



*The voice of rural child health*

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The House of Representatives Standing Committee on Health, Aged Care and Sport:

## Inquiry into Diabetes in Australia

*We acknowledge the Traditional Custodians of the lands and seas on which we work and live, and pay our respects to elders, past, present, and future.*

The Australian Paediatric Society (APS) is a Special Society of the Royal Australasian College of Physicians comprising over 400 consultant paediatricians in regional and metropolitan Australia. The APS has been a member of the National Rural Health Alliance for over 20 years. APS is the peak body for Australian rural and regional child health and has active National Allergy Council (NAC) representation.

Over 100 APS members manage paediatric Type 1 Diabetes (T1D) care, far outnumbering Australian paediatric endocrinologists. The number of children managed by APS members represent 30-40% of Australian children with T1D – more than the largest Australian specialist children’s hospital and spread over 62 regional and suburban centres.

The APS sincerely thanks the Federal Government for establishing the Inquiry into Diabetes and the opportunity to contribute the voice of rural child health. The focus of the APS submission is T1D in young Australians.

**This submission is a genuine attempt by passionate, time-poor paediatricians who have provided unfunded deliberation on the issues, recommending interventions that, from extensive professional clinical experience, we consider are most likely to improve health outcomes for young people with T1D using Federal Government funds most effectively.**

The APS Diabetes Committee is the most active paediatric diabetes interest group in Australia, providing:

- post graduate education of suburban and regional diabetes teams through an internationally endorsed annual 2-day paediatric diabetes workshop since 2007.
- the world first, international award-winning e-learning program for diabetes in schools (2017) based on a proven learning platform ([www.t1d.org.au](http://www.t1d.org.au))
- the scoping of regional T1D models of care and services (2022-23)
- the world-first, innovative and internationally branded solution to paediatric T1D data collection and audit (2022).
- advocacy to government and other peak bodies on a wide variety of issues relating to paediatric service delivery in suburban and regional Australia, including T1D.

## Summary of Recommendations

1. That the Parliamentary Inquiry give greatest priority to urgently address the crisis of continuing poor medical outcomes which imposes foreseeable harm upon a generation of young people with T1D.
2. That all regional and suburban T1D teams be supported to
  - a. collect T1D data through the innovative Diabeasy platform,
  - b. collaborate on annual regional data audit, and
  - c. be provided with annual SWEET membership.
3. That regional T1D teams receive equitable support from government in resource and postgraduate education funding to ensure HCPs are attracted to service those young people with T1D in their regions.
4. That Government supports upskilling of regional Australian T1D teams to develop and adopt the successful JHCH SWIMM program model of care.
5. That Government supports existing successful Models of Care and direct funds to provide equitable and sustainable outcomes in regional Australia.
6. That Government urgently reviews MBS item numbers for T1D to reflect its unique needs, skill levels and accessibility to quality specialist and CDE care in order to facilitate improved outcomes.
7. That Government facilitates postgraduate accredited T1D specific upskilling courses for Diabetes Educators, Dieticians and Psychologists as recommended by APS.
8. That Government creates more equitable access to insulin pumps, by dispensing with both the Private Health Insurance requirement and the JDRF program to create a new program, facilitated by NDSS which includes access to combined CGM/pump technology.
9. That Government creates a more representative and non-conflicted Voice representing the clinical needs of all Australians with Type 1 Diabetes
10. That Government suspends and urgently reviews the Diabetes Australia “Diabetes in Schools” program via a National Diabetes in Schools Summit with aims to resolve:
  - a. how complex care can be delivered to ALL Australian students with T1D.
  - b. how non-medical staff can receive the requisite accreditation and qualifications from a Registered Training Organisation.
  - c. legal compliance requirements to protect children, school personnel and Health care professionals.
11. That Government critically assess the current state of research funding allocation to ensure quality, transparency, and freedom from conflicted interests.
12. That a National T1D Strategy be developed, involving broad HCP (including rural HCPs) and consumer collaboration with the aim aligning with National Allergy Strategy that “that every Australian with Type 1 Diabetes needs timely access to evidence-based advice and management, together with effectively coordinated healthcare and support, as close as possible to where they live. That is, “the right care, at the right time, from the right health professional(s), in the right place.”

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### Terms of Reference addressed:

1. 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 use**.
2. New **evidence-based advances** in the prevention, diagnosis, and **management of diabetes**, in **Australia and internationally**
3. The broader **impacts of diabetes on Australia’s health system and economy**.
4. Any interrelated health issues between diabetes and obesity in Australia, including the relationship between type 2 and gestational diabetes and obesity, the causes of obesity and the evidence-base in the prevention, diagnosis, and management of obesity; and
5. The **effectiveness of current Australian Government policies and programs to prevent, diagnose and manage diabetes**.

This submission will focus particularly on Terms of Reference 2, 3 and 5, specifically about Type 1 Diabetes (T1D) relating to children, adolescents, and young adults.

# Medical Outcomes

## 1. Current measured T1D outcomes

Health outcomes for children with T1D in Australia are a national disgrace for a well-resourced nation. Most Australian tertiary centres and many regional centres return outcomes in the bottom quartile of published international data.

