescriptions for the 0–11 and 12–18 age groups, and only a minimal number of people aged 19–25 had prescriptions written by a paediatrician. General practitioners became the major source of prescriptions for people aged 19–24 and 25–30. Endocrinologists and other specialists provided around one-third of all prescriptions across all age groups.

What is not indicated by these results, however, is whether the GPs are linked to a diabetes centre or if they are providing care as part of a multi-disciplinary team. Research has shown that young people who attend a diabetes centre have better health outcomes than do young people who receive no health care or who visit a GP without attending a diabetes centre (Bryden et al. 2003). The importance of team-based expert care is emphasized in the latest clinical practice guidelines, which state that all people with Type 1 diabetes should receive multidisciplinary care (Craig et al. 2011).

How much morbidity and mortality do young people with diabetes experience?

The report analysed the rates of presentations for diabetes to hospital emergency departments in Victoria, New South Wales and Western Australia for 2005–06 to 2009–10. These datasets have different collection methods and definitions for many data items and although it was not possible to compare these data directly, the results were generally consistent.

Children aged 0–11 had the highest rate of presentations to emergency departments, and females were more likely to present than males in all age groups.

When young people aged 12–18 and 19–24 did present to emergency, a greater proportion needed more urgent medical attention than was observed in other age groups.

Data from the National Hospital Morbidity Database were also analysed. For the whole of Australia in 2009–10 among 0–30 year olds, there were 8,386 hospitalisations with a principal diagnosis of diabetes and a further 7,086 hospitalisations with diabetes as an additional diagnosis. Some of these hospitalisations could be prevented through better diabetes management.

Children aged 0–11 had the highest rate of hospitalisations for Type 1 diabetes but these were mainly for stabilising diabetes, being diagnosed with diabetes or to fit an insulin pump.

Hospitalisations for the serious acute complication of Type 1 diabetes, ketoacidosis, were observed at higher rates in people aged 0–24 compared with adults aged 25–30. They were also higher in females than in males.

The number of hospitalisations for Type 1 diabetes with ketoacidosis increased from 2002–03 to 2009–10 in all age groups except those aged 25–30. The most common and increasing additional diagnoses recorded in these hospitalisations was non-compliance with medical treatment. This was most evident in those aged 12–18. For this diagnosis to be recorded there needs to be a documented history of non-compliance. It suggests that people aged 12–18 increasingly are not following medical advice.

The second most common additional diagnoses in ketoacidosis cases were a group of acute illnesses such as infections. When a person with diabetes has an acute illness they may need to adjust their treatment and can need help from a medical professional. These data suggest that young people may not seek or have access to appropriate sick day advice from diabetes educators or other doctors and are hospitalised as a result.

The results for hospitalisations for long-term diabetes complications are noteworthy. These were relatively few, but in the 25–30 age group, there were about 50 admissions per 1,000 people with diabetes. It could be argued that when they were younger, people in the 25–30 age group did not have access to the current improved diabetes therapies and treatment regimes and this led to the development of complications. The other argument, however, is that these people are still very young to manifest such serious but preventable complications, which are evident even in the 19–24 age group.

Mortality data from Australia for the years 2001–07 provided another insight into the health experiences of young people with diabetes. The number of deaths increased with age, and more than half (53%) occurred in the 25–30 age group. This finding is supported by research in England into the mortality of people with diabetes aged 0–40, which found that most of the observed deaths (88%) occurred between the ages of 20 and 39 (Laing et al. 2005).

In our study, many of the deaths where diabetes was the underlying cause of death were related to either diseases associated with diabetes (cardiovascular- or kidney-related) or to misadventure, which commonly involved the presence of illicit drugs. Again, this last observation is matched by the English work, which found firstly, that 25% of the deaths were due to a chronic cause (in our study the rate was about 35%), and secondly, that 14% of the cases (deaths) had a record of drug abuse (Laing et al. 2005). Recently published Australian research has documented high levels of recreational drug use in people with diabetes (Lee et al. 2012).

The transition to adult health care

It is clear from the literature that non-attendance at diabetes clinics is a problem among young adults with diabetes. Many researchers, using different methods and different settings, have identified the problem. However, this conclusion needs to be compared against the broader finding that non-attendance occurs at all ages and throughout the health care system. The rates identified in the English research, however, were still higher in young adults (Mitchell & Selmes 2007).

While non-attendance is therefore not a unique problem for young people with diabetes, the consequences of non-attendance are of greater concern. Increased rates of diabetes-related morbidity, poorer wellbeing and the earlier onset of diabetes-related complications have been consistently observed to occur in young people who do not attend diabetes centres. The elevated mortality rates observed in the national British audit of young people aged 15–34 years with Type 1 diabetes, previously described in the introduction (National Health Service Information Centre 2011), together with the mortality data presented in this report, strongly argue for more than casual dismissal of the problem as just another instance of the wider problem of health service utilisation.

