



# **THE HOUSE OF REPRESENTATIVES STANDING COMMITTEE ON HEALTH, AGED CARE AND SPORT – PARLIAMENTARY INQUIRY INTO DIABETES**

## **Australia's Diabetes Epidemic: an overview**

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# AUSTRALIA'S DIABETES EPIDEMIC: AN OVERVIEW

## Introduction

Diabetes Australia, the Australian Diabetes Society and the Australian Diabetes Educators Association represent 1.5 million Australians living with known, diagnosed diabetes; approximately 500,000 Australians living with silent, undiagnosed type 2 diabetes; and around 2 million Australians living with prediabetes; as well as their families and carers, diabetes healthcare professionals and researchers.

We are dedicated to reducing the incidence and impact of diabetes on people, health systems and society. We work with people living with, or at risk of diabetes, their families and carers, health professionals, researchers, funders, other diabetes organisations and the community to positively change people's lives.

Given the scale and complexity of the diabetes epidemic, we will be making several submissions to the Inquiry including this overarching submission looking at the broad impact and key areas for reform. This will be augmented by submissions focusing on significant topic areas:

- Type 2 diabetes prevention and remission
- Diabetes-related technology
- The impact of diabetes on Aboriginal and Torres Strait Islander people

For in-depth information about these topics please see the relevant submission.

The Parliamentary Inquiry into Diabetes is an opportunity to act decisively to reduce the impact of the diabetes epidemic, save lives and safeguard the sustainability of Australia's health system. We strongly encourage the Committee to recommend that the Australian Government adopt the recommendations contained herein.

## Overview of the Diabetes Epidemic

The diabetes epidemic is one of the largest and most complex health challenges Australia has ever faced. There are now 1.5 million Australians living with all types of known, diagnosed diabetes including:

- 138,000 Australians living with type 1 diabetes
- 1.3 million Australians living with type 2 diabetes
- 47,000 women diagnosed with gestational diabetes in the past 12 months
- 12,000 Australians living with other types of diabetes.<sup>1</sup>

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<sup>1</sup> National Diabetes Services Scheme. NDSS Snapshots – All Types of Diabetes [Fact Sheet]. <https://www.ndss.com.au/wp-content/uploads/ndss-data-snapshot-202306-type2-diabetes.pdf>

There are also an estimated 500,000 people living with silent, undiagnosed type 2 diabetes.<sup>2</sup> The number of people living with diabetes continues to increase with more than 118,000 people diagnosed with all types of diabetes in the past 12 months.<sup>3</sup>

Since 2000 the number of Australians living with diabetes has increased by approximately 220% from 459,678 in 2000 to more than 1.5 million in 2022. In terms of prevalence, diabetes has increased from 1.2% of the population in 1989-90<sup>4</sup> to 5.6% in 2023. If the growth rates of the past decade continue, there will be more than 3.1 million Australians, around 8.3% of the projected population, living with diabetes by 2050.<sup>5</sup>

The number of people living with diabetes is significant and requires urgent action because it is a serious chronic condition that can cause debilitating and costly complications. For instance, the risk of a person living with diabetes developing a range of conditions is much higher than those who do not have diabetes including:

- Double the risk of dementia<sup>6</sup>
- Increases the risk of stroke by 1.5 times<sup>7</sup>
- Increases the risk of end-stage kidney disease by 12 times<sup>8</sup>

Diabetes is also the leading cause of preventable blindness in working age Australians as well as some cancers, coronary artery disease and myocardial infarctions. Almost 50% of people living with diabetes experience a mental health challenge every year<sup>9</sup> and one-third of Australians living with type 2 diabetes report some form of cardiovascular disease.<sup>10</sup> Almost 4000 people living with diabetes will develop dementia in a given year.<sup>11</sup>

Additionally, diabetes also leads to around 17,477 deaths per annum and is associated with around 10.5% of all deaths.<sup>12</sup> The number of diabetes-related deaths increased by 72.5% from 2000 to 2020.<sup>13</sup>

The epidemic's impact can be felt by every Australian either directly, as a person living with diabetes or caring for someone living with diabetes, or indirectly via its considerable impact on our health system and our economy.

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<sup>2</sup> Sainsbury, E. et al. (2020) 'The diagnosis and management of diabetes in Australia: Does the "Rule of halves" apply?', *Diabetes Research and Clinical Practice*, 170, p. 108524. doi:10.1016/j.diabres.2020.108524.

