



TYPE 1  
**diabetes**  
network

**PRE-BUDGET SUBMISSION TO  
THE TREASURER OF  
THE COMMONWEALTH OF AUSTRALIA  
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## EXECUTIVE SUMMARY

### The Challenge

- **Recommended blood glucose control, management of risk factors and complication screening rates are achieved by less than 20% of those with Type 1 diabetes** (Bryant et al., 2006, Gilbert et al., 2006).
- Mortality and avoidable hospitalisations continue to be high in Type 1 diabetics.
- The Diabetes Control and Complications Trial showed conclusively that tight self-management of blood glucose levels significantly improved health outcomes for those with Type 1 diabetes (The Diabetes Control and Complications Trial Research Group, 1993).
- Diabetes is a self-managed condition. It is the patient who monitors their blood glucose levels, adjusts and administers insulin and manages a life time of multidisciplinary care.
- For a self-managed condition, the voice of those with diabetes has largely been silent; at best consumer interests have been represented by employees of diabetes organisations. It is vital that the consumer be able to participate in the dialogue of health service provision if health outcomes for those with Type 1 diabetes are to be improved.

### Recommendation

The Type 1 Diabetes Network recommends that **evidence-based clinical practice guidelines for the management of Type 1 diabetes in adults** be developed collaboratively by health professionals and consumers and that these guidelines be produced for the use of both health professionals and consumers.

- The guidelines need to go beyond stating targets for physical or biochemical measures to address methods of treatment to reach these targets as well as dealing with other health and wellbeing issues that are often complicated by diabetes. As a minimum, guidelines are needed that address the efficacy of different insulin regimes and methods of delivery, the best practice use of continuous glucose monitoring systems, anaesthesia for type 1 diabetics, pregnancy with type 1 diabetes, an evidence-based approach to diabetes education and communication skills training for both practitioners and patients, including communicating long-term risks and the frequent onset of 'long-term complications' in young adults with Type 1 diabetes.
- Once developed these guidelines be disseminated and implemented through a multimedia education campaign amongst primary care providers, endocrinologists, diabetes nurse educators and consumers.

### Budgetary Impact

Significant impact to improve outcomes for type 1 diabetics could be made cost effectively.

- Development of guidelines : \$400,000
- Implementation and promotion : \$350,000

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## 1. Introduction

The Type 1 Diabetes Network is a ten year-old organisation, whose aim is to help type 1 diabetics achieve optimal quality of life. The Network is run by volunteers who have diabetes and contribute a broad range of professional skills and experiences from health and other relevant sectors.

The absence of guidelines for the management of Type 1 diabetes in adults underpins poor health outcomes in this population, limits the ability of health services to deliver quality, evidence-based care and impedes the effectiveness of consumer organisations to support the 140,000 Australians with Type 1 diabetes.

## 2. Background

Type 1 diabetes is an autoimmune disease which affects 140,000 Australians and comprises 10-15% of all cases of diabetes in Australia. It can be diagnosed at any age, though half of cases are diagnosed in childhood and three-quarters before 30 years of age. There is no cure. Despite the condition once being known as Juvenile Diabetes, it does not go away with age and more than 90% of the people living with Type 1 diabetes are adults.

Lifelong treatment of Type 1 diabetes involves multiple daily injections or insulin infusion and constant monitoring of blood glucose levels with finger prick blood tests as well as diet and activity levels. In addition to the immediate impacts of treatment and monitoring; long-term impacts of the condition include it being the most common cause of blindness before 60 years of age and a leading cause of kidney failure.

Health service, information and support needs for people with Type 1 diabetes are not well understood and consequently research and policy work has been minimal – furthermore, there is no coordination of professional or community initiatives.

### 2.1 Hospital admissions and bed days

In a major study by the Victorian government, diabetes complications were found to be the largest Ambulatory Care Sensitive Conditions (ACSC), where:

“hospitalisation is thought to be avoidable with the application of Public Health interventions and early disease management ...” (Victorian Government Health Surveillance and Evaluation Section, 2007a)

Complications of Type 1 diabetes alone were be responsible for 6,531 (4%) of all preventable hospital admissions in Victoria, and 36,703 (5%) of all ASCS hospital bed days, which is more than angina, asthma or ‘dehydration and gastroenteritis’. Of admissions for short-term diabetes complications, 75 % were attributable to Type 1 diabetes. (Victorian Government Health Surveillance and Evaluation Section, 2007b).

## 2.2 Mortality

There is little if any Australian research into the premature or avoidable mortality of people with Type 1 diabetes. A recent population-based study in Sweden concluded that: “In a well-developed health care system, there is still a significant excess mortality in young type 1 diabetic patients. We confirm a very large proportion of unexplained deaths in bed, which should be further studied. There is no clear excess death rate caused by suicide or traffic accidents among young diabetic subjects.” (Dahlquist and Källén, 2005).