In Australia, only a single study has demonstrated the fact of non-attendance at adult diabetes centres by young adults. This study measured a six-month attendance rate of only 82%. It also documented an increased rate of admissions for diabetic ketoacidosis and worse HbA1c values in the non-attenders. While confirmation of these results by other researchers is desirable, the importance of this work lies in its having unequivocally demonstrated the problem of non-attendance in young people with diabetes who are transitioning from the paediatric to the adult health care system. To validate and extend this work, the experience of other diabetes centres and reasons for non-attendance, including the possible impact of diabetes centre locations, should also be investigated.

Several transition programs in Australia have been established, which aim to increase the engagement of young adults with the health care system and to decrease morbidity. These programs have been designed to facilitate attendance by, for example, providing evening clinics and outreach staff who may be called upon after hours for advice or to provide appointment reminders.

Future work

In our review of the literature and analysis of routinely collected datasets, we identified a number of issues affecting young people with diabetes. These included the need to improve the rate of successful transition from paediatric to adult diabetes centres, and the elevated rates of morbidity observed especially in those aged 19–24 and mortality in people aged 25–30.

To confirm and extend our understanding of the problem of non-attendance at specialist diabetes centres it would be necessary to monitor the attendance and wellbeing of individuals at these centres over time. Longitudinal data that monitor changes in the behaviour and experiences of individuals as they progress through adolescent stages will also provide a more complete understanding of the problems they experience.

To build on the work described in the present report, access to linked data and improved study design will allow better control of confounding factors. In particular, the use of linked datasets will allow a person’s diabetes type to be controlled for throughout the analysis of different datasets. This has been a particular problem for understanding the results obtained from the insulin prescription data. The possible linking of morbidity and mortality events to a person’s insulin prescription records is also of great interest.

Indeed, a study linking data from the National Diabetes Services Scheme and the Pharmaceutical Benefits Scheme is currently being planned by the National Centre for Monitoring Diabetes.

Appendix A

Data sources and methods

Australian National Diabetes Information Audit and Benchmarking survey

The Australian National Diabetes Information Audit and Benchmarking (ANDIAB) survey is primarily a clinical review designed to identify and maintain the standards of medical care for people with diabetes. The National Association of Diabetes Centres has conducted these surveys since 1998.

Most, but not all, diabetes centres participate in the survey. From an epidemiological point of view, therefore, the full value of the survey is limited. Also, as for any clinical study, it reflects only the experiences of people attending a centre during the survey period. These people are more likely to have poorer control or diabetes complications, and their health is unlikely to be as good as that of people not attending a centre. Despite these reservations, the audit still provides important insights into the wellbeing of the under-30 population with diabetes.

The data studied for this report are based on a one-month audit of people who attended specialist diabetes centres or an endocrinologist during May or June, 2009. Data were collected using paper forms or electronically from established databases. Of particular relevance to this report was that data were provided by two large paediatric centres, which together represent a large and significant proportion of the Australian paediatric population. This population was surveyed using a separate paediatric/adolescent form.

For the total survey, data were provided on 8,563 people with diabetes, of whom 3,167 were aged 30 or under, and who were analysed in this study. Due to the different methodologies (in the centres sampled and the forms used), the analysis of persons aged 18 and under has been separated from that of persons aged 19 and over.

Emergency department data

Three states in Australia collect data from hospital emergency departments where a diagnosis is also recorded: New South Wales, Victoria and Western Australia.

The NSW emergency department data collection is known as the Emergency Department Information System. It collected unit record level data from about 85% of NSW emergency departments in 2007–08, the period for which data were available for this report. The collection contains data on the reasons for presentation to hospital emergency departments, the time of the presentation, and related diagnostic and procedural data.

The Victorian Emergency Minimum Dataset (VEMD) contains de-identified demographic, administrative and clinical data detailing presentations at Victorian public hospitals. Data are collected from all Victorian emergency departments (AIHW 2008a, 2008b).

The Western Australia Emergency Department Data Collection (EDDC) is a collection of patient-record level data for all attendances to emergency departments at public hospitals and publicly funded private hospitals in WA. Nine of the ten hospitals in metropolitan Perth and one rural hospital provide ICD–10 coded diagnosis data, and so provide useful data for this report. These records account for about 50% of all emergency department admissions in the State (Russell 2012).

In addition to data specifically related to episodes of care in WA emergency departments (e.g. presentation date and time, triage category, episode end status), the collection includes demographic data (e.g. name, date of birth, ethnicity) and data required under the Australian Health Care Agreement (e.g. whether an interpreter service was required). The EDDC is not an administrative database. It is created from data collected in a hospital's emergency department, from information systems designed for patient management. Data relating to a patient's episode of care are extracted from the information systems and imported into the EDDC.

National Diabetes Services Scheme dataset

The National Diabetes Services Scheme (NDSS), established in 1987, is an Australian Government initiative, administered by Diabetes Australia, which aims to ensure people have timely, reliable and affordable access to the supplies and services they require to understand and effectively self-manage their diabetes.

The Government provides funding to the NDSS for the subsidy of syringes and needles, blood glucose test strips, urine ketone test strips and insulin pump consumables.

