ANZSPED
AUSTRALIA AND NEW ZEALAND SOCIETY FOR PAEDIATRIC ENDOCRINOLOGY AND DIABETES

PRESIDENT
A/Prof Louise Conwell, Queensland Children's Hospital

TREASURER
Dr Carmel Smart, John Hunter Children's Hospital

SECRETARY
A/Prof Peter Simm, Royal Children's Hospital Melbourne

Submission to the House of Representatives Standing Committee on Health, Aged Care and Sport
Inquiry into Diabetes

31 August 2023

Dear Committee Secretariat,

Thank you for this opportunity to provide input into the Parliamentary Inquiry into Diabetes.

Australian and New Zealand Society for Paediatric Endocrinology and Diabetes (ANZSPED) is the premier professional body representing paediatric endocrinology in Australasia and is committed to high standards of clinical care, advocacy, education, stakeholder relationships and research in paediatric endocrinology. The Society has a broad membership of paediatric endocrinologists, paediatricians, nurses, allied health professionals and researchers. More about our society can be found here: https://anzsped.org/about-anzsped/.

ANZSPED has 330 members, including representation from all of states and territories across Australia and New Zealand. We have strong relationships with all key stakeholders with respect to the care and advocacy for young people and their families/caregivers affected by diabetes. These stakeholders include key consumer groups for example Diabetes Australia, and the Juvenile Diabetes Research Foundation (JDRF) and Australian Diabetes Society (ADS). We fully endorse the materials submitted by these stakeholders for this parliamentary enquiry, as our membership has heavily contributed to these papers.

There are particular themes related to the Inquiry's terms of reference that ANZSPED would like to highlight.

The causes of diabetes (type 1, type 2 and gestational) in Australia, including risk factors such as genetics, family history, age, physical inactivity, other medical conditions and medications used.

ANZSPED members are the principal investigators for the Environment Determinants of islet Autoimmunity (ENDIA, https://www.endia.org.au). Through this research program, we are leading a global effort to identify methods that may prevent type 1 diabetes in the future. The findings and impact from this large research portfolio is global, and likely to continue to yield insights and possibly preventative therapies in the decades to come.

With respect to type 2 diabetes, ANZSPED membership have contributed significantly to our understandings of the determinants of youth-onset type 2 diabetes (defined as that diagnosed before the age of 25 years). For example, partnerships with institutions such as Menzies School of Health Research (https://diabeteslifecourse.org.au) and Murdoch Children's Research Institute (Diabetes (mcri.edu.au)). The NHMRC research health priorities include preventing and managing comorbidities and chronic conditions, a significant issue in youth-onset type 2 diabetes.

Recommendations:

1. **Invest in diabetes research, ensuring proportionate and adequate funding compared to other medical conditions.**

   The National Diabetes Strategy recommends the development of a national research agenda, which will enable coordination of diabetes research across funding streams. We support the development and funding of a research agenda which has an equity focus and prioritises the importance of prevention and early life determinants. We also advocate for proportionate funding for diabetes research, the need for which has been clearly outlined by ADS in their Inquiry submission. We also advocate for research that leads to earlier detection of type 1 diabetes, and that reduces the impact of diabetes among priority groups, as outlined in the National Diabetes Strategy.

   We also note that youth-onset type 2 diabetes is increasing in prevalence around the world and disproportionately affects young people from socioeconomically disadvantaged and ethnically diverse populations[1, 2]. In Australia, Aboriginal and Torres Strait Islander young people living in Northern Australia have the highest reported prevalence in the world[3]. Other young people at high risk include Maori and Pacific Islander youth, and young people of refugee background. There are also well known intergenerational risks associated

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with youth-onset T2D diagnosed pre-conception, increasing the cardiometabolic risk for future offspring[4, 5]. However, our understanding of the pathophysiology, phenotypes and optimal treatments for these young people is still very limited and requires investment in research.

New evidence-based advances in the prevention, diagnosis and management of diabetes, in Australia and internationally AND The broader impacts of diabetes on Australia's health system and economy.

ANZSPED strongly believes that all Australians should be able to equitably access evidence-based diabetes technologies and medications. As outlined in the 2021-2030 National Diabetes Strategy[6], this requires partnership across government and organisations to reduce health inequities and maximise use of resources and technology so as to minimise the health and economic impacts of diabetes.

Recommendations:

1. **Fully fund insulin pump therapy for all people living with type 1 diabetes through the National Diabetes Services Scheme (NDSS).**

   Automated insulin delivery for type 1 diabetes is now considered gold standard internationally[7]. This consists of an insulin pump, a continuous glucose monitor and an algorithm that will adjust insulin delivery to keep glucose levels healthy. In Australia, continuous glucose monitors are funded through the NDSS, and has resulted in excellent uptake[8], and is cost effective[9]. However, insulin pump therapy remains non-funded, and those who are at highest risk of diabetes complications due to low socio-economic status have limited pathways to accessing an insulin pump. Insulin pumps are mainly acquired through private health insurance. Those families without private health insurance often do not meet criteria for provision of a pump through organisations such as JDRF and so these children remain without access to the recommended treatment. Funding for all Australians with type 1 diabetes will greatly improve long term outcomes (physical and mental) of those with type 1 diabetes, and the benefits will be more equitable if fully funded.

