Submission to the National Diabetes Strategy Committee from the Australasian Paediatric Endocrine Group: Critical Issues and proposed solutions. November 2014

1. Access to Multidisciplinary Team Care

Issue: Achieving optimal diabetes control is especially complex in the young and requires the support of an expert multidisciplinary team to deliver developmentally appropriate diabetes care. Not all children have this access in Australia and limitation of resources in the context of increased complexity of care has resulted in inadequate and deteriorating healthcare provider to patient ratios. State based hospital funding models (traditionally the providers of paediatric care) increasingly do not provide for outpatient care for chronic diseases.

Rationale: All published standards of care indicate the requirement for at least four interactions per year between an expert team (paediatric endocrinologist, diabetes nurse specialist, dietitian and social worker/psychologist) and the child with diabetes and his/her family as well as access to the team between visits.

Action: Documentation and endorsement of appropriate standards of care in a national strategy and the development of new, sustainable and adequate funding models for diabetes teams.

2. Transition of youth with Diabetes

Issue: Young adults with T1DM generally have the poorest metabolic control, yet are at highest risk of being lost to follow up to specialty diabetes services.

Rationale: Skilled, age appropriate clinical care is required to avoid preventable acute and chronic complications. This age group needs specific clinical support to transition from paediatric diabetes healthcare to adult models of care.

Action: It is essential to provide continuity and consistency of expert multidisciplinary team care, with a developmentally age appropriate approach within a “One Stop Shop”. This is likely to be cost effective. Institutional diabetes care services require support to provide such care in collaboration with GP’s using shared clinical guidelines. Ongoing audit of the process is critical.

3. Diabetes in Schools

Issue: The care provided in schools and at day care for children with diabetes varies considerably across Australia. Some manage well, while others suffer discrimination, lack of practical support with their diabetes care (insulin injections/blood testing) and undue anxiety in the school setting, potentially impacting metabolic control, quality of life and educational outcomes. There is inconsistency between States and school systems and expectations are not well defined and accepted.

Rationale: Children spend a significant time at school and engage in a range of activities that may impact on diabetes care. It is important for educational, social, developmental and metabolic reasons that management at school is optimal.

Action: A national audit of diabetes teams/ schools and teachers/ families and other relevant stakeholders would document the current level of support available to children in day care centres and schools and define the deficits. It is important to detail the school’s duty of care and adopt this as part of a national strategy. Involvement of educational authorities in this process is critical.

4. Access to new diabetes treatments and technologies

Issue: New technologies including pump therapy, continuous glucose monitoring (CGM) and sensor augmented pump therapy with and without embedded algorithms (closed loop and semi closed loop therapy) offer reduced risk of hypoglycaemia, improved glycaemic control and reduced burden of

care. Australia is lagging compared to other developed countries in allowing equitable access of all patients to the benefits of these treatments and this difference is likely to increase.

Rationale: There is increasing evidence for the benefits of these new approaches combined with clinical support especially for reduced hypoglycaemia risk

Actions: First, a process to allow assessment of technologies with a path to reimbursement is urgently required to allow unbiased evaluation of the benefits or otherwise of these treatments. Second, the provision of equitable access to technologies for all patients who would benefit from the use of technology, in particular pump therapy and CGM.

5. Prevention of Diabetic Ketoacidosis (DKA) in newly diagnosed patients

Issue: Surveys have shown that approximately 25-30% of newly diagnosed children with T1DM present in ketoacidosis. This figure has not improved in the last 20 years. Diabetic Ketoacidosis has significant morbidity and is the commonest cause of diabetes related mortality in childhood.

Rationale: DKA is preventable if the diagnosis of diabetes in made in a timely manner. Early diagnosis is simple and inexpensive. Studies have shown that rates of DKA can be reduced with education of the public and primary care health providers.

Action: Programs to be developed and trialled to raise the awareness of the incidence of diabetes in children and mode of presentation. Ongoing audit to assess the effectiveness of these programmes and areas that require increased attention.

6. Monitoring of diabetes care outcomes: national database

Issue: There is no information as to outcomes for children and young adults with diabetes.

Rationale: Monitoring/audit of glycemic control in the population of young people with diabetes can be a means to improve outcomes into adulthood and identify deficits in care. This approach is common in many developed countries and is considered a cost effective component of health care provision.

Action: Establishment of a national database to record outcomes (HbA1c) in children, adolescents and young adults with diabetes. Infrastructure already exists that can facilitate this initiative.

7. Preventing Type 2 Diabetes Mellitus in the young

Issue: Childhood obesity prevalence has increased over the last 3 decades, with around 20% of children affected in Australia. This increase has been associated with increasing rates of T2DM/IGT in the young, this has very poor prognosis and high cost.

Rationale: At risk children can be identified eg children of pregnant women with obesity, T1DM or gestational diabetes. This risk may be reduced through interventions at the time of pregnancy and early childhood.

Action: The development of educational and intervention programs to target overweight pregnancies and new parents. These programs may include paediatric follow up of at risk children.