Poor diabetes “glycaemic control” creates a tragic **irretrievable risk of shortened lifespan and medical complications** that will burden the person and health system for decades. These risks are measured by 3 variables:

- a blood test known as HbA1c. (the most commonly used)
- data from Continuous Glucose Monitoring (CGM) measuring Time in Range (glucose level 4-10mmol/l) or Time in Tight Range (3.6-8mmol/l)
- Data from CGM measuring glucose variability (Standard Deviation or Coefficient of Variation)

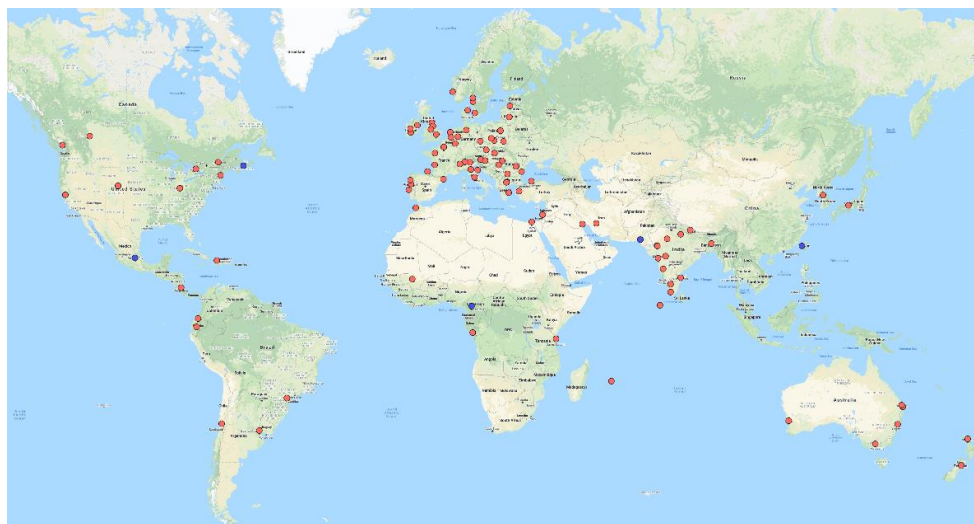
HbA1c data is collected from large metropolitan “tertiary” centres through the Government funded Australian Diabetes Data Network (ADDN) and by 87% of suburban and regional child diabetes teams without funding.

**For the purposes of the members of the Parliamentary Inquiry, the higher the HbA1c above target of 7%, the exponentially higher the risk of severe health outcomes (vision, kidney, and heart disease) and early death. The effects are irreversible. Some centres report that 40% of adolescents in their care have HbA1c greater than 9% which has almost inescapable future medical complications.**

SWEET is the “gold standard” international paediatric T1D database comprising over 100 child diabetes centres who analyse and feedback T1D at a cost of 330Euros annually. Only 4 Australian T1D centres contribute to SWEET for data analysis:

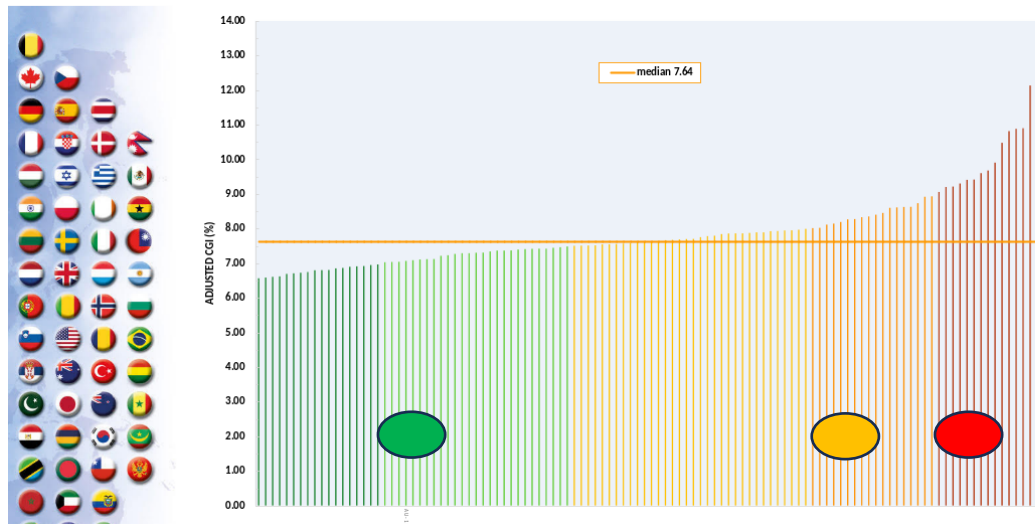
- John Hunter Childrens Hospital Newcastle (JHCH),
- Children Hospital Perth,
- Southeast Queensland Private and
- Team Diabetes Geelong.

SWEET provides important feedback for diabetes medical teams, including peer reviewed measures for severe complications such as Diabetic Ketoacidosis (DKA) and Severe Hypoglycaemia. It audits many screening and outcome parameters to assist improvements in quality of care.



SWEET also provides deidentified centre comparison of outcome measures including HbA1c adjusted to “Combined Glucose Indicator”. Comparison of the SWEET international outcome data with ADDN data, mostly originating from metropolitan Australian “tertiary” centres demonstrates how poorly Australian performance is compared to international best practice.

**SWEET** PEDIATRIC DIABETES  
**Adjusted Combined Glucose Indicator (adjusted CGI)**  
 T1DM, all ages, 01/01/2022 - 31/12/2022



**Fig 1 Australian SWEET data comparison** The green dot represents outcomes from 3 leading Australian centres (John Hunter Childrens Hospital, Team Diabetes Geelong, and Southeast Qld) who use a similar (SWIIM) model of care. The orange dot represents HbA1c outcomes from all Australian tertiary hospital units (adapted from ADDN). The red dot represents HbA1c outcomes figures as measured in regional Queensland (adapted from Wales et al) Ref 1

The situation is likely to be even worse, because:

- some Tertiary centres do not include regional outreach T1D services data that may be worse.
- a common model of ADDN data collection does not account for non-attendees who are highly likely to represent those with poor determinants of social health and worse outcome data.

