APPENDIX 2

Type 1 Diabetes in Australia: A Review

Type 1 diabetes is an autoimmune disease which affects around 100,000 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 together with diet and activity levels. In addition to the immediate burden of treatment and monitoring; long-term impacts of the condition can be devastating.

Health service, information and support needs for people with Type 1 diabetes are not well understood and there is no structured coordination of professional nor community initiatives so that duplication and replication are common.

1. Rising incidence and variable prevalence

The rate of new cases of Type 1 diabetes in Australian children has risen 21% from 19 cases per 100,000 children in 2000 to 23 cases in 2005, and is rising across all age groups (Catanzariti, Faulks et al. 2007).

The prevalence of Type 1 diabetes is not well understood, being recently reported as:

- 91,900 in the 2005-06 National Health Survey (Australian Institute of Health and Welfare 2006)
- 130,954 registrants to the National Diabetes Services Scheme (Diabetes Australia undated)
- 140,000 by Juvenile Diabetes Research Foundation (Juvenile Diabetes Research Foundation)
- “Over 100,000” by Diabetes Australia-Victoria (Diabetes Australia-Vic 2007)

An objective of the National Diabetes Register established in 1999 is to “assess the feasibility and cost of estimating the prevalence of insulin-treated diabetes” which could involve estimating the prevalence of Type 1 diabetes specifically, however this has not been reported to date (Australian Institute of Health and Welfare 2007).

2. Mortality

There is little research into the premature or avoidable mortality from Type 1 diabetes in Australia. One study found the rate of death among girls with Type 1 diabetes to be nearly 5 times greater than the general population of girls aged 10-17 years (Juvenile Diabetes Research Foundation). A 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." (Dahlquist and Källén 2005).

3. Hospital admissions

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

> "hospitalisation is thought to be avoidable with the application of Public Health interventions and early disease management … High rates of hospital admissions for ACSCs may provide indirect evidence of problems with patient access to primary healthcare, inadequate skills and resources, or disconnection with specialist services." (Victorian Government Health Surveillance and Evaluation Section 2007)

Complications of Type 1 diabetes alone were shown to be responsible for 6,531 (4%) of all ACSC or preventable hospital admissions in Victoria in 2001-02, putting it at the same level as cellulitis, and just below 'convulsions and epilepsy'. Furthermore, Type 1 diabetes complications were responsible for 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, however the majority (87%) of Type 1 diabetes complications admissions were for long-term complications (Victorian Government Health Surveillance and Evaluation Section 2007).

4. Complications and comorbidities

The medium- and long-term physiological effects of diabetes commonly include eye, kidney, heart and vascular diseases as well as a range of other less common conditions.

People with Type 1 diabetes are four times more likely to develop kidney disease. Over 40% of people with Type 1 diabetes develop severe kidney disease by the age of 50. 24% will develop diabetic retinopathy (eye disease) after 5 years, almost 60% after 10 years and 80% after 15 years (Juvenile Diabetes Research Foundation).

Impotence occurs in 30% - 50% of men with (all types of) diabetes.

Periodontal disease occurs with greater frequency and severity among people with diabetes. It has been reported in 30% of people aged 19 or older with Type 1 diabetes (Juvenile Diabetes Research Foundation).

Pregnancy for women with Type 1 diabetes carries significant risks for both mother and child. Rates of still-births have been shown to be almost twice that of the general population (McElduff, Ross et al. 2005). Significant pregnancy complications are more common in women with Type 1 diabetes including macrosomia (large babies), pre-eclampsia and congenital malformations of the child (TEMPLE, ALDRIDGE et al. 2006). Caesarean delivery is three to four times more frequent in pregnancies involving diabetes (Australian Institute of Health and Welfare 2002). Pregnancy can also cause the rapid progression of other complications in the mother, such as eye and kidney disease (McElduff, Cheung et al. 2005).

5. Other clinical outcomes

A study of patients in a major Sydney hospital clinic found that HbA1c values, the key monitoring blood test and predictor of long-term outcomes, satisfied the clinical target of less than seven per cent in only 13% patients with Type 1 diabetes (Bryant, Greenfield 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 glycemic 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."

6. Mental health

Depression is twice as common in people with Type 1 diabetes (Anderson, Freedland et al. 2001). Anxiety disorders are also more common, affecting between 14% and 40% of people with all types of diabetes (Grigsby, Anderson et al. 2002).

A review by Cameron et al (2007) concluded that "current rates of psychological ill health in diabetic youth … appear to be disturbingly high ... persist into early adulthood and possibly beyond … [and] appear to be prognostic of … earlier-than-expected onset of complications".

A fifteen year study by the Murdoch Children's Research Institute found that 38% of adolescents with Type 1 diabetes had been referred to mental health services since their diagnosis (Murdoch Children's Research Institute). A University of Western Australia survey in 2007 looked at 92 young adults with Type 1 diabetes aged 18 to 28 years and found that 35 per cent showed symptoms of depression. It also found that young adults with depressive symptoms had poorer glycaemic control (Diabetes UK 2008).

Eating disorders are much more prevalent in girls with Type 1 diabetes. A Canadian study found the prevalence of disturbed eating patterns in pre-teen girls with Type 1 diabetes to be 8%, eight times the rate in non-diabetics and 49% in teenagers, of which 8% met the criteria for an eating disorder (Colton, Olmsted et al. 2007).

7. Health and medical services

Type 1 diabetes services are generally delivered in tertiary hospitals or private specialist facilities, and often alongside services for people with Type 2 diabetes; a condition whose etiology and population differs significantly. There are some hospitals and diabetes centers that have informally developed a special interest in Type 1 diabetes through offering new treatment methods such as insulin pumps.