<sup>3</sup> National Diabetes Services Scheme. NDSS Snapshots – All Types of Diabetes [Fact Sheet]. <https://www.ndss.com.au/wp-content/uploads/ndss-data-snapshot-202306-type2-diabetes.pdf>

<sup>4</sup> Australian Bureau of Statistics 2001, *Diabetes in Australia: A Snapshot*, 2001, Australia cat. no. 4820.0, ABS, Canberra

<sup>5</sup> Diabetes Australia. *Change the Future: Reducing the Impact of the Diabetes Epidemic*. Diabetes Australia, Brisbane 2022.

<sup>6</sup> Alzheimer's Australia. *Dementia and Diabetes: A toolkit for community care workers*. Alzheimer's Australia, Victoria, accessed 28 August 2023. <https://www.dementia.org.au/sites/default/files/Worker%20Manual%20A4%20WEB.pdf>

<sup>7</sup> American Diabetes Association 2022, American Diabetes Association website, accessed 3 November 2022,

<sup>8</sup> Pálsson, R. and Patel, U., 2014. Cardiovascular Complications of Diabetic Kidney Disease. *Advances in Chronic Kidney Disease*, 21(3), pp.273-280.

<sup>9</sup> Diabetes Australia (2020) *Survey on the Mental and Emotional Impact of living with diabetes*, Surveyed by: Orima Research. 6 July 2020.

<sup>10</sup> Davis, T.M. et al. (2022) 'Cardiovascular disease management in Australian adults with type 2 diabetes: Insights from the CAPTURE study', *Internal Medicine Journal* [Preprint]. doi:10.1111/imj.15929.

<sup>11</sup> Diabetes Australia. *Change the Future: Reducing the Impact of the Diabetes Epidemic*. Diabetes Australia, Brisbane 2022.

<sup>12</sup> Australian Institute of Health and Welfare. (2022) *Diabetes: Australian Facts*. 21 August 2023.

<sup>13</sup> Ibid.

Diabetes accounts for more than 1.3 million annual hospitalisations, including around 19,000 emergency department presentations. This represents around 10% of total hospitalisations.<sup>14</sup> This includes:

- 966,000 hospitalisations for diabetes-related kidney disease<sup>15</sup>
- 100,000 hospitalisations for diabetes-related eye conditions<sup>16</sup>
- 5,163 diabetes-related amputations.<sup>17</sup>

The complexity of many of these admissions means that the average length of hospitalisation is significantly longer for a person living with diabetes than in a person without diabetes.<sup>18</sup>

It is also important to note that the impact of diabetes is unevenly distributed. For instance, people living in the most disadvantaged communities in Australia (SEIFA 1) are 2.5 times more likely to be hospitalised with a potentially preventable diabetes-related complication compared to those in the least disadvantaged communities (SEIFA 5).<sup>19</sup> Similarly, data shows that people living in remote Australia were three times more likely to be hospitalised with a diabetes-related complication than people living in major cities.<sup>20</sup>

Meeting the challenges associated with the growing numbers of people living with diabetes will require resolve, commitment and innovation. It also demands a dedicated investment. However, with smart policy and smart spending, we can reduce the impact of diabetes on Australians and reduce the long-term impact on the health system.

## **COVID-19**

Diabetes can exacerbate other health challenges, as the COVID-19 pandemic demonstrated.

People living with diabetes are at a higher risk of severe COVID-19 including hospitalisation, intensive care unit admission and even death. Around one in five deaths from COVID-19 (third most common co-morbidity) and around one third of all intensive care hospitalisations (most common co-morbidity) involved people living with diabetes.<sup>21</sup> With the CSIRO forecasting an increased risk of infectious disease outbreaks in the future, there is a very real risk that the diabetes epidemic will worsen the severity of any future pandemics.<sup>22</sup>

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<sup>14</sup> Australian Institute of Health and Welfare. (2022) Admitted patients. Australian Institute of Health and Welfare. 30 Oct 2022. <https://www.aihw.gov.au/reports-data/myhospitals/sectors/admitted-patients>

<sup>15</sup> Kwok, R, MacIsaac, R, and Ekinici, E. (2023) Change the Future: Saving Lives By Better Detecting Diabetes-related kidney disease. Diabetes Australia, Australia.

<sup>16</sup> Diabetes Australia. Change the Future: Reducing the Impact of the Diabetes Epidemic. Diabetes Australia, Brisbane 2022.

<sup>17</sup> Australian Institute of Health and Welfare. (2022) Diabetes: Australian Facts. 21 August 2023.

