

SUBMISSION IN RESPONSE TO THE PARLIAMENTARY INQUIRY INTO DIABETES

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Dear Secretariat,

Please find below a Submission in Response to the Parliamentary Inquiry into Diabetes.

The information below summarises 3 distinct points of view

- That of an adult having Type 1 diabetes for 35 years
- That of a parent looking after a child with T1D for 17 years (from aged 2)
- That of an entrepreneur in the digital health space with a mature diabetes solution

Firstly, there is no shortage of **well-intentioned and passionate people** from multiple professions trying to make a difference in the diabetes ecosystem. The key callouts of this submission are that the **methods, culture, structure and funding** of the ecosystem **are misaligned** to achieve **impact at scale**, and it is these things that need to be **modernised** to reduce the human and financial impact of the well-documented diabetes epidemic.

The state of diabetes care nationally and in Victoria is characterised by a conglomerate of dysfunctional organisations that compete for the same government budgets, and **largely fail to deliver impact at the scale required** to make a measurable difference to **education, prevention, management and health economics** of diabetes across Australia. The text below outlines some of the reasons for this and possible solutions.

Delivery of Care

Our current model of care is based on diabetes being managed by primary care ie GPs. However, GPs lack the time, scale and specialised training to manage diabetes effectively, but they are largely **in denial** about this. The AMA, an organisation with both hands deeply in the public purse, needs to be pulled into line to change the model of care (as we should have done with COVID injections).

We need to **harness our nursing population** (diabetes nurse educators) to provide the first level of support for basic diabetes needs (e.g. education, foot care, injection technique, etc), **moving to GPs for diagnostics** and referring to specialist care. **Siloed service delivery** means that diabetes nurse educators are unable to suggest changes to dose or diet or exercise, even when those changes are patently obvious. The recent change whereby diabetes nurse educators require 1000 hours of contact with diabetes to be 'credentialed' – even manning reception in a diabetes clinic – is arbitrary and is a blocker to more nurses adopting this field of practice.

Telehealth

The lack of qualified care is very apparent in **regional areas**. Many patients travel 4+ hours to visit specialists in the city. The government **MUST** provide streamlined **telehealth billing codes** to enable better care for these patients, for practitioners ranging from nurses to GPs and secondary care. The technology gap can also be helped through **telehealth centres in regional areas**, to help non-technical patients to successfully access these services.

Dogma

The diabetes ecosystem is riddled with unsubstantiated pseudo-science, including statements like ‘your brain needs carbohydrates to survive’, and promulgation of a **carbohydrate-overloaded diet** which has been **fattening our population** since the 1970s. A reduction in the consumption of carbohydrates and sugars leads to a reduction in (expensive) insulin, and associated insulin-magnifying drugs, which leads to weight loss and a healthier population. The government needs to fund studies into lower carbohydrate eating to overturn the pseudo-science, and make the benefits of low-carb incontrovertible, and place a **tax on sugar** to help disincentivise consumption. The government needs to **show backbone** to put this in place.

Delivery of Education

Successful management of diabetes requires **education and behaviour change at scale**. With the increasing demand on the health system at all levels, doctors and educators cannot match this scale, and we need to build far **better scaled mechanisms**.

The German health system takes the health education of people with diabetes seriously, with **multiple sessions run every month** to ensure every patient is well informed from diagnosis. The uptake of (expensive) insulin pumps in German health care is far lower than in Australia due to **better patient education** which leads to **better patient self-management**. The government needs to fund groups to provide this **always-on training**, in both virtual and in-person formats.

While the NDSS has led standardisation of educational material available to patients, there are a number of gaps with this content and its delivery:

- It is a pull model – whereby only patients who are actively seeking knowledge get educated. Our practitioners need to be able to **insist on a level of knowledge, graduation, and partner with patients** to provide pathways to improved self-management
- The marketing of sessions relies on **osmosis** rather than a professional multi-channel approach. As a result, sessions are very **poorly attended** and not at scale. **Marketing needs to be funded**, and coordinated across multiple channels
- **No-show rates** of attendees is very high. An experiment with a small pre-payment should be tested (refunded upon arrival)
- The material is pitched at a year 8 educational level. This makes it **patronising and generic** for anyone with even a basic level of education. This content needs to be split into different learning levels
- The health department needs to actively advertise **pro-health messages** about diet and exercise to lead to generational change (as for smoking, HIV, driver safety, gambling etc)