## 2.3 Other health outcomes

A study of patients in a major Sydney hospital clinic found that HbA1c values satisfied the clinical target of less than 7% in only 12 of 89 (13%) patients with type 1 diabetes (Bryant et al., 2006).

Adolescent and young adult periods are recognised as particularly problematic. An Australian needs assessment of children and adolescents with Type 1 diabetes found that 18-19 year olds had the worst glycaemic control of any other age group (Juvenile Diabetes Research Foundation, 1999). In an international review, Bryden et al (2001) demonstrate a “... poor outcome in a significant proportion of young adults with diabetes ...” and “... significant morbidity associated with diabetes during the transition from childhood to young adulthood.”

## 2.4 Health and medical services

Less than a third of patients with Type 1 diabetes in a major Sydney hospital clinic met best practice guidelines for monitoring of their condition by health professional consultations. 32% had consulted a diabetes educator in the previous 2 years and 17% a dietitian (Bryant et al., 2006). A cross-sectional survey of 652 Australians with Type 1 diabetes also found low rates of health professional consultation, with only 22% meeting UK guidelines which were used in the absence of Australia guidelines (annual consultations with each of endocrinologist, diabetes educator and dietitian). This study found that those not meeting the guidelines were more likely to be aged 18-25 (38% v 29%) but also found that compliance was not significantly influenced by age at diagnosis (average 19.5, 18.7), residence in metropolitan areas (79.9%, 80.1%) or gender (male 28.7%, 30.2%) (Gilbert et al., 2006).

Screening for long-term complications of diabetes is an essential element of monitoring Type 1 diabetes, as treatments for complications are most effective before symptoms appear. Annual screening for conditions affecting the eyes, kidneys, nerves and feet is recommended; a study of 652 Australian adults with Type 1 diabetes showed compliance with this recommendation was approximately 60% for eyes, kidneys and nerves, and as low as 20% for foot care (Gilbert et al., 2006). The study also demonstrated that adherence to complication screening did *not* improve significantly where patients were meeting the recommendations for health professional consultations described earlier, which demonstrates the role of the patient not the health professional as central to the management of this complex condition.

A major challenge is the size and geographic spread of the Type 1 diabetes population in Australia. In 2004, 1,859 people under 40 years of age were diagnosed with Type 1 diabetes (Australian Institute of Health and Welfare, 2006). They were educated in 260 diabetes centres across Australia, concentrated in

major metropolitan centres, however the majority of these centres saw less than 5 patients newly-diagnosed Type 1 diabetes in a year and reported inexperience and a lack of confidence in the less common form of diabetes (The Type 1 Diabetes Network, 2007).

Specialist physicians, or endocrinologists, are the primary medical care providers for people with Type 1 diabetes. The RACGP guidelines call for GPs to immediately refer people with Type 1 diabetes to specialist physicians rather than be managed and monitored in general practice (Royal Australian College of General Practitioners and Diabetes Australia, 2007). Despite this guidance, timely and equitable access to endocrinologists is an issue and people with Type 1 diabetes continue to consult general practitioners for advice about their condition's management. In a cross-sectional survey of 652 Australian adults with Type 1 diabetes it was found that 79% had done so in the preceding year and 46% in the preceding 3 months. In the same cross-sectional survey 84% had consulted an endocrinologist in the last year and 54% had done so in the last 3 months (Gilbert et al., 2006).

In the last decade, improvements in technology to support the management of Type 1 diabetes have been seen, and in several cases supported by government subsidies. Insulin pumps are being used by approximately 1 in 30 people with Type 1 diabetes. Access to new and emerging therapies is inequitable – informal activities such as a website listing by the Australian Diabetes Educators Association of 'Centres of Excellence in Pump Management' are providing some improvements for consumers, however as an example the listing (for which there are no criteria) includes no centres in Queensland, Tasmania, the ACT or the Northern Territory (Australian Diabetes Educators Association, 2008). Whilst pump therapy becomes more accepted but demand stretches the service system's capacity, the next advance in technology is already upon us: continuous glucose monitoring systems (CGMS) which became commercially available in August 2007, although earlier versions have been in use in major diabetes centres since 1999. Mirroring the early experience with insulin pumps more than a decade ago, progress has been slow in evaluating the effectiveness and developing guidelines for the best practice use of this technology and access is limited to a minority of major hospitals.

## 2.5 Clinical practice guidelines

There is a lack of consensus regarding best practice in the management of Type 1 diabetes in Australia, especially for adults, and minimal guidance either for clinicians or patients. There are no Australian guidelines for the care or management of Type 1 diabetes in adults.

Clinical practice guidelines have been defined as "summaries of evidence and often a first step in encouraging evidence-based practice and improving quality health care" (National Health Priority Action Council, 2006).

Clinical practice guidelines, and consumer resources which can summarise them, play an important role in supporting a patient to engage in self-management of their condition. They are also crucial to supporting the work of consumer organisations and peer-support networks to provide consistent and evidence-based information in a range of settings. For a conditions which demands intensive and complex self-management, and where peer-support is important, evidence-based guidelines are imperative.