<sup>18</sup> Carral F, Oliveira G, Salas J, Garcia L, Sillero A, Aguilar M. Care resource utilization and direct costs incurred by people with diabetes in a Spanish hospital. *Diabetes Res & Clin Prac.* 2002;56(1):27-34.

<sup>19</sup> Australian Institute of Health and Welfare. (2020) Disparities in potentially preventable hospitalisations across Australia, 2012-13 to 2017-28. Australian Institute of Health and Welfare. 21 August 2023. <https://www.aihw.gov.au/reports/primary-health-care/disparities-in-potentially-preventable-hospitalisations-australia/summary>

<sup>20</sup> Australian Institute of Health and Welfare. (2022) Diabetes: Australian Facts. 21 August 2023.

<sup>21</sup> COVID-19 National Incident Centre Surveillance Team. COVID-19 Australia: Epidemiology Report 64: Reporting period ending 31 July 2022. *Commun Dis Intell* (2018). 2022 Sep 12;46.

<sup>22</sup> Naughtin C, Hajkowicz S, Schleiger E, Bratanova A, Cameron A, Zamin T, Dutta A (2022) Our Future World: Global megatrends impacting the way we live over coming decades. Brisbane, Australia: CSIRO.

## Cost

Diabetes has a massive financial impact on Australia. Diabetes Australia's most recent modelling places the annual cost at \$17.6B per annum.<sup>23</sup> A 2014 Deloitte Access Economics Report found diabetes costs Australia around \$5.63B per annum in lost productivity.<sup>24</sup>

According to the AIHW, diabetes costs the health system around \$3.14B per annum including:

- \$827 million via the Pharmaceutical Benefits Scheme (PBS)
- \$374 million for public hospital outpatient care
- \$758 million for public hospital admitted patients
- \$290 million for GP services.<sup>25</sup>

The costs of treating diabetes increase as people age with more than 54% of costs relating to people aged 60 and over. With Australia's aging population these costs will likely increase significantly in the coming decades.

## Australia's response

Australia has an excellent foundation for limiting the impact of diabetes including universal health coverage through Medicare and the PBS, the National Diabetes Services Scheme (NDSS), which is the envy of the world, and well-trained and dedicated health professionals.

We have a major challenge in front of us but doing nothing is not an option. Without action, diabetes will continue to have an unacceptable impact on the physical, emotional and financial wellbeing of Australians, as well as our health system.

## Australian National Diabetes Strategy 2021-2030

Many key actions to support Australia's response to the diabetes epidemic are outlined in the *Australian National Diabetes Strategy 2021-2030 (ANDS)*. This Strategy has the support of both sides of politics and the Australian and State and Territory Governments. However, despite the bipartisan commitment to implementation many of the key recommendations remain unfulfilled.

***Recommendation: Develop a new implementation plan for the National Diabetes Strategy with clear timelines, funding and deliverables***

## National Diabetes Services Scheme (NDSS)

Established in 1987, and delivered since its inception by Diabetes Australia, the National Diabetes Services Scheme (NDSS) is a world-leading diabetes support and services scheme. An enhanced NDSS should be the backbone of a comprehensive plan to address the diabetes epidemic.

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<sup>23</sup> Lee C, Colagiuri R, Magliano D, Cameron A, Shaw J, Zimmet P, and Colagiuri S, 2013. The cost of diabetes in adults in Australia. *Diabetes Research and Clinical Practice*, 99(3), pp.385-390.

<sup>24</sup> Deloitte Access Economics. (2014) Productivity impacts of diabetes

<sup>25</sup> Australian Institute of Health and Welfare. (2022) Diabetes: Australian Facts. 21 August 2023.

The NDSS database is the only one of its kind in the world. Improved data linkages and interactivity could enable more effective complications' screening and interventions to support more successful preventive treatments. This represents one of the most cost-effective, straightforward and impactful actions Australia could take to improve targeted preventive diabetes healthcare. The database is currently utilised to deliver eye check reminders through the highly successful KeepSight program.

There are clear international examples that could be followed. For instance, the NHS Scotland's My Diabetes My Way interactive website allows people living with diabetes, and their healthcare team, to store and access a range of important diabetes data which can be used to calculate a person's risk of different diabetes-related complications. Studies have shown this to be a cost-efficient self-management intervention that can help people improve their diabetes management and reduce the risk of serious health issues.<sup>26</sup>

***Recommendation: Optimise the NDSS database to enable it to better provide recall and reminder notices to people living with diabetes to increase rates of preventive diabetes health checks***

## Diabetes-related stigma

Diabetes-related stigma is widespread with around 80 per cent of people living with the condition reporting being blamed or shamed.<sup>27</sup> More than two-thirds of people living with type 1 diabetes say people make false assumptions about what they can do because of their diabetes, while more than 50 percent of people with type 2 diabetes say people assume they are overweight.<sup>28</sup> Additionally, living with overweight and obesity is associated with significant stigma.