Accordingly, there is irrefutable data demonstrating how poorly the well-resourced nation Australia is doing on the world stage in terms of quality of outcome for persons with T1D. Continued inaction on addressing this crisis, continued mismanagement of valuable resources, poor investment choices and failure of government programs will unnecessarily commit thousands of young people with T1D to

- a shortened life span.
- expensive and far-reaching medical complications.

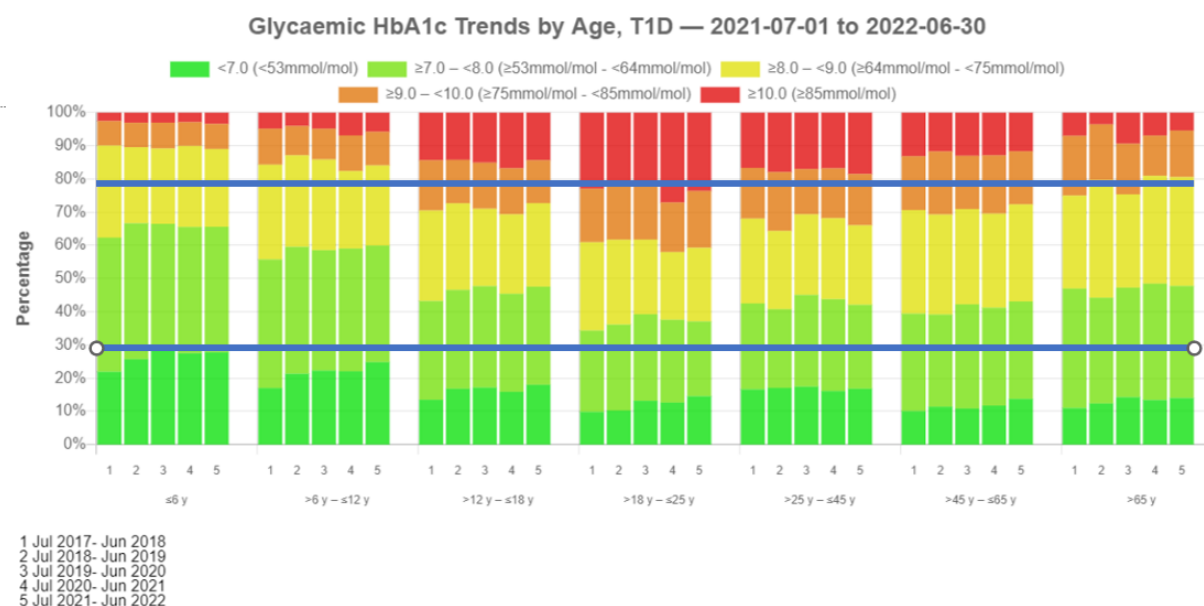
Failure to address these problems escalates the risk of mental health problems and magnifies inequities in regional Australia.

**The Parliamentary Inquiry should consider why such poor outcomes are being produced by most Australian centres when world standard outcomes can be produced by some Australian centres.**

The APS considers the critical issues relate to

- lack of priority to clinical outcomes because outcome data remains de-identified
- understaffing and lack of access to Diabetes Educators and other HCPs
- overburdening of large centres because of very few private T1D teams' availability
- lack of access and failure to implement technology effectively.
- failure of tertiary centres to collaborate on outcomes.
- intransigence on models of care

### 1.1.4 Glycaemic HbA1c Trends by Age



**Figure 2 ADDN data compared to SWEET international outcomes. Blue bars represent SWEET average above 9mmol/l (SWEET average 20% overall) and below target 7mmol/l (SWEET average 30% overall). Australian ADDN outcome data is sign falls well short of SWEET average outcome data.**

**Recommendation 1. That the Parliamentary Inquiry give greatest priority to urgently address the crisis of continuing poor medical outcomes which imposes foreseeable harm upon a generation of young people with T1D.**

## 2. Inequitable audit

ISPAD Clinical Consensus Guidelines 2022 state: “Every young person with diabetes should have a minimum of four HbA1c measurements per year (at 3-month intervals). It is recommended that centres regularly audit HbA1c levels, benchmark their data against consensus statements and, if possible, contribute their data to registries and quality improvement initiatives.” (ref 2)

The Federal Government (via JDRF) has funded Australian Diabetes Database Network (ADDN) since 2013. JDRF is the recipient of Australian Government funding from the Australian Research Council (through a Special Research Initiative) and the Department of Health and Ageing. However, ADDN data collection has only been from **metropolitan tertiary centres**, with few of the 62 suburban and regional T1D units. JDRF has now withdrawn funds from ADDN and ADDN’s future is clouded.

**Collection of T1D data and corresponding audit of suburban and regional diabetes T1D units is essential to understand deficits, appropriately target resources and enable effective policy and equitable funding allocation.**

The 2022/23 APS Models of Care scoping survey revealed that 92% of the 40 regional centres responding wish to join a regional Australian database with open audit and 58% considered their outcomes would improve with such an initiative.

Australia, and the World Health Organisation, recognises T1D as a disability. The Convention on the Rights of the Child and United Nations Convention on the rights of persons with disabilities (to which Australia is a signatory) article 31 states that: *Parties undertake to collect appropriate information, including statistical and research data, to enable them to formulate and implement policies to give effect to the present Convention.*

**Omission of a process to capture regional Australian T1D data is a breach of Human Rights and discriminates against those with T1D in regional Australia.**

The Australian Paediatric Society has

- considered the resource barriers to collect regional T1D data.
- supported an innovative seamless model of data collection (Diabeasy) that is compatible with both SWEET and ADDN. [www.diabeasy.com.au](http://www.diabeasy.com.au)
- received no funding support despite request from JDRF despite the potential integration into the JDRF Diabetes Index.
- funded the Diabeasy update and roll out as a priority because of need but requires further seed funding to deliver data collection, annual regional paediatric T1D audit and SWEET membership.
- collaborated with SWEET to be an endorsed product and has secured a rate of 220 Euros pa for each of those regional centres to become SWEET members.

