

Parliamentary Inquiry into Diabetes



The Alfred Alliance in Diabetes (AAD) is a newly-formed entity, comprising several institutions co-located with the Alfred Hospital, in Melbourne, each of which is engaged with diabetes through research and/or care delivery. This includes The Alfred Hospital, Baker Heart and Diabetes Institute, Monash University and Nucleus Network. The AAD has world-leading authorities and expertise in diabetes research from bench to public health and is engaged in delivering both community-based and highly specialised care.

The AAD welcomes this opportunity to provide input into the Parliamentary Inquiry into Diabetes.

The size of the diabetes challenge is well attested to, both in Australia and overseas. A few salient features of this are presented here.

- Diabetes affects more than 500 million people globally⁽¹⁾.
- Some of the highest rates of diabetes are seen in First Nations peoples, among whom the burden of complications of diabetes is extraordinarily high⁽²⁾.
- Diabetes is the leading cause of kidney failure across the whole population⁽³⁾.
- Diabetes is among the leading causes of vision loss among working-age adults⁽⁴⁾.
- Diabetes is responsible for more than 50% of all lower limb amputations⁽⁵⁾.
- Diabetes is a major risk factor for most manifestations of cardiovascular disease⁽⁶⁾.
- The acute metabolic complications of diabetes including hypoglycaemia and hyperglycaemic emergencies (which are avoidable) significantly impact quality of life and healthcare resource use⁽⁷⁾.
- At any point in time in Australia, 1 in 3 people hospitalised have diabetes⁽⁸⁾.
- In addition to the well-known complications of diabetes noted above, diabetes is now known to also increase the risks of developing a much broader range of diseases, including cancer, dementia, depression and liver disease⁽⁹⁾.

In contrast to the stark challenges listed above, there have been a number of recent developments that suggest that improvements in outcomes are possible. These include:

- clear evidence that newer drugs can slow down the development of both heart and kidney disease in people with diabetes⁽¹⁰⁾

- developments in insulin pumps and continuous glucose monitoring that lead to significantly improved control of blood glucose in type 1 diabetes⁽¹¹⁾
- possibly other types of diabetes with severe insulin-deficiency
- evidence to suggest that in Australia, and in some other countries the incidence of type 2 diabetes (i.e. the annual rate at which new cases are presenting) is falling⁽¹²⁾.

Ensuring that all Australians with diabetes are able to benefit from such developments, and that we can start to reduce the huge disease burden listed above is central to this submission.

The National Diabetes Strategy was developed to provide a framework to address many of the above issues. Unfortunately, implementation of its recommendations has been limited. The AAD calls for these recommendations to be fully implemented.

In addition to those recommendations, the AAD would like to specifically highlight four issues, which we feel are critical to improving the lives of people with diabetes, and delivering the care that has been demonstrated to be effective. Importantly, each of these recommendations is readily achievable, without major changes to health systems. The four issues are:

1. Provide equitable and affordable access to newer evidence-based technologies and treatments.
2. Ensure that all Australians with diabetes can access care from professionals with adequate training and healthcare infrastructure to deliver up to date, evidence-based care.
3. Significantly strengthen our surveillance of diabetes and diabetes health care practices, and incorporate this activity into those of the soon-to-be-formed Centre for Disease Control.
4. Increase funding available for research into diabetes.

The following discussion expands on each of these recommendations.

1. Provide equitable and affordable access to newer evidence-based technologies and treatments.
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The last decade has seen major developments in the tools available to manage diabetes. Ensuring that these are available to all Australians is critical for issues of equity, and for ensuring that, at a population level, the benefits of these developments can be realised as well as maximised.