Diabetes Australia's recent national community consultation found 21% of people living with diabetes identified stigma and discrimination as one of the biggest challenges associated with living with the condition.<sup>29</sup> The major sources of stigma for people living with diabetes were identified as the broader community (74%), the media (51%) and health professionals (36%).

Diabetes-related stigma manifests in a variety of ways including the circulation of inaccurate or misleading information about diabetes and widespread use of harmful stereotypes.

The impact of diabetes-related stigma is profound with around 50 per cent of people living with this condition experiencing a mental health challenge in a given year.<sup>30</sup> This in turn can lead to people disengaging from diabetes management, which significantly increases a person's risk of serious diabetes-related complications.

Overcoming any widespread stigma, including diabetes-related stigma, cannot be achieved by policy decisions alone. Strong and committed leadership from all sectors of society are required

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<sup>26</sup> Cunningham, S. et al. (2019) 'My diabetes my way: User experiences, clinical outcomes and health economics impact of an electronic personal health record for diabetes', *International Journal of Integrated Care*, 19(4), p. 624. doi:10.5334/ijic.s3624.

<sup>27</sup> Diabetes Australia (2020) Survey on the Mental and Emotional Impact of living with diabetes, Surveyed by: Orima Research. 6 July 2020.

<sup>28</sup> Ibid.

<sup>29</sup> Diabetes Australia. 2023. Top line report: Diabetes National Community Consultation. Where To: Victoria.

<sup>30</sup> Diabetes Australia. 2020 Survey on the Mental and Emotional Impact of living with diabetes, Surveyed by: Orima Research. 6 July 2020.

to drive cultural change. However, it is critical any policy response to the diabetes epidemic alleviates the burden of stigma rather than exacerbating it.

***Recommendation: Fund education campaigns that raise awareness and understanding of all types of diabetes rather than propagating myths and falsehoods***

***Recommendation: Adopt the Diabetes Australia Language Position Statement as the agreed community standard when writing and speaking about diabetes***

***Recommendation: Ensure the reduction of diabetes-related stigma is a core consideration in the development of any new government policy or initiative***

## Annual Cycle of Care

The annual cycle of care is a checklist designed to help people living with diabetes and their healthcare teams keep up-to-date with the range of health checks that are essential to optimal diabetes management and ongoing complications prevention. However, the best available evidence shows that most Australians living with diabetes are not getting regular health checks including:

- 50% not getting HbA1c checks
- 29% not getting their blood pressure checked
- 51% not getting their cholesterol checked
- 73% not getting their kidneys checked
- 41% not getting their weight checked.<sup>31</sup>

A number of factors contribute to this including the complexity of living with diabetes and the difficulty in accessing health checks. The difficulties in accessing health checks can relate to a shortage of GPs, particularly in regional and remote areas, as well as a lack of clear incentives for GPs to ensure all checks are completed within recommended timeframes. The decision to remove the Annual Cycle of Care MBS incentive in 2022 has not helped. While the uptake of the incentive was low (around 18%), its existence helped reinforce the importance of these checks with GPs.

It is essential that any and all reforms in diabetes care, particularly in primary care, are focused on making it easier and more convenient to have health checks and enable earlier intervention to reduce the impact of diabetes-related complications. There are opportunities in the recently announced Unleashing the Potential of our Health Workforce Review into scope of practice (see below) to support and empower other health professionals, including credentialled diabetes educators and nurse practitioners, to help boost Annual Cycle of Care checks.

Other potential reform areas include changes to pathology to make it easier for people to access checks and funding to better support preventive chronic disease care (see below).

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<sup>31</sup> Sainsbury E, et al. 2018. Burden of Diabetes in Australia: It's Time for More Action. Novo Nordisk, Sydney, Australia.

## Type 1 Diabetes

Type 1 diabetes is an autoimmune condition where the body's own immune system is activated to destroy the beta cells in the pancreas which produce insulin. It is not known what triggers the autoimmune reaction, however environmental factors are suspected to be involved. There is no cure, it is lifelong and can occur at any age.