Already 300 Persons with T1D (PWT1D) have been entered in the Diabeasy database with over 1000 patient visits captured. Data is seamlessly updated to both SWEET and ADDN in addition to facilitating self-audit and open collaboration with other regional centres.

Failure to support T1D data collection and audit is just one examples of inequity and disregard applied to children with T1D in regional Australia and their medical teams and the failure of government to hear or listen to the voice of regional Australia.

**Recommendation 2. That all regional and suburban T1D teams be supported to collect T1D Data through:**

- **the innovative Diabeasy platform,**
- **collaborate on annual regional data audit, and**
- **be provided with annual SWEET membership.**



### 3. Rural Disadvantage

Regional Australian children consistently demonstrate poorer health outcomes for chronic disease compared to better resourced metropolitan children. This is contrary to the recommendations of the Convention on the Rights of the Child and specifically to the United Nations Convention on the Rights of Persons with Disabilities article 25:

*(State must) provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, and Provide these health services as close as possible to people's own communities, including in rural areas. (ref 3)*

Yet regional Australian children and child health services are consistently ignored in funding applications and denied a voice in Expert Working Groups and major government advisory groups, including Medical Services Advisory Committee and National Diabetes Strategy. The rural voice is sometimes an inconvenient truth.

One example of omitting regional services is the inability for paediatric rural or private suburban T1D teams to claim a Medicare rebate for **Point of Care Hba1c testing** (a vital part of the medical consultation) when metropolitan tertiary centres and all general practices are entitled to do so. The cost of the test (about \$15) is either passed on to the rural consumer (increasing their financial burden) or it creates a financial disincentive to service the rural children with T1D. A recent scoping survey of regional diabetes centres indicate only 62% provide Point of Care Hba1c (with the \$8000 machine often funded by charities) and only 28% receive some form of test rebate.

Postgraduate education for regional T1D teams is self-organised through the Australian Paediatric Society without government support. Metropolitan units who are part of the Alliance (see below) are often supported by other resources including government funding (e.g., NDSS). Inequity is rife.

*“The social determinants of health, encompassing “the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life (WHO),” strongly predict the likelihood of an individual achieving recommended or optimal glycemic targets. ISPAD recognizes that these disparities represent significant barriers to optimal care, and collective efforts are needed to understand and address systemic inequities including medical racism and societal policies that entrench generational poverty. As such, there is a responsibility for health care professionals to advocate on behalf of young people with diabetes who have limited access to healthcare, including technology. Indeed, health providers are known to have implicit bias with respect to offering diabetes technology, which drives inequity. Specifically, healthcare reimbursement policies and wider government policy that drives socioeconomic disparities are essential to improve health equity. For the person with diabetes, this should translate to equity in accessing an appropriately resourced multi-disciplinary care team (including dietetic, nursing, psychology, social work, and medical expertise), access to technologies such as CGM and automated insulin delivery, and modern insulin analogs. “(Ref 2)*

**Recommendation 3. That regional T1D teams receive equitable support from government in resource and postgraduate education funding to ensure HCPs are attracted to service those young people with T1D.**



## 4. Models of Care

The 2022/23 APS Models of Care scoping survey has demonstrated that several models of care exist in regional Australia, some far more successful than others.

**Existing successful models of care should be the template for supported models and replicated throughout regional Australia.** When successful models of regional T1D care are ignored and unsustainable “solutions” are generated from metropolitan “experts”, the inequity of health and service delivery for rural Australians will persist.

There is a need for increased flexibility in models of care to allow optimal response to the needs of that community to enable the PWT1D receives the right care at the right place at the right time.

**The critical components of the appropriate models of care relate to**

- a) multidisciplinary skill level,
- b) sustainability,
- c) accessibility and
- d) access to resources.

### **a. Multidisciplinary Skill level**

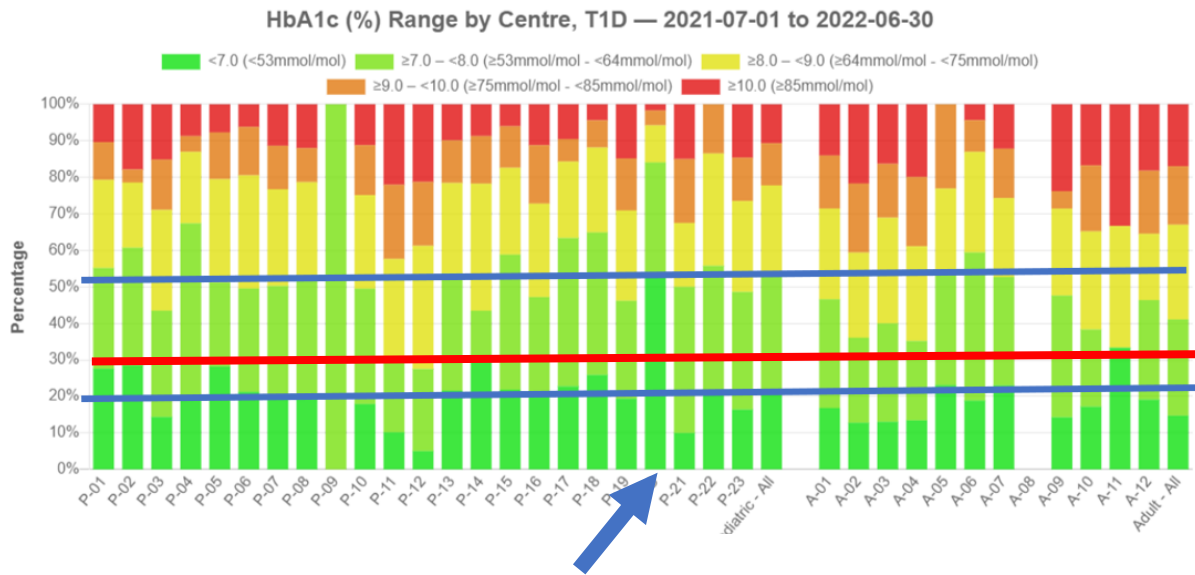
Regional teams generally follow the models and philosophies of tertiary units in Australia with superior outcomes. In Australia that is the John Hunter Childrens Hospital Newcastle (JHCH). JHCH have developed a model of care program that is being increasingly adopted by regional Australian Centres. By implementing key aspects of the JHCH “Success With Intensive Insulin Management” (SWIIM) program, many regional centres have improved outcomes.