2. **Expand access to newer diabetes medications for youth with type 2 diabetes.**

   In light of the rapid progression seen in youth-onset type 2 diabetes, and its association with serious complications at a young age, we need to prioritise the use of medications that are known to be effective and improve outcomes. There is increasing evidence for the use of medications such as GLP-1 receptor agonists (eg Dulaglutide, Semaglutide) and SGLT-2 inhibitors (eg dapagliflozin) for young people with type 2 diabetes. Their use in youth-onset type 2 diabetes is now also described and recommended in multiple international guidelines[10, 11]. Currently, however, Australian young people aged under 18 years of age only have access to these medications 'off-label' as they have not been licensed for use in Australia in this age group, in contrast to other countries. This is despite their efficacy in this condition having now been clearly shown in multiple studies. Young people have also been disproportionately affected by the ongoing worldwide shortage of GLP-1 receptor agonists as many wholesalers have prioritised supply for existing patients or patients in whom the use would not be considered 'off-label'.

3. **Expand access to Continual Glucose Monitoring Systems (CGMS) under the National Diabetes Subsidy Scheme (NDSS) for young people with type 2 diabetes who are on insulin.**

   These devices are currently subsidised for young people with type 1 diabetes, but not for young people with type 2 diabetes, many of whom are also treated with insulin. This makes it very difficult to effectively titrate insulin doses to optimise blood glucose levels. It also makes it difficult to prevent low blood glucose levels (hypoglycaemia), which can be very dangerous. CGMS use has been shown to be feasible and acceptable in adolescent patients with type 2 diabetes[12] and significantly improved the time that glucose levels are in the desirable range in adults with type 2 diabetes[13, 14]. CGMS is also recommended in international guidelines for young people with type 2 diabetes who require insulin, or in whom there is inadequate finger-prick blood glucose level monitoring for safety[11].

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The effectiveness of current Australian Government policies and programs to prevent, diagnose and manage diabetes.

As outlined in the National Diabetes Strategy, there needs to be stronger focus on prevention and awareness of diabetes amongst the Australian community, as well as improvement in Australian Government processes and programs facilitating access to health care so as to reduce the burden of diabetes and diabetes related complications.

Recommendations:

1. **Streamline pathways for approval of new diabetes technologies and medications.**

   ANZSPED considers the current timelines for accessing new diabetes technologies and medications to be slow, especially through the Therapeutic Goods Administration and Pharmaceutical Benefits Advisory Committee – government agencies. We also note that there is currently no pathway to expedite approval of medical devices, such as CGMS and insulin pumps. As such, Australians with type 1 and type 2 diabetes often need to wait longer than those in similar Western nations to access new therapies and medications in a timely fashion. ANZSPED therefore calls for pathways related to diabetes to be streamlined and prioritised so as to shorten this timeframe, and for more collaboration between the Therapeutic Goods Administration, Pharmaceutical Benefits Advisory Committee and clinicians.

2. **Optimise and adequately fund the national Diabetes in Schools program**

   This program has been successful in supporting young people with type 1 diabetes since 2019 and provides training for school staff to support medication administration and safe diabetes management.

   However, the current program require further funding to allow expansion to reflect need.

   a) The program currently covers 5 hospitals, providing training and support to schools where students are patients of these hospitals. However, many paediatric diabetes services and hospitals do not have access to the program, creating an inequitable situation across Australia and impacting on children and young people's full and safe participation in school. A national roll-out to all paediatric diabetes services is required.
   b) The program does not currently provide any training or support to pre-schools or daycare providers, limiting children's safe engagement in these settings, and also impacting on the ability of their parents to be employed.
   c) The program does not currently provide any training or support to young people living with type 2 diabetes. We note that school is a critical location for health care in the context of the socioeconomic inequities facing many young people living with type 2 diabetes[15] and that these young people need assistance and supervision with medication.

3. **Ensure that those disproportionately affected by diabetes are prioritised for access to improved models of care and treatments.**

   In the context of youth-onset type 2 diabetes being seen internationally as a 'disease of poverty'[2], equity of access to health care and medications is critical. Prioritising youth-onset type 2 diabetes so as to reduce health inequities in disproportionately affected populations aligns with the goals of the 2021-2030 National Diabetes Strategy[6]. Youth-onset type 2 diabetes is also more rapidly progressive than diabetes diagnosed at a later age and has a worse prognosis[1]. The majority of youth with type 2 diabetes will have complications by 15 years post-diagnosis[16], and 50% will have end-stage kidney failure within 20 years[17], thus age 35 years for those diagnosed at 15 years. We therefore need to prioritise improvements in care and access for this group of young people.

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Thank you once again for the opportunity to provide our submission to the Inquiry into Diabetes - should the Committee require further information, please do not hesitate to get in contact via secretariat@anzsped.org

On behalf of ANZSPED,

Dr Martin de Bock

Co-Chair, Diabetes Subcommittee
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