Free registration to the NDSS is available for anyone who is a resident in Australia, has been diagnosed with diabetes by a medical practitioner and holds a current Australian Medicare card or Department of Veteran Affairs file number.

The NDSS database is a source for prevalence estimates of all types of diagnosed diabetes in Australia, especially in young people. The NDSS provides information about individuals who register. It is updated regularly and provides both demographic and diagnostic information. There are some limitations in data items such as diabetes type and insulin-use status and also in how the data were recorded on the database historically.

The data on the registrants to the NDSS were used in two ways in this report. The first is to determine the diabetes prevalence (number living with) in Australians aged 0–30. The dataset is the most reliable source of prevalence data for this age group. The data used in this report are the number of registrants at December 2010 by reported diabetes type.

The second way in which the NDSS dataset is used in this study is for its information on the supply of products related to diabetes. Data on the purchase of consumable products from the NDSS from 2004 to July 2011 were obtained from Diabetes Australia with approval from the Department of Health and Ageing (data custodians). The products analysed were blood glucose test strips, syringes and needles, and the disposable components used for insulin pumps. The dataset contained 1.93 million sales records for 43,230 people aged 30 and under. The way in which these data may be analysed is described in Box 3.1.

National Hospital Morbidity dataset

The National Hospital Morbidity Database (NHMD) compiles episode-level records from admitted patient morbidity data collection systems in Australian hospitals. The database contains data relating to admitted patients in almost all hospitals in Australia.

The data supplied are based on the National Minimum Data Set (NMDS) for admitted patient care and include demographic, administrative and length of stay data, as well as data on the diagnoses of the patients, the procedures they underwent in hospital and external causes of injury and poisoning. Most of the data used in this report were for the financial year 2009–10. Some trend information was also included from 2000–01 to 2009–10.

The scope of the NMDS is episodes of care for admitted patients in all public and private acute and psychiatric hospitals, free-standing day hospital facilities and alcohol and drug treatment centres in Australia. Hospitals operated by the Australian Defence Force, corrections authorities and in Australia's off-shore territories are not included. Hospitals specialising in dental, ophthalmic aids and other specialised acute medical or surgical care are included.

The counting unit in the NHMD is the separation, described as hospitalisations in this report. Separation is the term used to refer to the episode of admitted patient care, which can be a total hospital stay (from admission to discharge, transfer or death) or a portion of a hospital stay beginning or ending in a change of type of care (for example from acute care to rehabilitation).

Although hospital separations data are a valuable source of information about admitted patient care, they have limitations as indicators of ill health. Sick people who are not admitted to hospital are not counted and those who have more than one separation in a reference year are counted on each occasion.

Hospital separations data do not include presentations in the emergency department that do not require admission to hospital or episodes of non-admitted patient care provided in outpatient clinics. The following care types were excluded when undertaking the analysis: 7.3 (newborn - unqualified days only), 9 (organ procurement – posthumous) and 10 (hospital boarder).

Data on diagnoses are recorded uniformly using the International Statistical Classification of Diseases and related health problems, 10th revision, Australian modification (ICD-10-AM 6th edition) (National Centre for Classification in Health 2010). Information on procedures was recorded using the *Australian Classification of Health Interventions* (ACHI). The relevant diagnosis and procedure codes used in this report are described in the notes for each figure or table.

A data quality statement for the AIHW National Hospital Morbidity Database can be found in Appendix 1 of *Australian hospital statistics 2010-11* (AIHW 2012a).

National Mortality dataset

The National Mortality Database (NMD) is a register of information on all deaths that occur in Australia. It contains information on the cause of death supplied by the medical practitioner certifying the death or by a coroner. Causes of death data are divided into an underlying cause, which describes the immediate cause and circumstances leading to a person's death, and some associated causes of deaths, the other medical conditions that have contributed to the death. Both the underlying and contributing causes of death for people with diabetes that were registered in the period January 2001 to December 2007 have been analysed for this report.

Data quality statements underpinning the AIHW National Mortality Database can be found in the following ABS publications:
ABS Quality declaration summary for *Causes of death 2010* (Cat. no. 3303.0)
<http://www.abs.gov.au/Ausstats/abs@.nsf/0/D4A300EE1E04AA43CA2576E800156A24?OpenDocument> and
ABS Quality declaration summary for *Deaths, Australia 2010* (Cat. no. 3302.0)
<http://www.abs.gov.au/Ausstats/abs@.nsf/0/9FD0E6AAA0BB3388CA25750B000E3CF5?OpenDocument.>

Pharmaceutical Benefits Scheme dataset

The Pharmaceutical Benefits Scheme (PBS) is an Australian Government initiative that subsidises prescribed drugs for all Australians. This scheme has existed for sixty years. Recent changes in the data recorded by the Department of Health and Ageing (DoHA) have enabled anonymously identified individuals within the dataset to be linked to basic demographic details, and their prescribed insulin supply over time to be followed.