A multicentre SWEET study (ref 4) concluded that the size of the T1D centre influences quality of care in paediatric patients. Centre size is related to diabetes care on a broad level: best metabolic control is found in medium sized centres that care for  $\geq 50$  to 100 patients. In centres that care for  $\leq 20$  patients, “glycaemic control” (HbA1c) is worst, occurrence of DKA is highest and visits per year are fewest. Use of “technical diabetes treatment” increases with centre size. Nevertheless, up to date diabetes care can be organized without a centralized approach with overall satisfying treatment results, but the smallest and the largest centres ( $>200$  patients) should be aware of their potential challenges and weaknesses.

Part of the solution to improve medical outcomes is to not further overburden metropolitan units with PWT1D who could be cared for in suburbs or regional centres whilst ensuring such centres are skilled and sustainable.

**Recommendation 4. That Government supports upskilling of regional Australian T1D teams to develop and adopt the successful JHCH SWIIM program model of care.**

### 1.2.1 HbA1c (%) Range by Centre, T1D



**Fig 3 John Hunter Childrens Hospital data compared with other centres from ADDN data 2022 - Blue arrow is JHCH data. Blue bars represent % of persons with T1d reaching target HbA1c <7%. Top bar = John Hunter Children’s Hospital, bottom bar = average ADDN paediatric centres. SWEET average (red bar) =30%. Other than JHCH (>50%), only centre p14 and a11 of other 34 centres reach SWEET average 30%**

It is unclear why the Government / JDRF have funded Perth Childrens Hospital to examine Models of Care when the **data already exists and recommended solutions already apparent**. The APS would rather the Government fund successful solutions urgently rather than fund a multimillion-dollar project that may delay the implementation of higher standards in regional Australia and waste more valuable time that is crucial to our children with T1D. Any program that seeks or purports to report on regional Australian models of care must involve experienced regional HCPs.

### **Recommendation 5 – That Government supports existing successful Models of Care and direct funds to provide equitable and sustainable outcomes in regional Australia.**

#### **b. Sustainability**

**Sustainability** will only occur with the recognition of the complexity of T1D care and the appropriate MDS item number review. This critical issue for regional areas and private models of care in metropolitan areas has been of little interest to metropolitan tertiary specialists attached to large hospitals.

T1D is a very complex condition involving serious medical issues, technology, emotional (anxiety, depression) and associated conditions (coeliac, thyroid, adrenal), family stressors, multidisciplinary expertise in nutrition, exercise, school and is energy, time and resource consuming for health professionals to produce peak performance. It is **not an easy condition to manage**, and HCPs require education and training on several skill levels. Teamwork is essential. Some models of T1D care have already shown it is possible for regional children with T1D to match or better outcomes compared to city centres.

Sustainability of models of care is the key to success.

**a. Sustainability requires Medical Benefits Schedule (MBS) reform.**

Currently, some MBS items provide no sustainable value to the PWT1D or the Government and should be reviewed with funds re-allocated. These include:

- **Team Care Arrangement** to enable a Credentialed Diabetes Educator (CDE) to claim MBS fee. While APS acknowledges the need for the patient's general practitioner to be kept fully aware of the PWT1D progress and participate in multidisciplinary case meeting, if possible, it would **save cost and inconvenience** if the paediatrician/endocrinologist already involved provided the eligible referral to the CDE and other allied health team members when required. This would provide the TCA at **no extra cost** as part of annual review. This efficient model already exists in paediatrician eligibility to refer to psychologists to generate patient rebate under a mental health plan.
- **Annual referral from a GP** for the non-curable T1D requires unproductive GP time, inconvenient and unproductive parent time, out of pocket/MBS cost and **adds no value**.

In order to facilitate improved outcomes, the APS recommends that T1D be considered a unique condition within the MBS that:

1. T1D does not require annual **GP referral** (subject to keeping the GP informed) because the condition is incurable and requires specialist input.
2. Indefinite referral recognises the need for **annual T1D review (item 132)** with complication screening, school plan completion, CDE and other items.
3. A team care plan be initiated by a **paediatrician/paediatric endocrinologist** at no extra cost.
4. **Consultations on T1D data upload**, interpretation and advice have clear MBS definition and rebate.
5. **CDE remuneration** be given
  - a. an increased number of visits commensurate with those allocated to eating disorders.
  - b. on and off campus T1D education of school staff

The increased CDE remuneration and accessibility is highly likely to facilitate the emergence of smaller regional teams and suburban teams that can take the pressure off the large metropolitan hospitals. In the 2022/23 APS Regional Diabetes Models of Care scoping survey, over 60% of participants agreed to the need to increase frequency of CDE, with most responses requesting the number be up to 20 visits per year. 42% considered this initiative would improve patient outcomes.

