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*By email: [nicola.dunbar@safetyandquality.gov.au](mailto:nicola.dunbar@safetyandquality.gov.au)*

Dear Dr Dunbar,

We have been advised by the Chronic Illness Alliance that you are interested in exploring the complexities of managing risk in primary care as it relates to chronic medical conditions, and the Type 1 Diabetes Network would like to provide you with some information relating to the example of Type 1 Diabetes and the experiences of people living with this complex self-managed condition.

The Type 1 Diabetes Network is a ten year-old consumer group run by volunteers, people living with Type 1 Diabetes ourselves, which provides support and information services as well as conducting research into information and support needs of people with Type 1 Diabetes and their health service utilisation.

As you would be aware, Type 1 Diabetes affects approximately 140,000 Australians. The cause is not completely understood, however, it is not related to lifestyle; it is believed that people have a genetic predisposition and a trigger factor such as a virus causes the body's immune system to incorrectly identify insulin-producing cells as foreign and destroy them. Managing Type 1 Diabetes is a complex question of balance: it is treated with multiple daily insulin injections, healthy eating, regular exercise and constant monitoring of blood glucose levels through taking small samples of blood from fingertips and frequent adjustment of insulin doses by the patient.

We will respond directly to the consultation questions outlined in 'Patients at risk of critical illness and serious adverse events: Application in primary care'.

### **1. What does "at risk" mean in primary care?**

Your consultation paper identified Ambulatory Care Sensitive Conditions as a way to examine risk in primary care. For people with diabetes, the relevant category is diabetes complications. It would be important to draw the distinction between short-term and long-term diabetes complications, as does a detailed review of this category of ACSC presentations published by the Victorian government in 2007: 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.<sup>1</sup>

<sup>1</sup> Victorian Government Health Surveillance and Evaluation Section (2007). The Victorian ambulatory care sensitive conditions study: Diabetes complications in Victoria, 2001–02. Melbourne, Victorian Government Department of Human Services.

Please find below an exploration of case scenarios that will comprise diabetes complications and possible intervention points and strategies to reduce risk in each scenario.

<b>Short-term complications and risk in Type 1 Diabetes</b>	<b>Drivers and possible intervention points for reduction of risk <i>in primary care</i></b>
<b>Diagnosis complicated by diabetic ketoacidosis (DKA) is common in both children and adults</b>	<ul style="list-style-type: none"> <li>• <b>Misdiagnosis in primary care is frequently reported by Adults</b>, where treating clinicians sometimes understand Type 1 Diabetes to be a disease only diagnosed in childhood. High blood glucose levels are subsequently treated as for Type 2 Diabetes with tablets and diet, or symptoms (lethargy, thirst, urination) are given another diagnosis, eg. UTI, fatigue, virus. Delayed diagnosis dramatically increases the risk of hospitalisation, severe illness and death.</li> <li>• For children, in 1999, Vanelli demonstrated that a <b>school-based campaign centred on recognising early symptoms</b> of Type 1 Diabetes reduced the cumulative frequency of ketoacidosis in children with type 1 diabetes in the province of Parma from 78% to 12.5%; after the first 2 years of the campaign, none of the newly diagnosed children with diabetes were admitted to hospital with severe or moderate ketoacidosis. In the two provinces in which the campaign was not carried out, the incidence of DKA remained at the higher level (83%).<sup>2</sup></li> </ul>
<b>Diabetic Ketoacidosis (DKA)</b>	<ul style="list-style-type: none"> <li>• Subsequent work by Vanelli's team in Italy has included <b>establishment of a hotline</b> using widely-available telephone technology for parents of children with Type 1 diabetes, many of whom were reporting difficulties finding an experienced paediatrician to manage a DKA emergency. The hotline has resulted in "ketoacidosis being prevented in a number of children and large admittance costs avoided".<sup>3</sup></li> <li>• <b>Sick Days</b> (fever, vomiting, alcohol-related, other) accelerate progression of DKA – excellent guidelines and a consumer booklet for prevention and early self-management of DKA were produced by the Australian Diabetes Educators Association (ADEA) in 2006 however their implementation, and dissemination to people with diabetes, has been very limited.</li> <li>• <b>People diagnosed as children with Type 1 Diabetes upon reaching adulthood</b> have few opportunities for education about their condition themselves and frequently report poor knowledge beyond day-to-day management, with their parents having been educated at their diagnosis. The group would be an important target for any improvement in this area.</li> </ul>
<b>Severe hypoglycaemia</b>	<ul style="list-style-type: none"> <li>• <b>Pregnancy</b> in women with Type 1 diabetes is a key risk factor for the onset of severe hypoglycaemia, especially the earliest stages and throughout the first trimester. Pre-pregnancy counselling and education by teams specialised in managing pregnancy with pre-existing type 1 diabetes offers an opportunity to ensure women are both aware and prepared for this scenario. Plans are currently underway to mail a consumer booklet about pregnancy with pre-existing diabetes to all women with Type 1 diabetes aged 16-40. The booklet should also be provided in an ongoing manner. A pre-pregnancy education course has been developed by endocrinologists Drs Conn and Nankervis at the Royal Women's Hospital, Melbourne whose roll-out more widely could be of significant benefit as well.</li> </ul>