Technology

- The diabetes technology landscape is **structurally flawed**, favouring large pharmaceuticals with very deep pockets. For example, insulin pumps cost approx. \$AUD 7000 and \$1000/year for consumables and have an 80% profit margin (source: Medtronic annual report). This margin is used indirectly to fund diabetes organisations (e.g. \$AUD 10,000 per page to advertise in the Diabetes Australia magazine), making our diabetes organisations **beholden** to these companies and to the **most expensive care model**. This 80% margin is also used to fund clinical trials that demonstrate that **pumps are superior to worst-possible care** ie a patient manually guessing their own doses. There are **no studies funded that support the use of App-supported dosing** (e.g. an Australian dosing App, costing ~ \$100/year) compared to either pumps or to worst-possible care. The potential health economic improvements are

staggering (112,000 people with Type 1 Diabetes x pump consumables @ \$1000/year = AUD \$112M/year vs AUD \$11M/year for an equivalent App) but somehow **we refuse to fund a \$250K study to save \$100M/year** or part thereof.

- There are **structural barriers** that prevent smart phone apps providing fold decreases (10-100x lower) in health care costs. The low cost base of Apps makes funding clinical trials nearly impossible, which makes regulatory coverage expensive and reimbursement practically impossible. If government wants to see an improvement in health economics, it needs to **shift funding to the left** as well as **provide an active support mechanism for regulation of Apps**. Under Bob Hawke, our regulatory bodies were told to **actively support Australian companies** ie to provide them with prescriptive direction on how best to achieve outcomes e.g. Saudi Arabia provides relevant ISO compliance standards to Saudi companies for free. Pride in and support of Australian-made needs to be renewed inside our bureaucracy.
- Existing funding mechanisms have failed, such as the DART grant scheme, funded by donations through Diabetes Australia and given overwhelmingly to BakerIDI, have **ignored annual grant submissions over 5 years** to support research into new and emerging diabetes-related technology.
- Diabetes organisations do not have the regulatory or information technology background to recommend suitable apps to patients. Evidence of this is the promotion of dosing apps which have **never been TGA-approved**, and have dangerous overdosing flaws even when setup correctly. Other apps which are no longer TGA listed also continue to be promoted. Organisations continue to promote overseas apps that do not support Australian units of blood glucose measurement, and lack basic data validation, leading to dosing errors. This is even more concerning given that repeated requests have been made by TGA-approved Australian App makers to partner with these organisations.
- At a diabetes camp, an endocrinologist **actively dismissed a child's medication ratios** (provided by an Australian App), and parents were told that only use insulin pens or a pump were allowed (this is despite the App being TGA approved). At the end of the camp the **endocrinologist apologised** to the parents as the child's blood sugars had been extremely high throughout the entire 3 days. This culture of ignoring innovation that occurs from outside medicine is appalling, and Australia's complete inability to harness innovation is why **all our medical devices startups leave Australia or die here**.
- WA Health (CAHS) led a recent RFQ to combine education with a small degree of patient monitoring. Unfortunately CAHS had no understanding of Protected Health Information (PHI), Security, the Privacy Act, or Regulatory Compliance, and the RFQ was eventually withdrawn with no improvement for people with diabetes in Western Australia, despite an existing solution being available in market for 6 years.

Regulatory

- The TGA needs to understand and accept that there is a substantial group of well-educated patients (from professions outside of medicine) who find the current regulatory and medical engagement model patronising e.g. several years ago at a Diabetes Congress at the Melbourne Convention Centre, patients were excluded by the TGA from the halls with insulin and medical device manufacturers. This reflects an outdated one-size-fits-all approach to patients. Shouldn't patients be able to learn about new treatments to then ask their doctor about them? Or are doctors somehow infallible and all-knowing?
- The #WeAreNotWaiting movement was created by parents who were frustrated with the glacial rate of improvement in diabetes technology, and successfully built an Open Source

artificial pancreas solution and distributed it globally for free. This provided the forcing function to regulators in the US and EU to revisit the unnecessarily bureaucratic regulatory process that we are still held back by in Australia.

- The TGA needs to **review and improve regulatory pathways** for the efficient assessment of new and emerging diabetes-related technology. Currently, insulin dose calculators are regulated identically to insulin pumps (which is ludicrous), and creates a burden of regulation that is completely inappropriate and of low value.

Thank you for the opportunity to provide feedback on diabetes in Australia.

I hope that this document will provide momentum to make changes.

Regards,

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