6. **Point of Care HbA1c:** rebates should be made available to all suburban and regional teams as a matter of equity and consideration given to government funding the HbA1c machines rather than charities.

**Recommendation 6. That Government urgently reviews MBS item numbers for T1D to reflect its unique needs, skill levels and accessibility to quality specialist and CDE care in order to facilitate improved outcomes.**

## Psychosocial Outcomes

It has been clearly established that emotional health disorders, such as anxiety and depression are far more frequent in adolescents and young adult with T1D than those without T1D. (ref 5) This imposes extra costs. In regional Australia, there is very little expertise in understanding the mental health issues related to T1D. So, accessibility to appropriate emotional health professionals is sparse and must be addressed.

### a. Accessibility and affordability of skilled health care

Accessibility to skilled personnel in regional areas is not just related to emotional health care but rather significant psychosocial impact occurs when there are few T1D skilled HCPs in the region. This causes emotional distress to families, further compounded by those families not reaching the expected T1D outcomes that will potentially harm their child.

APS is currently discussing, collaborating, and promoting accredited postgraduate upskilling courses in Child T1d diabetes Education, dietetics and psychology to upskill HCPs in regional areas who are frequently without that skillset. This MUST be at no cost to the HCP who may even be compensated to successfully complete the course.

**Recommendation 7: That Government facilitates accredited postgraduate T1D upskilling courses for Diabetes Educators, Dieticians and Psychologists as recommended by APS.**

### b. Cost and Finance

The APS considers the matter of the cost of managing T1D is one of the major psychosocial issues that impacts management. The costs can particularly impact families who are otherwise already financially struggling with cost-of-living increases. JDRF has prepared an excellent paper describing the costs per patient per year from their own pockets, to be in the order of \$15,000.

Many families

- a. cannot afford private health insurance let alone the cost of an insulin pump (approximately \$9000).
- b. struggle to support required equipment despite being heavily subsidised by the Federal Government through NDSS.
- c. experience family disruptions of work and school when required to attend face-to-face meetings with local or visiting specialists.

In regional areas there is frequently a disconnect between consultant paediatrician and a state government employed hospital diabetes educator. Facilitation of multidisciplinary care is essential. Frequently families with T1D are given reduced charges or bulk billed for CDE services, as the recognition of financial impact by the healthcare professional is real.

By the HCPs reducing potential income in servicing those regional patients, a disincentive is created to service rural PWT1D.

### d. Employment and family disruption.

Over 40% of families in a diabetes survey conducted by the APS conducted in 2018, indicated they had to either change employment or reduce work hours because of the family impositions of T1D. This has flow on affects to the workforce. These issues have also been recognised by the JDRF study.

**e. Discrimination and stigma.**

The APS school survey in 2018 noted the significant incidents of discrimination, particularly in secondary school. Stigma is a function of discrimination and misinformation. PWT1D report that by invariably linking services and terminology to Type 2 Diabetes, confusion and stigma is magnified.

By prioritizing appropriate supportive medical care, financial and emotional support and revising the unlawful Diabetes in Schools program, discrimination and therefore stigma, is likely to reduce.

## Technology equity of access

### a. Insulin Pumps

Currently, Private Health Insurance (PHI) is required by most families to subsidise cost of an insulin pump. Families subscribe to PHI in regional Australia in regions that have no private hospitals and is otherwise a waste of money.

The Government Insulin Pump Program, facilitated through JDRF and is very restricted in funds and eligibility and is well beyond its initial intent.

The NDSS is providing an excellent program for clinicians/ PWT1D accessing CGM and insulin pump consumables.

**Recommendation 8: That the Federal Government creates more equitable access to insulin pumps, by dispensing with both the Private Health Insurance requirement and the JDRF program to create a new program, facilitated by NDSS and includes access to combined CGM/pump technology.**

### b. Continuous Glucose Monitoring

The CGM program, accessible for all PWT1D at either no cost or subsidised cost is a success. The Government has listened to the voice of consumers and HCPs and delivered a cost-effective program, that is of value and benefit to all. Please do not tamper with this program.

### c. Funding attached to person with T1D.

As part of resource reallocation to reduce the financial burden on persons with T1D, the Government should seriously consider an annual allocation of funding attached to the person and rebated only upon use of T1D authorised services.

This may include rebates for insulin pumps/ CGM/medical visits/vision/ dietician/ psychologist / exercise physiologist etc. This is in addition to the recommended T1D Health Care Card.

Such a model will increase PWT1D choice of team and enable sustainable private teams. The limit of funding may be graded to age need (younger with highest funding). It should be means tested because all disability is equal.

## Voice to Government

### a. Restricted consumer, rural and health team voice

The ability for APS to represent rural child T1D needs and promote efficient workable non conflicted solutions has been stifled by a group of peak bodies colluding to be the only voice to Government.

Known as the “Alliance,” the participating entities include:

- Diabetes Australia
- ADS (a Diabetes Australia subsidiary)
- ADEA (a Diabetes Australia subsidiary)
- ANZSPED representing mainly tertiary paediatric endocrinologists.
- JDRF

The problem created by this consortium is that broad clinician advocacy has been compromised because participating organisations are bound to support decisions made by other members of the Alliance who may have pecuniary interests. The Alliance does not represent the regional voice and the independent consumer voice.

Consequently, the Government has been misinformed on some aspects of T1D need. Government access to independent consumer advocates Type 1 Voice is minimised. Consequently, consumers should be congratulated for raising their voice to a level that it could not be ignored, leading the Government to develop the successful CGM initiative.