Those Australian guidelines which do exist include varying and sometime contradictory information about Type 1 diabetes, as follows:

	<b>Author</b>	<b>Addresses Type 1?</b>
Type 1 Diabetes in Children and Adolescents, 2005	Australian Paediatric Endocrine Group, endorsed by NH&MRC	Children (up to 18 years) only
Management of Diabetes in General Practice, 2007	Royal Australian College of General Practitioners and Diabetes Australia	Recommends immediate referral of all Type 1 diabetes to specialist physicians
various	Diabetes Australia Guideline Development Consortium	All relate to Type 1 diabetes
Therapeutic Guidelines - Endocrinology, 2004	Therapeutic Guidelines Limited (independent not-for profit)	Yes – with a focus on management in general practice / primary care.
Consensus guidelines for the management of type 1 and type 2 diabetes in relation to pregnancy, 2005	The Australasian Diabetes in Pregnancy Society	Yes.
Type 1 diabetes in adults, 2004	National Institute for Clinical Excellence (NICE), United Kingdom	Yes in the context of the UK National Health Service.

### 3. Existing policy initiatives

Diabetes-specific policy documents developed and commissioned by Australian governments frequently focus on Type 2 diabetes, whilst also incorporating some ambiguity in referring to the group of conditions and policy direction as affecting diabetes as a whole.

The currently most significant policy document is the National Service Improvement Framework (NSIF) for Diabetes, published by the Australian Health Ministers' Conference in 2005 as an overarching framework for both state and federal governments.

Whilst there remains little, if any, policy focusing on Type 1 diabetes, it is of concern that the *NSIF for Diabetes* has been developed within the context of the National Chronic Disease Strategy, where chronic disease refers to conditions with modifiable risk factors, and therefore prevention is a major focus. Type 1 diabetes is not preventable, nor caused by lifestyle factors of any kind and therefore, has quite a separate nature to 'modifiable risk factor chronic diseases' and there are systemic problems with taking the same approach across both types of conditions.

Some examples of this problematic issue are highlighted in the following table of policy initiative which have resulted from the NSIF for Diabetes and the National Diabetes Strategy:

Policy initiative	Author	Relevance to Type 1 Diabetes
NSIF for Diabetes : Evidence-based guidelines	Various including Diabetes Australia and Australian Paediatric Endocrine Group	Eleven guidelines have been commissioned that include: <ul style="list-style-type: none"> <li>• children and adolescents with Type 1 diabetes, 2005</li> <li>• six regarding Type 2 diabetes</li> <li>• diabetic retinopathy, 1997, does not distinguish between types of diabetes</li> </ul> <b>No guidelines for adults with Type 1 diabetes included in this program</b>
Outcomes and Indicators for Diabetes Education - A National Consensus Position. Diabetes Australia, Canberra 2007.	The Diabetes Unit - Australian Health Policy Institute The University of Sydney for Diabetes Australia	" The outcomes and indicators are expected to be .... applied to all people with diabetes regardless of the type, duration or stage of their diabetes."
National Diabetes Register	Australian Institute of Health and Welfare	Focuses on insulin-treated diabetes and provides a range of excellent data on Type 1 diabetes however there is some confusion between insulin-treated Type 2 and Type 1 diabetes.
National System for Monitoring Diabetes in Australia	Australian Institute of Health and Welfare	Modelled on "Preventing Chronic Disease: A Strategic Framework (NPHP 2001)" – and therefore focused on Type 2 Diabetes which has modifiable risk factors rather than Type 1 Diabetes which does not.
National Integrated Diabetes Program (NIDP)	DOHA/Medicare/ Divisions of General Practice	Purports to be for all diabetes, however focuses on general practice and RACGP guidelines for management of diabetes in general practice clearly state that all Type 1 should be referred to specialist physicians.

Policy documents which have explicitly investigated the needs of the Type 1 diabetes population include:

- National Needs Assessment for Children and Adolescents with Diabetes (Juvenile Diabetes Research Foundation, 1999)
- National Diabetes Strategy and Implementation Plan (Colagiuri et al, for the Australian Government Department of Health and Ageing, 1995)

#### **4. Conclusion**

In order to improve the outcomes for people with type 1 diabetes in Australia, there needs to be a clear distinction made between the subtypes of diabetes, and clinical practice guidelines for the management of type 1 diabetes in adults should be developed for both clinicians and consumers.

The implementation and uptake of these guidelines should be supported by an education campaign including dissemination of guidelines through the Royal Australian College of Physicians, the Endocrinology Society of Australia, the Divisions of General Practice and the Australian Diabetes Educators Association. Promotion of the consumer guidelines should be achieved through diabetes services, pharmacies, the National Diabetes Services Scheme and consumer organisations.

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