The government subsidy is applied when the cost of a drug dispensed at a pharmacy exceeds the patient co-payment threshold, and it is only these records that are claimed by pharmacists, and so are reported to DoHA for inclusion in the PBS dataset. All insulin prescriptions cost more than the co-payment and so are available for analysis.

Insulin is the hormone in the blood that controls a person's circulating levels of glucose. It exists in a number of different forms, and these differ in their origins (human, animal and synthetic) and their activity profile. Of particular significance is how quickly the insulin starts working and its duration. Table 1.2 summarises this information for the different forms, together with their identifying information.

For this report, PBS data for 2007, 2008 and 2009 were obtained from DoHA and analysed. This dataset contained 265,270 records of insulin prescriptions which were filled for 34,147 individuals aged between 0 and 30.

The prescription supply records were linked to individuals with a personal information number, which enabled all insulin prescriptions supplied to each individual to be followed over the study period. Each de-identified record in the extracted PBS dataset included demographic and pharmaceutical information as well as prescriber details.

PBS cohort selection

It is not possible to specifically determine the type of diabetes a person has, based on the pattern of insulin purchases they have made. Some conclusions may be drawn, however, and if these are acted on, more established insulin purchasers will be more likely to be identified.

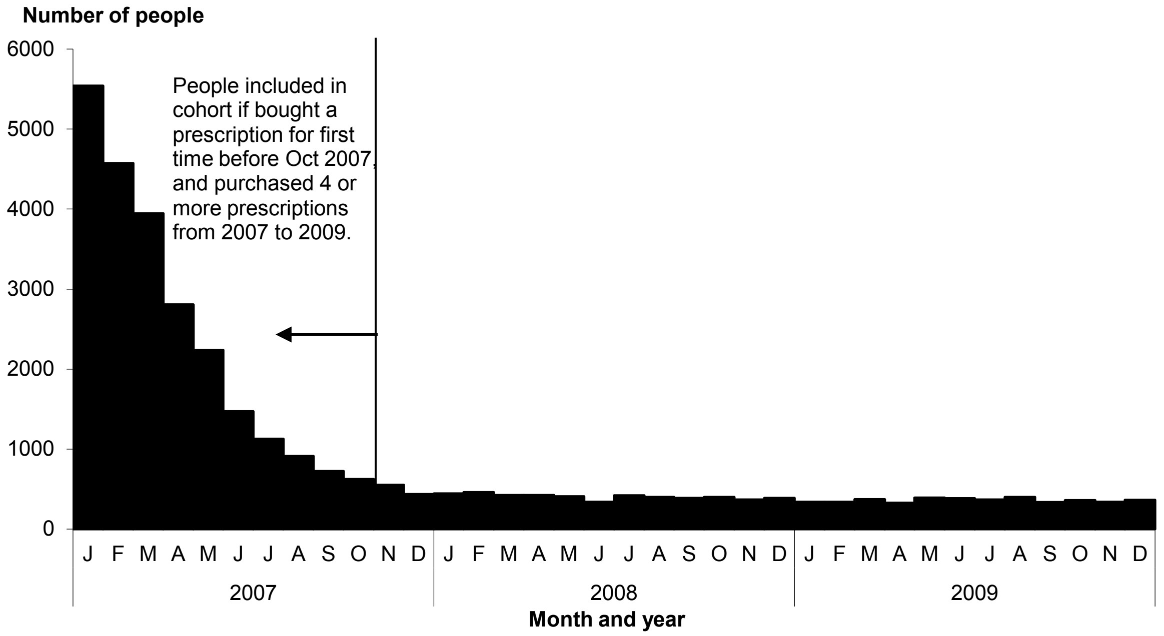
These purchasers were considered the best population in which to investigate the questions being posed in this report, because they have adjusted to their illness and have experience in managing it. Contrasting this, people being prescribed insulin for the first time are more likely to have atypical experiences. As much as possible, therefore, these novel users of insulin were excluded from the analysis. How this was achieved is described in the following paragraphs.

Gestational diabetes is a condition that can occur throughout a pregnancy, but more commonly it occurs in the later stages. Because of this limited period of illness, a single prescription for insulin should provide a sufficient quantity to control the mother's glucose levels for the remainder of her pregnancy. Contrasting this, a person with Type 1 or Type 2 diabetes will require insulin on a continuing basis. Females in the dataset who had only a single script recorded across the study period were therefore removed from the analysis.

Other people who were prescribed insulin for the first time can, to an extent, be distinguished from established users, by analysing the number of prescriptions for each person in the dataset that were filled over time. Figure A.1 shows the distribution of the dates of the first prescription record for each person in the PBS dataset, where the first prescription for each person is recorded after 1 January 2007. The larger number of records for 2007 are due mostly to pre-existing, prevalent, cases of diabetes who will be regular insulin users. The relatively small but regular number of the other records observed each month in 2008 and 2009, however, are consistent with these records being for new incident cases in those months.

Although some new cases will inevitably be present in the 2007 data, as they were in the 2008–09 data, the relative volume of these in 2007 is much less than the volume of pre-existing insulin users.