The result of listening only to the Alliance voice is one of the causes of poor T1D outcomes especially in regional Australia. The existence and influence of the Alliance has directly led to discrimination against rural services and rural children with T1D.

The creation and roll out of the unlawful and discriminatory Diabetes in School is a living example of the conflicted interests of the Alliance producing a sham wasteful program that propagates rather than reduces risk to the student with T1D. The MBS delisting of Fiasp is another example of failure. (Attachment)

The template of the National Allergy Council (NAC) is a successful example of clinicians working with consumers for the best possible outcome. Because the solutions for T1D are separate from Type 2 Diabetes, a solution may be to replicate the NAC model to a voice that is comprehensive for the **clinical outcomes** of children with T1D and may include:

- ANZSPED (metro child T1D)
- ADEA (Diabetes Education)
- APS (Rural child T1D)
- T1Voice (consumer T1D)
- ADS (adult T1D)

Diabetes Australia is represented by its subsidiaries ADS and ADEA. JDRF could return to its core business of T1D research. T1Foundation is represented by its subsidiary T1Voice and should be funded in its own right as the peak community support agency for T1D.

**Recommendation 9. That Government creates a more representative and non-conflicted Voice representing the clinical needs of all Australians with Type 1 Diabetes**



# T1D in Schools

## 1. Background

The Australian Paediatric Society has been at the forefront of management of diabetes in schools for the past 9 years. The APS has been concerned that the peak bodies have lacked the desire to understand and address the complexities of executing complex medical care, including administration of a dangerous drug to children in a workplace situation where the employees, while being highly skilled teaching professionals, have only first aid training on medical issues.

## 2. Legal Frameworks and Collaboration

The APS has strongly advocated for a collaboration to find solutions that protect the interest of all parties and facilitate the best possible management of students with T1D. The expert legal advice from Arnold Bloch Leibler, to which the APS, APEG, DA and ADEA were given access, clearly outlined some of the legal and human rights principles of managing students with T1D in the school workplace. It is a tragedy that only the APS heeded that advice and worked towards a workable solution.

Since 2015 APS has been part of a collaborative process to develop the solutions for children with T1D at school. When Diabetes Australia change the Diabetes in Schools (DIS) submission to Government in early 2017, the APS and peak independent consumer organisation Type 1 Voice could not condone the changes which exposed children, school staff and HCPs to potential risks. Rather than collaboratively address the objection, both Type 1 voice and APS were removed from the ongoing participation in the DIS Expert Working Group, replaced by adult T1D body and now Diabetes Australia subsidiary Australian Diabetes Society (ADS) who have no expertise in T1D at school.

## 3. Initiatives

Due to the inertia of the newly formed DIS Expert Working Group, the Australian Paediatric Society collaborated with many Australian and international experts to produce the first e-learning program for T1d in schools, ([www.t1d.org.au](http://www.t1d.org.au)) based on ISPAD guidelines and using the proven learning platform, Moodle. The APS made access to this e-learning free of charge. Over 10,000 courses were completed between 2017 and 2019 before Diabetes Australia “reinvented the wheel” by rolled out an arguably poor imitation of the T1D e-Learning course, using \$6m Federal Government DIS grant.

APS offered the DIS consortium free access to the T1D e-learning module in 2018 not only to save costs, but to allow access to all 14,000 students with T1D in Australia as a training aid. The APS offer was rejected on the basis that members of the Alliance chose to “protect the funding for Diabetes Australia”. This placed many schools in a position of being without knowledge or access to internationally endorsed and award winning T1D e-Learning courses, causing many schools to remain in a state of ignorance about the appropriate management of an unwell student with T1D whilst in the custody of a school. Predictable tragic outcomes did indeed occur.

The APS has produced several documents to assist parents and families to navigate the school system. These include (and not limited to):

- T1D, a school guide for parents.
- T1D a school guide for clinicians
- “Never Assume Vomiting Cause” poster,
- T1D position statement on CGM at schools,
- T1D position statement on school camps,
- School camp training checklist,

- Adopting a Clear and Unambiguous Language campaign
- School camp required training for the individual (all available on [www.t1d.org.au](http://www.t1d.org.au))

#### 4. Diabetes in Schools – a failed unlawful program

The Federally funded Diabetes In Schools program provides the ultimate example of a dysfunctional Federal Government policy and programs that facilitate propagation of poor medical outcomes for PWT1D. It was foreseeably a program that was bound to fail and now \$21m has been spent on a sham program with not a cent going to schools or students with type 1 diabetes. A compliant program would have been structured very differently.

The DIS program is

- unlawful.
- discriminatory.
- has the potential for ongoing harm to children.
- exposes quid pro quo arrangements tarnishing credibility and trustworthiness of peak diabetes bodies.

Schools:

- have Workplace obligations to employees to provide them with the skills and training that meets legal and regulatory obligations and
- must protect students from harm that is reasonably foreseeable.
- comply with disability discrimination protections.

Diabetes Australia and the Alliance altered the international definitions of Levels of Education and Training resulting in a noncompliant program with ambiguous and clouded roles and responsibilities. It is noted that the changes coincidentally provided a financial advantage to members of the Alliance. A table outlining the compliance issues is attached (attachment)

Specifically:

- Level 1 and 2 online education provides no qualification for school employees to fulfill their **obligation** to provide emergency response and first aid management requirements of a student with type 1 diabetes.
- Level 3 “skills training” does not provide **any authority, accreditation, or qualification** for medically unqualified school employees to undertake **complex medical care** and **administer dangerous drugs** to students equivalent to a Division 1 Registered Nurse.
- Delivery of medical training to medically unqualified employees is NOT the jurisdiction of the doctor, or medical team. **A students’ medical team cannot “qualify”, authorise, or train an organisation’s employee to undertake complex medical care and administer drugs.** Advice received from medical insurers to doctors is that this program exposes doctors (and their Diabetes Educators) to significant medicolegal risk.