Diabetes technology

Insulin pumps deliver insulin continuously, and allow the amount of insulin being delivered to vary according to needs. Continuous glucose monitors (CGM) measure glucose levels throughout the day and night. Whilst pumps and CGM each improve the ability to keep the blood glucose levels as close as possible to a tight 'physiological' range, connecting them with each other through 'closed loop' or

'hybrid closed loop' systems significantly enhances the benefits of each device⁽¹¹⁾. The resultant improvement in blood glucose levels not only improves quality of life, but reduces the risk of developing many of the most feared (and costly) complications of diabetes, such as vision loss and kidney failure. These technological aids have become mainstream treatment for type 1 diabetes, but are also of benefit to some people with:

- type 2 diabetes, particularly those being treated with insulin
- cystic fibrosis-related diabetes
- diabetes as a result of pancreatic disease or pancreatic surgery
- monogenic diabetes
- latent autoimmune diabetes, or
- insulin-treated diabetes in pregnancy.

Subsidies for access to CGM have recently been expanded to cover all people with type 1 diabetes. This has been of great benefit. However, access to subsidised CGM for people in the above groups is much more difficult. Indeed, most people using CGM in these categories are self-funding. At approximately, \$100 per month, this is unaffordable for many people, leading to significant inequity.

Insulin pump access is much more limited. The JDRF administers a federally-funded program that subsidises insulin pumps for those aged under 21 years. For everyone else, the approximate \$8000 cost of a pump needs to be funded from health insurance (but typically not provided by basic cover) or from their own pocket. With a manufacturer's warranty of 4 years, this is a sum that needs to be found repeatedly. This essentially limits a treatment that has become the standard of care to only those who can afford it. This inequity is not acceptable, and should be remedied by an insulin-pump subsidy program that provides access to this technology to all people with type 1 diabetes or other diabetes types with marked insulin deficiency.

Sophisticated algorithms linking continuous glucose measurements to an insulin pump, in order to deliver the appropriate amount of insulin across the 24 hours of the day, are the only way to get close to normal physiological glucose levels for people with type 1 diabetes. Providing equitable access to the pumps and the CGM devices that provide this technology is an essential component of delivering high-quality care to all people with diabetes, irrespective of their financial means.

Diabetes medications

Medications developed to treat type 2 diabetes have been shown to have major benefits on the complications of diabetes, but PBS restrictions leave significant numbers of people unable to access these drugs at a subsidised price. Furthermore, evidence from both Australia and overseas indicates that, even among those accessing subsidies, uptake of such medications is socio-economically patterned.

Multiple studies have now demonstrated that SGLT2 inhibitors reduce the risk of developing kidney disease and heart failure by approximately 30–40%, and of myocardial infarction and stroke by about 12%⁽¹⁰⁾. The GLP-1 receptor agonists have

been demonstrated to have a similar or slightly greater effect on myocardial infarction and stroke, and possibly also reduce kidney disease and heart failure. Whilst both drug classes do lower blood glucose, it has become absolutely clear that their benefits for cardiovascular and kidney disease do not rely on the lowering of blood glucose. Trials show that the benefits are apparent for people with well-controlled diabetes, and even for people without diabetes.

The original registration and PBS subsidies of these drugs was based purely on their glucose-lowering effects, and were appropriately restricted to those whose glycaemic control was inadequate. Several years ago, diabetes treatment guidelines in Australia and overseas responded to the accumulating evidence of benefit of these drugs by recommending a risk-based approach to their use. The guidelines recommend their use in anyone with type 2 diabetes who also has established cardiovascular or kidney disease, or is at high risk of these conditions, irrespective of glycaemic (blood glucose) control. PBS subsidies continue to restrict these agents to those with inadequate glycaemic control. For example, a person with type 2 diabetes, and an HbA1c of 6.9% (representing adequate blood glucose control), who has a myocardial infarction is unable to access the PBS subsidy for either of these drug classes, despite recommendations to do so by all major diabetes guidelines. However, a person with an HbA1c of 7.1% and no cardiovascular or kidney disease is eligible for PBS subsidy of these drug classes.

Recent analyses of data from Australians with diabetes⁽¹³⁾ show that the 20% of the population, who live in the most disadvantaged parts of Australia have an approximate 10–20% lower chance of receiving these drug classes (SGLT2i or GLP1-RA), compared to those living in the least disadvantaged areas. This is despite the fact that people in such areas actually have a greater burden and risk of cardiovascular and kidney disease.