For this reason, the decision was made to limit the analysis to people whose first recorded date of supply occurred in the period January–October 2007, and who had four or more prescriptions for insulin in the three-year period (2007 to 2009). In this reduced dataset, there were 21,136 people, for whom 257,044 prescription records were linked.



Note: January 2007 is the start of data extract. All persons will buy their first prescription after this date in this data set.

Source: AIHW analysis of PBS data.

Figure A.1: Distribution of first insulin prescription dates for people aged 0–30, in 2007–2009

One other issue for the analysis of this insulin data is how to combine the data for the different types of insulin supplied to each individual. A Scottish study used the 'cumulative volume' (presumed per person) of the separate or premixed insulin formulations, on the basis that an amount of 100 international units (IU) (the standard volume dispensed) is the same, whether it is for rapid or long acting insulin (Morris et al. 1997). This was the approach used in the present study. There remains a clear potential for further analysis of these data, on the different forms of insulin, than has been reported here.

The dataset, as it has been refined, was used to answer the following questions:

- What kinds of insulin were bought?
- How many prescriptions are being filled?
- What combinations of insulin are bought?
- Who supplies insulin to people in the different age groups?

Appendix B

Emergency department presentations in New South Wales

Of the 1,323 presentations for diabetes to a New South Wales emergency department, the highest proportion was for people in the 12–18 age group (37%) (Table B.1). Presentations by people aged 0–11 represented around 26% and by people aged 19–24, 23%. Around 15% of presentations were by people aged 25–30.

When these presentations were expressed as annual rates per person with diabetes in New South Wales, children aged 0–11 had the highest rate (28.8 presentations for diabetes per 100 people with diabetes) (Table B.1). In contrast, the average annual rate was 20.4 for people aged 12–18, 11.1 for those aged 19–24 and 5.4 for those aged 25–30.

Table B.1: Average annual emergency department presentations for diabetes in NSW for people under 30, by age group, 2005–06 to 2009–10

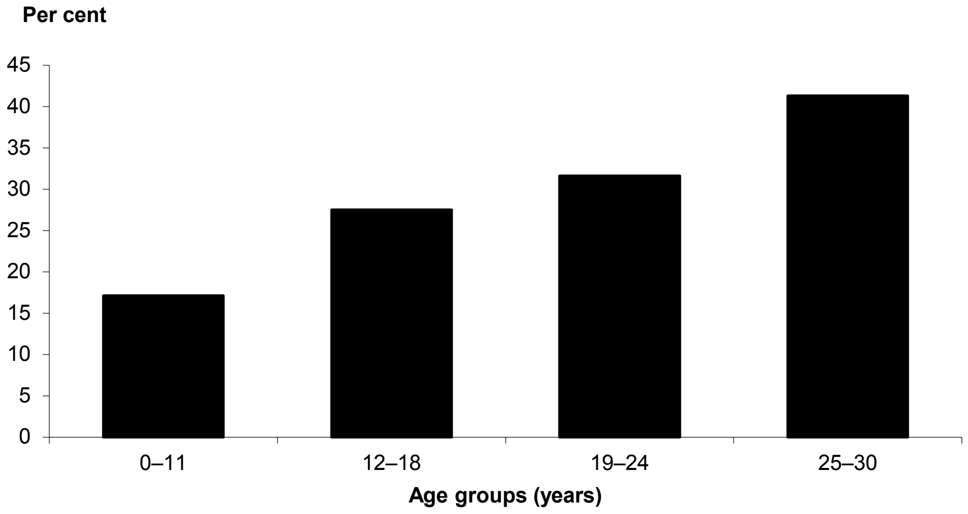
	Emergency department presentations		
Age group (years)	**Average number**	**Per cent**	**Annual rate per 100 people with diabetes**
0–11	338	25.6	28.8
12–18	483	36.5	20.4
19–24	302	22.8	11.1
25–30	200	15.0	5.4
0–30	**1,323**	**100**	**13.3**

Note: Data source covers approximately 85% of emergency departments in NSW.

Source: AIHW analysis of NSW Emergency Department Information System.

Arrival by ambulance

The proportion of presentations for diabetes that arrived by ambulance varied by age group and was higher in the older age groups (Figure B.1). Of presentations by people in the 25–30 age group, 41% arrived by ambulance. In comparison, 17% of presentations by those aged 0–11, 28% of presentations by those aged 12–18 and 32% of presentations by those aged 19–24 arrived by ambulance.



Note: Data source covers approximately 85% of emergency departments in NSW.

Source: AIHW analysis of NSW Emergency Department Information System .

Figure B.1: Proportion of diabetes presentations that arrived by ambulance in each age group, NSW, 2005–06 to 2009–10

Triage category

Around 1% of presentations for diabetes had the triage category Resuscitation and this varied only slightly between the age groups (Table B.2). Presentations with the triage category Emergency were higher in the older age groups, with 31% of presentations by people aged 12–18, 29% of those aged 19–24 and 27% of those aged 25–30 given this category. This compares with 24% of Emergency category presentations by people aged 0–11.