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 study, 84% had consulted an endocrinologist in the last year and 54% had done so in the last 3 months (Gilbert, Thornley et al. 2006).

Best practice is rarely attained in terms of ongoing monitoring and education. 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. Only 32% had consulted a diabetes educator in the previous 2 years and 17% a dietitian (Bryant, Greenfield et al. 2006). A cross-sectional survey of 652 Australian with Type 1 diabetes in 2006 also found low rates of health professional consultation, with only 22% meeting international 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%) nor gender (male 28.7%, 30.2%) (Gilbert, Thornley et al. 2006).

Screening for long-term complications 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%, and as low as 20% for foot care (Gilbert, Thornley et al. 2006). The study also demonstrated that adherence to complication screening did *not* improve significantly where patients were maintaining frequent health professional consultations as described earlier.

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 such cases per year and commonly reported lack of confidence in working with Type 1 diabetes (The Type 1 Diabetes Network 2007).

In the last decade, improvements in technology to support the management of Type 1 diabetes have been seen. For example, 'insulin pumps' are programmable devices that deliver insulin much more precisely and flexibly than standard injection therapy and lead to significant improvements in glycaemic control; ongoing running costs are now subsidised by the federal government and upfront costs are fully reimbursable with basic levels of private health insurance. At 31 December 2007, insulin pumps were being used by 4,989 Australians which is 3.8% of people with Type 1 diabetes[1]. Access to new and emerging therapies is inequitable – informal activities such as a website listing 'Centres of Excellence in Pump Management' provide 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 2006, and have been trialled in major diabetes centres since 1999. Mirroring the early experience with insulin

[1] Statistics supplied by Diabetes Australia from the National Diabetes Services Scheme. The National Diabetes Services Scheme (NDSS) is an initiative of the Australian Government administered by Diabetes Australia.

pumps, 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.

8. 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:

Guideline	Author	Addresses Type 1?
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 2 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 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.

9. 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, specific policy focusing on Type 1 diabetes, it is of concern that the *NSIF for Diabetes* is dominated by the issues of the more prevalent condition Type 2 diabetes. Furthermore, the NSIF 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 can and is a major focus, yet it excludes long-term or chronic diseases which occur (often much earlier in life) without the presentation of risk factors, such as Type 1 diabetes, rheumatoid arthritis and epilepsy to name but a few. This latter group of conditions and their affected populations have quite a separate nature to those with 'modifiable risk factor chronic diseases' and there are systemic problems with taking the same approach with both distinctly different types of conditions.

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

Policy initiative	**Author**	**Addressed Type 1?**
NSIF for Diabetes : Evidence-based guidelines	Various including Diabetes Australia and Australian Paediatric Endocrine Group	Eleven guidelines commissioned, including: • children and adolescents with Type 1 diabetes, 2005 • six regarding Type 2 diabetes • diabetic retinopathy, 1997, does not distinguish between types of diabetes **No guidelines for adults with Type 1 diabetes**
Outcomes and Indicators for Diabetes Education - A National Consensus Position.	The Diabetes Unit - Australian Health Policy Institute, The University of Sydney	" 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 where Type 1 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 explicitly investigate 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)

10. Consumer involvement and representation

Consumer involvement in policy, research and service development for Type 1 diabetes, and diabetes as a whole, has been minimal. The National Service Improvement Framework (2006) was developed by an Expert Panel comprising no consumer representatives. The National Diabetes Strategy and Implementation Plan (1995) included minimal consumer input.

Some of the diabetes consumer organisations which exist in Australia as follows:

Organisation	Overview	Funding	Members	Proportion represented
Diabetes Australia	Federated group of diverse state and territory-based consumer membership organisations, plus two professional bodies and two foundations. Founded in 1937.	Government contracts, membership subscriptions and donations	170,000 consumer members nationally *	20.1% of all people diagnosed with diabetes #
Juvenile Diabetes Research Foundation	Mission is "to find a cure for Type 1 diabetes and its complications through the support of research". Founded in 1982.	Fundraising campaigns, private donations and partnerships	4,415 consumer members (Juvenile Diabetes Research Foundation 2007).	3.4 % of all people diagnosed with Type 1 diabetes ^
The Type 1 Diabetes Network	Unstaffed, consumer network run by volunteers who have Type 1 diabetes. Founded in 1997.	Private donations, advertising and project grants. DGR registration effective 1 July 2007.	2,821 consumer members of mailing list	2.2 % of all Australians diagnosed with Type 1 diabetes ^

* This figure has been calculated from summing the membership figures of state and territory-based consumer organisations of the Diabetes Australia Federation, as follows. The circulation of the organisation's national magazine is reported as "approximately 170,000" which provides some validation. Victoria 26,000, New South Wales approx 57,000, Tasmania approx 5,100, Western Australia 15,637, Queensland 45,173, South Australia 20,000. ACT and NT – figures not publicly available. Note: Membership numbers are not disclosed in the annual reports of Diabetes Australia-NSW or Diabetes Australia-Tasmania. The figures for these states were calculated from membership income disclosed, and based on average membership subscription of $20. (Diabetes Australia-Tasmania 2006; Diabetes Australia - New South Wales 2007; Diabetes Australia - Victoria 2007; Diabetes South Australia 2007; Diabetes WA 2007; Diabetic Association of Queensland 2007)

\# Based on 844,062 NDSS registrants at 30 June 2007 (Diabetes Australia 2007)

^ Based on 130,954 NDSS registrants with Type 1 diabetes at 30 June 2007 (Diabetes Australia 2007)

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TYPE 1 diabetes network

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TYPE 1 diabetes network

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