It is critical that we ensure that appropriate uptake of highly-effective drugs is maximised. A limited expansion of PBS subsidies would go some way to addressing this. It would also help to send a powerful signal to non-specialists about the importance of these drug classes for preventing cardiovascular and kidney disease. However, this is highly unlikely to completely close the socio-economic gap. Addressing systemic challenges in healthcare delivery will be essential for a fuller solution. Importantly, the availability of both population-level and audit data (see recommendation 3, below) will be central to tracking and supporting any attempts to narrow this gap.

2. Ensure that all Australians with diabetes can access care from professionals with adequate training and healthcare infrastructure to deliver up to date, evidence-based care

The care of people with diabetes requires a well-supported and skilled workforce from primary through to advanced specialty care. GPs, specialists, diabetes nurse educators, dieticians, mental health professionals, podiatrists, exercise physiologists

and aboriginal health workers are all part of the multi-disciplinary team needed to provide appropriate care. Not every person needs to see each of these professionals, but for the more than 1 million Australians with diabetes there need to be adequate numbers of such professionals to provide services for those who need them.

Diabetic foot care provides a good example. Interdisciplinary foot clinics significantly improve outcomes and reduce amputation rates for those with foot ulcers. Every healthcare professional dealing with diabetes should know how to access a local interdisciplinary foot clinic, but it has been estimated that only 10% of the required numbers of such services exist in Australia⁽¹⁴⁾.

A particular area of concern is the provision of care for people using insulin pumps and CGM. Whilst these devices have huge potential, they require support from a highly-skilled workforce. Diabetes Nurse Educators train and support people in using the devices, and interpreting the information the devices provide. Dieticians are necessary for teaching people how to estimate the carbohydrate load of each meal. The specialist physicians (and sometimes GPs) who care for people using these devices need the time and skill to interpret the complex data they produce. An insulin pump and a CGM will typically produce several hundred data points each day, describing glucose levels and insulin delivery. Downloading the data, and interpreting the automated reports and complex data patterns within the confines of a standard 'follow-up' appointment is extremely challenging. A Medicare item for use by appropriately trained healthcare professionals would help to support the costs of this, and encourage the uptake of training. This would, in turn, ensure that expensive technology is used in the most appropriate way, and delivers the best outcomes.

3. Significantly strengthen our surveillance of diabetes and diabetes health care practices, and incorporate this activity into those of the soon-to-be-formed Centre for Disease Control or its collaborating organisations.

Surveillance of diabetes is a critical tool in responding to the challenges that diabetes poses at a national, community and personal level. Surveillance tracks the total burden of disease, its variation across population sub-groups, the distribution of the types of its serious manifestations, the way in which is treated, and the trajectories of each of these over time. Such surveillance is essential for healthcare planning, for identification of at-risk and/or under-served sub-groups, and for assessing the success or otherwise of interventions or changes in policy and practice. In particular, it would allow assessment of the implementation of the components of the National Diabetes Strategy. The bulleted list of features of the diabetes challenge at the beginning of this document, and in many other similar documents, is but one example of the importance of surveillance.

Surveillance of diabetes in Australia is primarily conducted by the Australian Institute of Health and Welfare (AIHW), as well as by additional *ad-hoc* reports published by researchers and NGOs.

The most recent AIHW report on diabetes⁽²⁾ highlights some of the strengths and weaknesses of the currently-available information that underpins these reports. Some examples of this include:

- The prevalence and incidence of diabetes are drawn from analyses of the National Diabetes Services Scheme (NDSS). While the NDSS is believed to capture a very high proportion of all Australians with diagnosed diabetes, and therefore facilitates very granular analyses, its exact reach, and therefore reliability for the purpose of national reporting, has not been accurately determined.
- The extent of the overlap between diabetes and other chronic diseases such as kidney and heart disease is based on analyses of the 2011–12 Australian Health Survey. Thus, it uses data that are 12 years old to describe the current challenge of diabetes.
- Information about hospitalisations among people with diabetes collates data from all states and territories, but depends on accurate coding of diabetes status at hospital discharge to know who has diabetes. Such coding is not always reliable. In particular, it will miss many people whose primary reason for admission may, rightly or wrongly, not be perceived to be connected to diabetes. Linking a national diabetes register to hospital admission data would overcome this.
- Data on the use of medicines to control blood glucose comes from the PBS and RPBS, and so effectively captures the whole population. However, some medicines are also used by people without diabetes. This is increasingly the case for drugs such as SGLT2i and GLP-1RA, which have potent benefits for reducing cardiovascular and renal risk in people without as well as with diabetes. Tracking the use of these in people with diabetes will be increasingly challenging from PBS and RPBS data alone.