Urgent presentations were the most common type overall, accounting for 60% of all presentations by people aged 0–30 with diabetes (Table B.2). A higher proportion of these presentations were for those aged 0–11 (66%) when compared with the other age groups.

Semi- or Non-Urgent presentations accounted for about 10% of presentations by people aged 0–11 and 12–18. In comparison, 13% of presentations by people aged 19–24 and 15% of presentations by those aged 25–30 were classified as Semi- or Non-Urgent.

Table B.2: Proportion of presentations for diabetes in each age group, by triage category, NSW, 2005–06 to 2009–10

Age group (years)	Resuscitation	Emergency	Urgent	Semi- or Non-Urgent
		Per cent		
0–11	1.3	23.8	65.5	9.5
12–18	0.8	30.8	58.6	9.8
19–24	0.7	28.6	58.0	12.6
25–30	0.7	26.8	57.3	15.2
0–30	**0.9**	**27.9**	**60.0**	**11.2**

Note: Data source covers approximately 85% of emergency departments in NSW.

Source: AIHW analysis of NSW Emergency Department Information System.

The proportion of presentations for diabetes that departed the emergency department for more treatment in hospital was highest in the younger age groups (Table B.3). About 84% of presentations by people in the 0–11 age group required further treatment in a hospital. This compares with 83% of presentations by those aged 12–18, 78% of presentations by those aged 19–24 and 75% by those aged 25–30.

Table B.3: Proportion of presentations for diabetes in each age group, by departure type, NSW, 2005–06 to 2009–10

Age group (years)	Hospital	Other
	Per cent	Per cent
0–11	84.0	16.0
12–18	82.5	17.5
19–24	78.1	21.9
25–30	75.4	24.6
0–30	**80.8**	**19.2**

Notes

1. Hospital departure includes the following categories: 5 Departed: Transferred to another hospital without first being admitted to the hospital from which transferred, 9 Departed: for other facility, 12 Admitted: Transferred to another hospital, 1 Admitted to Ward/inpatient unit, not a Critical Care Ward, 10 Admitted: To Critical Care Ward 11 Admitted: Via Operating Suite.
2. Other departure types include: 2 Admitted & discharged as inpatient within ED, 4 Departed: Treatment completed, 6 Departed: Did not wait, 7 Departed: Left at own risk, 13 Admitted: Left at own risk.
3. Presentations that were dead on arrival or died in the emergency department are not included.
4. Data source covers approximately 85% of emergency departments in NSW.

Source: AIHW analysis of NSW Emergency Department Information System.

Emergency department presentations in Western Australia

The average annual number of presentations to a Western Australian emergency department for diabetes in 2005–06 to 2009–10 was 321 (Table B.4). The highest proportion of these were for people aged 12–18 (40%). About 24% were for people aged 0-11, 21% for people aged 19-24 and 15% for people aged 25-30.

Table B.4: Average annual emergency department presentations for diabetes in WA for people aged 0–30, 2005–06 to 2009–10

	Emergency department presentations		
Age group (years)	Average number	Per cent	Rate per 100 people with diabetes
0–11	78	24.2	29.3
12–18	127	39.5	21.9
19–24	68	21.1	10.2
25–30	48	15.0	5.5
0–30	**321**	**100**	**13.4**

Note: These data were obtained from 9 of the 10 metropolitan and one rural hospital, and represent about 50% of all ED admissions in WA.

Source: AIHW analysis of Western Australia Emergency Department Data Collection.

Per person with diabetes, children aged 0–11 had the highest average annual rate of emergency department presentations (29.3 presentations per 100 people with diabetes). This compares with a rate of 21.9 for those aged 12–18, 10.2 for those aged 19–24 and 5.5 for those aged 25–30.

Arrival by ambulance

The proportion of presentations for diabetes that arrived by ambulance was lowest in people aged 0-11 (21%) (Table B.5). In comparison, 29% of presentations by those aged 12–18, 26% by those aged 19–24 and 40% by those aged 25–30 arrived by ambulance.

Table B.5: Proportion of presentations for diabetes in each age group that arrived by ambulance, WA, 2005–06 to 2009–10

Age group (years)	Per cent
0–11	20.8
12–18	29.1
19–24	25.9
25–30	40.1
0–30	**28.0**

Note: These data were obtained from 9 of the 10 metropolitan and one rural hospital, and represent about 50% of all ED admissions in WA.

Source: AIHW analysis of Western Australia Emergency Department Data Collection.

Around 2% of presentations for diabetes had the triage category Resuscitation and this did not vary between the age groups (Table B.6). Presentations with the triage category Emergency ranged from 35% in those aged 25–30 to 20% in those aged 0–11. They accounted for 29% of presentations by those aged 12–18 and 32% by those aged 19–24.