<sup>2</sup> Vanelli, M., 2007, Education and public information: preventing diabetic ketoacidosis in Italy, Diabetes Voice, Volume 52, [www.worlddiabetesday.org/files/dka/DKA001\\_DV2007\\_Vanelli\\_EN.pdf](http://www.worlddiabetesday.org/files/dka/DKA001_DV2007_Vanelli_EN.pdf). Accessed 13 October 2008.

<sup>3</sup> Vanelli, M., "Hello, diabetes." Preventing DKA in children with a telephone hotline service', Diabetes Voice 53.2. [www.worlddiabetesday.org/files/dka/DKA009\\_DV2008\\_Vanelli\\_EN.pdf](http://www.worlddiabetesday.org/files/dka/DKA009_DV2008_Vanelli_EN.pdf). Accessed 13 October 2008.

<b>DKA or severe hypoglycaemia</b>	<ul style="list-style-type: none"> <li>• <b>Drug and Alcohol use</b> in people with Type 1 diabetes is no less prevalent than in the general community, and an exploratory study (unpublished to date) by the National Drug and Alcohol Research Centre in 2002 found usage rates to actually be higher. Usage can increase the risk of short-term complications of diabetes. There is minimal consumer information about managing Type 1 diabetes in relation to drug and alcohol use and that which is available (such as 'Going Out, Staying Out' produced by Royal Children's Hospital, Melbourne) has not been widely disseminated.</li> </ul>
<b>Hospital admissions not directly related to diabetes</b>	<ul style="list-style-type: none"> <li>• <b>Hospital admissions, planned and emergency, for people with Type 1 Diabetes are managed poorly when a diabetes team is not involved.</b> Such visits, especially those planned, may be initiated in primary care and/or opportunities exist in primary care to improve the planning and management. It has been proposed by The Type 1 Diabetes Opinion Leaders Group that : a) Everyone requires a <b>pre-determined Diabetes Plan</b> that can be immediately enacted upon admission to hospital or in other emergencies; and b) All planned admissions should include <b>pre-admission planning</b> for diabetes management in hospital with a diabetes team, supported by a <b>comprehensive patient information resource</b>.<sup>4</sup></li> </ul>
<b>Emergencies at school</b>	<ul style="list-style-type: none"> <li>• On the whole, children with Type 1 Diabetes are managed by specialised teams in tertiary hospitals, however there are concerns that the <b>training of teachers and schools about the basic needs of children with Type 1 diabetes occurs haphazardly.</b> The Type 1 Diabetes Opinion Leaders Group proposed that a national system for annual education of school staff about common medical conditions including Type 1 Diabetes would improve the care of children and reduce the severity of adverse events.</li> </ul>