Two critical steps are essential to bring diabetes surveillance in Australia into line with that already undertaken in many other high-income countries.

First, we need to capitalise on the NDSS. A high proportion of Australians with diabetes are registered on the NDSS, and although the amount of information captured by the NDSS is quite modest, linkage of the NDSS to a range of Commonwealth and state/territory data sources provides a powerful means of whole-of-population surveillance for diabetes. This is currently limited by the costs and huge time delays in performing such linkages, and the very small number of individuals and organisations with access to such linked data. Furthermore, although it is estimated that 80% to more than 90% of all Australians with diabetes are registered on the NDSS⁽⁹⁾, no formal assessments of its reach have been performed. Formalising the NDSS as a diabetes surveillance system would involve regularly assessing its reach, and developing strategies to strengthen data quality. Additionally, accelerating its incorporation into the National Integrated Health Service Information (NIHSI) data linkage project is essential. The NDSS has extraordinary potential as a data source that, when linked to other data, can hugely enhance our ability to understand the challenges we face. Very modest investments into strengthening its role as a whole of population surveillance system and providing enduring linkages to other data sources will make this a reality.

Second, with diabetes care provided by such a large range of healthcare providers and settings in Australia (primary, secondary and tertiary care), there is a critical need to evaluate and inform clinicians about whether they are delivering best practice care whilst also capturing the patient experience. Clinical audit feedback (clinical care benchmarking) such as that provided by the Australian Diabetes Clinical Quality Registry (previously known as Australian National Diabetes Audit) is able to identify variation in practice (including low quality/value care) and highlight/support quality improvement activities. The opportunity now exists to deliver an enhanced Australia-wide approach to quality improvement in diabetes care with:

1. Linkage of audit data to the NDSS and national hospitalisation and outcome datasets to measure the longitudinal impact of change.
2. Development of technological solutions at the point of care including an electronic diabetes data dashboard and decision support tools
3. Healthcare professional educational and peer support resources to share knowledge related to effective use of audit data and practice change.

The Federal Government's plan to establish a new Centre for Disease Control (including its collaborating organisations) presents an ideal framework for surveillance of diabetes and diabetes health care practices. Chronic diseases like diabetes account for a huge proportion of the healthcare burden and costs, and need to form a core of the activities of the new Centre.

4. Increase funding available for research into diabetes.

A final, critical element is research funding. NHMRC reporting of its own expenditure⁽¹⁵⁾ demonstrates a 35% fall in research funding for diabetes between 2013 and 2022. Over the same time period, NHMRC funding of obesity research has fallen by just over 50%. Whilst the MRFF is covering some of the shortfall, the investment should be growing. We cannot rely on overseas research. We need to understand our own, unique environment, and continue our strong contribution to global science. The combination of academia and healthcare delivery provides better research and better care. Unfortunately, funding rates for diabetes research are so low that retaining and attracting researchers is reaching a critically challenging stage. The relative attractions of full-time clinical practice or of research into other disciplines are starving diabetes of the necessary talents.

Summary

In summary, we support the full implementation of the National Diabetes Strategy, and specifically provide the following recommendations:

1. Provide equitable and affordable access to newer evidence-based technologies and treatments.
2. Ensure that all Australians with diabetes can access care from professionals with adequate training and healthcare infrastructure to deliver up to date, evidence-based care.
3. Significantly strengthen our surveillance of diabetes and diabetes health care practices, and incorporate this activity into those of the soon-to-be-formed Centre for Disease Control.
4. Increase funding available for research into diabetes.

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