Table B.6: Proportion of presentations for diabetes in each age group, by triage category, WA, 2005–06 to 2009–10

Age group (years)	Resuscitation	Emergency	Urgent	Semi- or Non-Urgent
		Per cent		
0–11	2.3	20.1	70.7	6.9
12–18	2.7	28.7	62.0	6.6
19–24	2.1	32.4	58.1	7.4
25–30	2.5	34.7	53.7	9.1
0–30	**2.4**	**28.3**	**62.1**	**7.2**

Note: These data were obtained from 9 of the 10 metropolitan and one rural hospital, and represent about 50% of all ED admissions in WA.

Source: AIHW analysis of Western Australia Emergency Department Data Collection.

Urgent presentations for diabetes were the most common type overall, accounting for 62% of all presentations by people aged 0–30 (Table B.6). A higher proportion of these presentations was for children aged 0–11 (71%) when compared with the other age groups. Semi- or Non-Urgent presentations accounted for about 7% of presentations by people aged 0–11, 12–18 and 19–24. In comparison, 9% of presentations by those aged 25–30 were classified as Semi- or Non-Urgent.

About 94% of presentations for diabetes by people aged 0–11 required further treatment in a hospital (Table B.7). This compares with 91% of presentations by those aged 12–18, 83% by those aged 19–24 and 85% by those aged 25–30.

Table B.7: Proportion of presentations for diabetes in each age group, by departure type, WA, 2005–06 to 2009–10

Age group (years)	Hospital	Other
	Per cent	Per cent
0–11	94.0	5.9
12–18	90.7	9.3
19–24	83.1	16.8
25–30	84.7	15.2
0–30	**89.0**	**11.0**

Notes:

1. These data were obtained from 9 of the 10 metropolitan and one rural hospital, and represent about 50% of all ED admissions in WA.
2. Hospital departure includes the following categories: Admitted to ED for observation, Admitted to ward/other and transferred to other hospital.
3. Other departures include the following categories: ED service event completed and departed under own care, left at own risk, and unknown.
4. Presentations that were dead on arrival or died in the emergency department are not included.

Source: AIHW analysis of Western Australia Emergency Department Data Collection.

Appendix C Additional tables

Table C.1: People with diabetes by diabetes type, sex and age group, December 2010

	Diabetes type		
Age group (years)	Type 1	Type 2	Other
	Number		
Males			
0–11	1,773	n.p.	85
12–18	3,633	219	90
19–24	3,656	556	76
25–30	4,006	1,552	70
Females			
0–11	1,624	n.p.	83
12–18	3,255	338	100
19–24	3,235	855	98
25–30	3,413	2,386	122
Persons			
0–11	3,397	n.p.	168
12–18	6,888	557	190
19–24	6,891	1,411	174
25–30	7,419	3,938	192
0-30	**24,595**	**5,990**	**724**

Source: AIHW analysis of NDSS data.

Table C.2: Rate of diabetes by diabetes type and age group, December 2010

	Diabetes type		
Age group (years)	Type 1	Type 2	Other
	Number per 100,000 population		
0–11	100	n.p.	5
12–18	339	27	9
19–24	351	72	9
25–30	371	197	10

Source: AIHW analysis of NDSS data.

Table C.3: Summary of median amounts of different insulin types dispensed per day, by age group, Australia, 2007–09

Insulin type	Number of people using	Age group (years)				
		0–11	12–18	19–24	25–30	0–30
		Median monthly dose (IUs)				
Rapid	19,080	41.3	48.9	46.1	48.5	**46.7**
Short (S)	5,178	20.8	22.0	26.3	36.1	**23.7**
Long (L)	15,988	25.2	37.2	33.7	33.2	**32.9**
Intermediate (I)	9,424	22.4	22.0	24.5	28.2	**24.2**
All types	**21,123**	**86.9**	**100.8**	**88.1**	**89.9**	**92.3**

Source: AIHW analysis of PBS data.

Table C.4: Proportion of diabetes presentations by triage category and whether they 'departed' to hospital or to their place of residence, Victoria, 2005–06 to 2009–10

		Age group (Years)			
Triage category	Departure type	0–11	12–18	19–24	25–30
		Per cent			
Resuscitation	**Hospital**	0.9	0.8	0.8	1.2
	Residence	0.0	0.0	0.3	0.0
Emergency	**Hospital**	21.8	31.3	29.2	17.2
	Residence	2.3	2.1	2.7	3.0
Urgent	**Hospital**	57.6	47.0	43.3	42.7
	Residence	16.1	14.5	14.5	18.3
Semi- or Non-urgent	**Hospital**	6.9	4.9	6.4	10.7
	Residence	4.2	4.3	6.6	14.0

Notes:

1. Hospital departure includes the following categories: Wards, Short Stay Unit, Transfer out of this Hospital to another Hospital, Transfer to another Hospital, Emergency Medical Unit, Medical Assessment and Planning Unit, Intensive Care Unit, Another hospital campus, Coronary Care Unit and Mental Health Observation/Assessment Unit.
2. Residence includes: Aged Care residency, Home, Left at own risk after treatment started, Correctional/Custodial Facility.
3. Presentations involving a death in the emergency department are not included.