<b><u>Long-term complications and risk in Type 1 Diabetes</u></b>	<b>Drivers and possible intervention points for reduction of risk <u>in primary care</u></b>
<p>Microvascular complications of diabetes: Kidney damage/failure, proliferative (vision-threatening) retinopathy (eye disease), neuropathy (nerve damage to the extremities, sometimes resulting in amputation)</p>	<p>Risk of developing these devastating long-term complications of diabetes can be reduced, or their deterioration minimised, through optimal management of blood glucose levels and other health risk factors; as well as through screening and early identification.<sup>5</sup></p> <p>In people with Type 1 diabetes, these complications can present at very young ages. For example, 80% develop retinopathy (vision-threatening eye disease) after 15 years of Type 1 Diabetes. For a person diagnosed with Type 1 diabetes as a child, this can clearly be occurring during the young adult years.</p> <p><b>Improved blood glucose control</b> – Only 13% of patients with Type 1 Diabetes in a major Sydney hospital outpatient clinic achieved the clinical target of less than 7% HbA1c, the key predictor of long-term complications.<sup>6</sup> A cross-sectional survey of 652 Australians with Type 1 Diabetes in 2006 found low rates of health professional consultations, with only 22% meeting international guidelines (annual consultation with endocrinologist, diabetes nurse educator and dietician).<sup>7</sup></p>

<sup>4</sup> The Type 1 Diabetes Network (2008) A Statement of Issues affecting Australians with Type 1 Diabetes. [www.d1.org.au/issues](http://www.d1.org.au/issues). Accessed 14 October 2008.

<sup>5</sup> The Diabetes Control and Complications Trial (1993) showed conclusively that tight self-management of blood glucose levels significantly improved health outcomes for people with Type 1 Diabetes.

<sup>6</sup> Bryant, W., J. R. Greenfield, et al. (2006). "Diabetes guidelines: easier to preach than to practise?" *Medical Journal of Australia* 185(6): 305-309.

<sup>7</sup> Gilbert, K., S. Thornley et al. (2006). Non-adherence to the 'traditional model' of medical management in Australian adults with type 1 diabetes mellitus and its impact on complication screening and self-management. *World Diabetes Congress*. Cape Town.

	<p>Evidence-based guidelines for the management of Type 1 diabetes and evidence for what improves blood glucose levels would be a valuable addition. Limited evidence is available about what works in this regard. There is some evidence for: new technologies such as insulin pumps whose access is currently dependent upon private health insurance; patient information resources; and peer learning opportunities which are limited and difficult to access.</p> <p><b>Routine complication screening</b> - Long-term complications need be identified and treated before they become symptomatic in order to optimise outcomes. Routine screening or monitoring for complications is essential. No systematic recall or screening programs exist. Guidelines for adults with Type 1 Diabetes do not exist in Australia, as described earlier, such that there is no consensus on what screening should be done, when, how and by whom. The Gilbert and Thornley et al's study of Australian adults with Type 1 diabetes, cited immediately above, showed that complication screening rates were only 60%, and as low as 20% for foot care. The study also found that adherence to complication screening did <i>not</i> improve significantly where patients were maintaining frequent health professional consultations. Furthermore, many consumers and health professionals believe that the "system for the essential long-term monitoring of Type 1 Diabetes is inefficient and highly ineffective"<sup>8</sup> thwarting the efforts of those who do understand the need to maintain annual or more frequent monitoring or screening and attempt to do so.</p> <p>The Type 1 Diabetes Opinion Leaders Group has proposed: a) an automated system for routine complication screening recall and review to increase rates from 20% currently; and b) Medicare Benefits Schedule (MBS) reviewed to better support management of complex chronic diseases which cannot be prevented, such as Type 1 Diabetes, including: • broadening the scope of professions that initiate care plans to include endocrinologists; • ensuring indefinite referral legislation is reviewed by both patient groups and providers of services and improved so that it can be consistently issued and accepted.</p>
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**Other scenarios not fitting the diabetes complications category:**