All people living with type 1 diabetes require insulin administered daily via an insulin pump or multiple injections and regular monitoring of glucose levels via multiple finger prick checks or a continuous or flash glucose monitoring technology.

There are currently almost 140,000 Australians living with type 1 diabetes including:

- 4,273 people who have been diagnosed in the past 12 months
- 15,110 children and young people aged 20 or under; and
- 48,269 people aged 60 or over.<sup>32</sup>

### ***Economic impact***

Analysis by JDRF Australia has found that type 1 diabetes costs Australia around \$2.9B per annum, with almost 20% of those costs borne by the Australian Government.<sup>33</sup> Healthcare costs of treating diabetes-related complications are a significant driver of this impact. The lifetime cost associated with a person living with type 1 diabetes without diabetes-related complications is \$143,000; however, this rises to \$738,000 when complications develop.<sup>34</sup>

There is a clear economic argument for ensuring people living with type 1 diabetes can access the treatments and technologies, including insulin pumps and glucose monitoring technology, that help them reduce their risk of complications. JDRF Australia's research found that providing all Australians living with type 1 diabetes with lifetime access to diabetes technology would cost around \$120,000 per person but deliver around \$174,000 in lifetime saving due to reduced impact of diabetes complications, representing a net saving of \$54,000 or a benefit-cost ratio of 1.5.<sup>35</sup>

### ***Early diagnosis***

One key area requiring urgent access is improving early diagnosis of type 1 diabetes. Every year around 900 people are hospitalised in a potentially life-threatening condition because the early warning signs of type 1 diabetes are missed.<sup>36</sup>

These early warning signs are often referred to as the '4Ts':

- Tired – unexplained or excessive fatigue
- Thirsty – a thirst that can't be quenched
- Thinner – sudden or unexplained weight loss
- Toilet – going to the toilet a lot

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<sup>32</sup> National Diabetes Services Scheme. NDSS Snapshots – All Types of Diabetes [Fact Sheet]. <https://www.ndss.com.au/wp-content/uploads/ndss-data-snapshot-202306-type1-diabetes.pdf>

<sup>33</sup> JDRF Australia. Economic Cost of Type 1 Diabetes in Australia. Sydney, April 2021. Available at: [https://jdrf.org.au/wp-content/uploads/2021/06/The-economic-cost-of-T1D.pdf?utm\\_source=pardot&utm\\_medium=email&utm\\_campaign=accenture\\_report\\_release&utm\\_content=first\\_send\\_wide\\_audience\\_cash\\_header](https://jdrf.org.au/wp-content/uploads/2021/06/The-economic-cost-of-T1D.pdf?utm_source=pardot&utm_medium=email&utm_campaign=accenture_report_release&utm_content=first_send_wide_audience_cash_header)

<sup>34</sup> Ibid.

<sup>35</sup> Ibid.

<sup>36</sup> Ibid.



Studies have shown awareness campaigns can reduce the number of people diagnosed in diabetic ketoacidosis by more than 60%.<sup>37</sup>

Another emerging and important tool to support the early identification of people at risk of type 1 diabetes is genetic screening. Screening, combined with emerging therapies such as teplizumab, have been shown to delay the development of type 1 diabetes by up to three years. This is likely to be an evolving priority for the prevention of type 1 diabetes in the future.

In addition to the substantial health and psychosocial benefits for the individual and their families, diagnosing type 1 diabetes before diabetic ketoacidosis was associated with savings to the economy of up to \$33,000 per person.<sup>38</sup>

***Recommendation: Australia urgently needs a national awareness campaign to increase community and health professional knowledge of the 4Ts to support earlier detection and minimise costly and dangerous hospitalisations***

## Type 2 Diabetes

Type 2 diabetes is a condition in which the body becomes resistant to the normal effects of insulin and gradually loses the capacity to produce enough insulin in the pancreas. This condition has strong genetic and family-related (non-modifiable) risk factors and is also often associated with modifiable lifestyle risk factors. We do not know the exact genetic causes of type 2 diabetes. People may be able to significantly slow or even stop the progression of the condition through changes to diet and increasing the amount of physical activity they do.

There are currently more than 1.3 million people living with type 2 diabetes and registered with the NDSS including:

- More than 65,000 people who were diagnosed in the past 12 months,
- Almost 1 million people who are aged 60 years or older, and
- More than 322,000 people using insulin to manage their diabetes.<sup>39</sup>

Type 2 diabetes disproportionately impacts Aboriginal and Torres Strait Islander people, people from low socio-economic backgrounds or who are experiencing other forms of economic or social marginalisation.