Source: AIHW analysis of Victorian Emergency Minimum Dataset (VEMD).

Table C.5: Hospitalisations with a principal diagnosis of diabetes, by type of diabetes and age group, Australia, 2009–10

	Diabetes type			
Age group (years)	Type 1	Type 2	Other	Unknown
	Number			
0–11	1,861	17	7	12
12–18	2,780	67	20	15
19–24	1,710	118	9	13
25–30	1,485	231	18	23

Note: Diabetes hospitalisations are classified according to the ICD-10AM code (E10-E14).

Source: AIHW analysis of National Hospital Morbidity Database.

Table C.6: Rate of hospitalisations with diabetes as principal diagnosis, by diabetes type and age group, Australia, 2009–10

	Diabetes type			
Age group (years)	Type 1	Type 2	Other	Unknown
	Number per 1,000 people with diabetes			
0–11	548	n.p.	n.p.	n.p.
12–18	404	n.p.	n.p.	n.p.
19–24	248	84	n.p.	n.p.
25–30	200	59	n.p.	n.p.

n.p. Not publishable because of small numbers, confidentiality or other concerns about the quality of the data.

Note: Diabetes hospitalisations are classified according to the ICD-10AM code (E10-E14).

Source: AIHW analysis of National Hospital Morbidity Database and National Diabetes Services Scheme (December 2009).

Table C.7: Rate of hospitalisations for Type 1 diabetes with no complications and poor control, by age group, Australia, 2009–10

	No complications		Poor control	
Age group (years)	Males	Females	Males	Females
	Number per 1,000 people with Type 1 diabetes			
0–11	231	256	59	87
12–18	113	107	62	82
19–24	29	44	28	45
25–30	27	33	24	42

Note: Diabetes hospitalisations are classified according to the ICD-10AM code (No complications (E10.9) or poor control (E10.65)).

Source: AIHW analysis of National Hospital Morbidity Database and National Diabetes Services Scheme (December 2009).

Table C.8: Rate of hospitalisations for Type 1 diabetes with ketoacidosis or hypoglycaemia, by age group, Australia 2009–10

	Ketoacidosis		Hypoglycaemia	
Age group (years)	Males	Females	Males	Females
	Number per 1,000 people with Type 1 diabetes			
0–11	147	195	53	67
12–18	153	229	28	28
19–24	114	169	24	20
25–30	60	84	22	24

Note: Diabetes hospitalisations are classified according to the ICD-10AM code (ketoacidosis E10.11, E10.12, E10.15 E10.16 and hypoglycaemia E10.64).

Source: AIHW analysis of National Hospital Morbidity Database and National Diabetes Services Scheme (December 2009).

Table C.9: Hospitalisations for Type 1 diabetes with ketoacidosis, by age group and year, Australia

	Year							
Age group (years)	2002–03	2003–04	2004–05	2005–06	2006–07	2007–08	2008–09	2009–10
	Number							
0–11	377	437	397	498	506	569	542	577
12–18	785	906	931	1035	1103	1365	1363	1301
19–24	602	674	666	739	790	846	916	963
25–30	504	502	431	448	386	453	468	526

Note: Diabetes hospitalisations are classified according to the ICD-10AM code (ketoacidosis E10.11, E10.12, E10.15 E10.16).

Source: AIHW analysis of National Hospital Morbidity Database.

Table C.10: Hospitalisations for Type 1 diabetes with hypoglycaemia, by age group and year, Australia

	Year							
Age group (years)	2002–03	2003–04	2004–05	2005–06	2006–07	2007–08	2008–09	2009–10
	Number							
0–11	185	203	182	173	210	214	259	202
12–18	212	199	212	188	185	175	195	193
19–24	114	151	136	134	141	139	161	152
25–30	139	151	131	155	163	140	145	172

Note: Diabetes hospitalisations are classified according to the ICD-10AM code (hypoglycaemia E10.64).

Source: AIHW analysis of National Hospital Morbidity Database.

Table C.11: Rate of hospitalisations for long-term complications of Type 1 diabetes, by age group and sex, Australia, 2009–10

Age group (years)	Males	Females
	Number per 1,000 people with Type 1 diabetes	
0–11	2	1
12–18	3	3
19–24	10	18
25–30	32	58

Note: Diabetes hospitalisations are classified according to the ICD-10AM code (E10.2-E10.5, E10.7 E10.8, E10.61-63 and E10.69).

Source: AIHW analysis of National Hospital Morbidity Database and National Diabetes Services Scheme (December 2009).

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Diabetes among young Australians is the first report from the National Centre for Monitoring Diabetes to examine the management and impact of diabetes in youth in Australia. Diabetes affects a considerable number of young people: in 2010, about 31,300 Australians aged 0–30 years with diabetes were registered with the National Diabetes Service Scheme. Most (79%) had Type 1 diabetes.

This report explores how young Australians with diabetes are managing their condition, their use of health services and the diabetes-related health problems they experience.