<p><b>Pregnancy carries significant risks for both mother and child</b></p>	<p>Rates of still-birth are almost twice that of the general population. Significant complications of pregnancy are more common including macrosomia, pre-eclampsia and congenital malformations of the child. Caesarean delivery is 3-4 time more frequent. Pregnancy can cause the rapid progression of long-term complications detailed above.</p> <p><b>Pre-pregnancy counselling and education</b> is advocated as well as planning pregnancies so that the woman is in optimal health and very tight diabetes control at the time of conception. Information needs to be provided to women before they become pregnant about the risks and how to minimise them. Also, upon conception a woman with Type 1 diabetes, if not already linked in, needs to be referred for specialist care and intensive, specialised monitoring to reduce the risks. The Australian Diabetes in Pregnancy Society has published clinical guidelines, and in partnership with consumer groups an accompanying patient information resource on this topic. There remain additional opportunities to bring the issue to the attention of primary care providers and ensure immediate referral to specialised care.</p>
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<sup>8</sup> The Type 1 Diabetes Network (2008) A Statement of Issues affecting Australians with Type 1 Diabetes. [www.d1.org.au/issues](http://www.d1.org.au/issues). Accessed 14 October 2008.

<b>Mental health</b>	<p><b>Diagnosis with long-term complications</b> is identified as key point of intervention where all people with Type 1 Diabetes should be offered referral to a mental professional or counsellor in order to manage depression, anxiety or more severe responses to this sometimes devastating and terrifying diagnosis.</p> <p><b>Routine screening of mental health</b> of people with Type 1 Diabetes is recommended given the known rates of mental distress experienced by this population. Eating disorders are eight times as common amongst pre-teens with Type 1 diabetes and rates of psychological ill health amongst diabetic youth have been described as 'disturbingly high'.<sup>9, 10</sup>. A Western Australian survey of 92 18-28 year-olds found that 35 per cent showed symptoms of depression and that young adults with depressive symptoms had poorer glycaemic control, predicting higher rates of long-term complications in future.<sup>11</sup></p>
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## 2. Can patients at risk in primary care be identified in advance?

We would propose that people with Type 1 Diabetes experience a wide range of issues which make it a high risk condition. People with Type 1 Diabetes however report frequent confusion from healthcare providers whom they encounter in the primary care setting, both at diagnosis in adults as described above, and in ongoing management and presentations, between Type 1 and Type 2 Diabetes, which result in a range of risks and unnecessary exacerbations of illness.

## 3. How should patients at risk be managed in primary care?

The Royal Australian College of General Practitioners and Diabetes Australia's 'Management of Diabetes in General Practice' recommends "immediate referral of all Type 1 diabetes to specialist physicians."<sup>12</sup> Yet, access to specialist physicians (endocrinologists) is a major issue in both metropolitan and regional Australia. Furthermore, there are no evidence-based guidelines for the management of Type 1 diabetes in adults in Australia which would support a GP or other physician be required to lead the management there is no consensus about how this should best be done. An ongoing program from the Department of Health and Ageing commissioned the development of eleven guidelines for diabetes, but Type 1 diabetes in adults was unfortunately not amongst them.<sup>13</sup>

The implementation of guidelines for the management of Type 1 diabetes in adults would greatly enhance the capacity of primary care to manage this complex condition, and reduce risk. The process could be somewhat expedited through adoption and/or adaption of other countries' guidelines such as those very recently revised by the National Institute for Clinical Excellence (NICE) in the United Kingdom.<sup>14</sup>

## 4. What systems are needed to support the identification and management of patients at risk?

**Enrolled populations**, which have been trialled to enhance chronic illness care in the United Kingdom, New Zealand and other jurisdictions, would increase the system's capacity to identify and monitor people with Type 1 Diabetes – especially monitoring for long-term complications. Diabetes Australia administers the National Diabetes Services Scheme (NDSS) with funding from the Federal Government Department of Health and Ageing, which is a registry of all people with diabetes. It has, however, had limited and highly restricted use to date and not been used for

<sup>9</sup> Cameron, F. J., E. A. Northam, et al. (2007). "Routine Psychological Screening in Youth With Type 1 Diabetes and Their Parents. A notion whose time has come? ." *Diabetes Care* **30**: 2716-2724.