Yet, Diabetes Australia’s contracts make financial payments subject to the student’s medical team signing off that medically unqualified school employees are competent to perform complex medical care and administer drugs to students. **This is akin to a doctor signing off a medically un-qualified beautician to inject Botox without the beautician holding any requisite and compliant accreditation.**

The effect of the “Diabetes in Schools” program is that the Federal Government is financially incentivising and enforcing medical treatment and advice (“education & training”) to children, schools,

and school employees. Patient health care is being determined by the exclusive dealings and contracts that breach Competition and Consumer legislation.

By DIS exclusively funding tertiary hospitals, staffed by members of the Alliance, discriminates against an entire cohort of students with a disability by excluding over 4000 rural children who do not receive care at the metropolitan centres.

At Minister Butler's invitation, the APS requested specific legal compliance responses from Diabetes Australia in February 2023. (attachment), Despite repeated assurance from DHHS that a response was forthcoming, none has been received. DHHS has not also provided the specific funding distributed to the members of the Alliance relating to the DIS program. There has been no public disclosure of the many publicly funded DIS reports which should be scrutinised given the funds used by Diabetes Australia to employ their own school "State Coordinators" to broker arrangements, a cost that appears unjustified. The only recipients of DIS funding are city-based tertiary hospitals who are bound by contract to exclusively to prescribe the DIS program. The public should be provided with open audit of the NDSS showing who is receiving the \$21m spent so far on the unlawful DIS program.

### **Solution**

A Federal National Summit of T1D Stakeholders, similar to the inclusive Federal National Allergy Summit which spawned the National Allergy Council.

This requires collaboration **without the predetermined outcomes** which plagued the DIS program with strategy based upon best practice ISPAD Position Statement on Diabetes in Schools (attached). The summit must include stakeholders missing from the DIS stakeholder process including:

- Independent consumer organisations (Type 1 Foundation, Type 1 Voice)
- Workplace Safety experts
- Teacher Unions
- Nurse Unions
- Legal experts

The key issue is to provide an accredited training program to qualify staff to lawfully execute complex T1D care including administration of a dangerous drug (insulin) to a child in the Workplace.

**Recommendation 10: That Government suspends and urgently reviews the Diabetes Australia "Diabetes in Schools" program via a National Diabetes in Schools Summit, with aims to resolve:**

- **how complex T1D care can be delivered to ALL Australian students.**
- **how non-medical staff can receive the requisite accreditation and qualifications from a Registered Training Organisation.**
- **legal compliance requirements to protect children, school personnel and Health care professionals.**

## Research

### Overview

The APS believes there is a rich quality of world class T1D research in Australia. There are however several funded projects that are poor / low quality / repetitive of established observations and appear to more consistent with activity for its own sake rather than seeking better understanding of how to improve outcomes for PWT1D. To quote Sir Humphrey Appelby *"We don't measure success by results but by activity and the activity is considerable and productive."* (source Yes Minister, "How to run a hospital")

The disparate and potentially conflicted sources of funding research remain a concern when so many entities are allocated T1D research funding by the Federal Government. There now exist significant tensions among research institutions that available funding has been directed to one particular region of Australia.

### Solution

The APS supports a reduced number of entities that provide research funding that is allocated free of conflicted interest, transparent and on merit.

**Recommendation 11: That Government critically assess the current state of research funding allocation to ensure quality, transparency, and freedom from conflicted interests.**

In summary, a collaborative comprehensive approach is required to facilitate best possible outcomes for those living with T1D. All peak organisations must have a voice. Programs and policies that are wasteful should be abandoned. A broad National T1D Strategy should be formulated with the person with T1D at the centre. Organisations should have defined roles, become transparent and accountable and address conflicted interests.

**Recommendation 12: That a National T1D Strategy be developed, involving broad HCP (including rural HCPs) and consumer collaboration with the aim aligning with National Allergy Strategy that "that every Australian with Type 1 Diabetes needs timely access to evidence-based advice and management, together with effectively coordinated healthcare and support, as close as possible to where they live. That is, "the right care, at the right time, from the right health professional(s), in the right place."**

Contact for recipient: Dr Peter Goss FRACP Dated 31<sup>st</sup> August 2023

## References

1. Wales J Yates J Peer review of rural and tertiary Queensland paediatric diabetes services: A pilot project from the National Health Service Volume55, Issue6 June 2019 Pages701-706
2. de Bock M, Codner E, Craig ME, et al. ISPAD Clinical Practice Consensus Guidelines 2022: Glycemic targets and glucose monitoring for children, adolescents, and young people with diabetes. *Pediatr Diabetes*. 2022;23(8): 1270-1276. doi:10.1111/pedi.13455
3. <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-persons-disabilities>
4. Size matters: Influence of center size on quality of diabetes control in children and adolescents with type 1 diabetes—A longitudinal analysis of the DPV cohort *Pediatr Diabetes*. 2022 Feb; 23(1): 64–72.
5. Cengiz E, Danne T, Ahmad T, et al. ISPAD Clinical Practice Consensus Guidelines 2022: Insulin treatment in children and adolescents with diabetes. *Pediatr Diabetes*. 2022;23(8):1277-1296.

## Addendums

- Table Diabetes in Schools Compliance
- APS PS Schools 2023
- APS Fiasp Fiasco
- ISPAD Position Statement on Type 1 Diabetes in Schools
- Letter to Diabetes Australia re unlawful Diabetes in Schools program Feb 2023