<sup>10</sup> Colton, P. A., M. P. Olmsted, et al. (2007). "Five-Year Prevalence and Persistence of Disturbed Eating Behavior and Eating Disorders in Girls With Type 1 Diabetes." *Diabetes Care* **30**: 2861-2862.

<sup>11</sup> Diabetes UK (2008). *Diabetes Blues*.

<sup>12</sup> Royal Australian College of General Practitioners and Diabetes Australia (2007). *Diabetes Management in General Practice 2007/8*. Canberra.

<sup>13</sup> The Type 1 Diabetes Network, 2008, 'Type 1 Diabetes in Australia: A Review', [www.d1.org.au/issues](http://www.d1.org.au/issues)

<sup>14</sup> See 'Type 1 diabetes in adults, full guideline, main section' published 22 August 2008, available at <http://www.nice.org.uk/Guidance/CG15/Guidance/pdf/English>

clinical management purposes. Increasingly, public awareness and information campaigns are being distributed via the NDSS database and some restricted research has been undertaken. Further opportunities may exist there.

**Telephone and web-based specialist advice** – There is evidence from Parma in Italy that a telephone hotline reduces hospitalisation and moderate to severe DKA for children with Type 1 Diabetes. Such a service or services would have enormous benefits if targeted both at people with Type 1 diabetes (children and adults) to support self-management, and at primary care and other generalist healthcare providers, to obtain secondary consultation by clinicians specialised in the management of Type 1 diabetes when required. This would provide additional benefits for people living, or health professionals practising, in rural and remote areas of Australia where access to specialist services is especially limited, though access in metropolitan areas is also problematic.

**Diabetes Plan.** It has been proposed that all people with Type 1 Diabetes should have a pre-determined plan for managing their condition which can be immediately enacted upon admission to hospital or other emergency.<sup>15</sup>

### **A Statement of Issues affecting Australians with Type 1 Diabetes**

I enclose a copy of this statement which our organisation developed this year in partnership with a wider range of diabetes organisations, professional associations, and consumers. A range of the issues and solutions in the Statement relate to the management of risk for people with Type 1 Diabetes.

I also enclose a background document which I prepared earlier this year, 'Type 1 Diabetes in Australia: A Review', which explores a range of the issues outlined in this paper further.

### **In summary, we would strongly support action in the following areas to reduce risk in primary care for Australians with Type 1 Diabetes:**

- Prompt diagnosis of both adults and children with Type 1 Diabetes
- Complication screening register and recall
- 24-hour secondary consultation service, telephone-based, for GPs and hospital doctors to access a team with expertise in Type 1 Diabetes
- Help Desk – 24-hour phone and email access to specialist advice
- Pre-determined Diabetes Plans for management of emergencies
- National system for annual education of schools about common medical conditions
- Routine screening and review of mental health

I would be pleased to discuss our contribution with you at your convenience. I am contactable on 0402 515 825 or by email to [kate@d1.org.au](mailto:kate@d1.org.au).

We look forward to hearing of the progress of your consultations and would be pleased to assist in any way possible as you proceed.

Yours sincerely,



**Kate Gilbert**  
**Founder & Honorary President**

cc: Dr Christine Walker, Chronic Illness Alliance

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<sup>15</sup> The Type 1 Diabetes Network (2008) A Statement of Issues affecting Australians with Type 1 Diabetes. [www.d1.org.au/issues](http://www.d1.org.au/issues). Accessed 14 October 2008.