Type 2 diabetes has been described as the epidemic of the 21<sup>st</sup> century and, as outlined above, prevalence has increased rapidly over the past 30 years. Please see our submission *Reducing the impact of type 2 diabetes: detection, prevention and remission* for an in-depth consideration of these issues.

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<sup>37</sup> King et al. A diabetes awareness campaign prevents diabetic ketoacidosis in children at their initial presentation with type 1 diabetes 2012: 13(8) 647-51.

<sup>38</sup> JDRF Australia. Economic Cost of Type 1 Diabetes in Australia. Sydney, April 2021. Available at: [https://jdrf.org.au/wp-content/uploads/2021/06/The-economic-cost-of-T1D.pdf?utm\\_source=pardot&utm\\_medium=email&utm\\_campaign=accenture\\_report\\_release&utm\\_content=first\\_send\\_wide\\_audience\\_cash\\_header](https://jdrf.org.au/wp-content/uploads/2021/06/The-economic-cost-of-T1D.pdf?utm_source=pardot&utm_medium=email&utm_campaign=accenture_report_release&utm_content=first_send_wide_audience_cash_header)

<sup>39</sup> National Diabetes Services Scheme. NDSS Snapshots – All Types of Diabetes [Fact Sheet]. <https://www.ndss.com.au/wp-content/uploads/ndss-data-snapshot-202306-type1-diabetes.pdf>

## **Heterogeneity of type 2 diabetes**

Recent research has revealed type 2 diabetes is much more complex than previously thought. In 2018, researchers proposed four distinct, replicable sub-types of type 2 diabetes, based on clinical and biochemical factors in large Scandinavian cohorts.<sup>40</sup> These cohorts were:

- Severe insulin-deficient diabetes (about 17.5% of people) characterised by low insulin secretion and GAD negative, relatively low BMI, hard to manage blood glucose levels and a higher risk of diabetic retinopathy
- Severe insulin-deficient diabetes (about 15.3% of people) characterised by insulin resistance, relatively high BMI and a higher risk of kidney complications
- Mild obesity-related diabetes (about 21.6% of people) characterised by relatively high BMI, no insulin resistance
- Mild age-related diabetes (about 39.1% of people) characterised by older age of onset and milder impacts on glucose levels than most other sub-groups.

An additional sub-type (impacting about 6.4% of people) with similar features to type 1 diabetes and latent autoimmune diabetes in adults was also detected.

Following this research several other studies in other countries have identified sub-types that are the same or similar to the initial research, as well as novel sub-types that seem unique to certain ethnic populations.<sup>41</sup>

One of the immediate implications of this research is the fact that some people living with type 2 diabetes may be at much higher risk of diabetes-related complications than other groups. This could support enhanced genetic screening or other programs that may be able to identify people at the higher risk of diabetes-related complications.

In particular, research is urgently required into the complexity of type 2 diabetes in Aboriginal and Torres Strait Islanders to support better detection and management of diabetes in this cohort. Many Aboriginal and Torres Strait Islander people are diagnosed with type 2 diabetes at a younger age than non-Indigenous Australians and progress to diabetes-related kidney disease and lower limb amputations earlier than non-Indigenous Australians.

## **Prediabetes**

Prediabetes is a condition in which blood glucose levels are too high, but not high enough to be diagnosed as diabetes. At least 2 million Australians are estimated to be living with prediabetes.<sup>42</sup> Around a one-third of people living with prediabetes will develop type 2 diabetes within 10 years. Progression is more likely in women who have been diagnosed with gestational diabetes and in certain ethnic groups.

One of the most cost-effective early interventions is to provide support to help a person living with prediabetes to improve their diet. The International Diabetes Federation recognises primary care as the best place to provide people with diabetes with professional nutritional advice; however, studies have found that only as few as one in five people with type 2 diabetes or

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<sup>40</sup> Ahlqvist, E et al. 2018. Novel subgroups of adult-onset diabetes and their association with outcomes: a data-driven cluster analysis of six variables. *The Lancet Diabetes & Endocrinology*, 6(5), pp.361-369.

<sup>41</sup> Anjana, R., Baskar, V., Nair, A., Jebarani, S., Siddiqui, M., Pradeepa, R., Unnikrishnan, R., Palmer, C., Pearson, E. and Mohan, V., 2020. Novel subgroups of type 2 diabetes and their association with microvascular outcomes in an Asian Indian population: a data-driven cluster analysis: the INSPIRED study. *BMJ Open Diabetes Research & Care*, 8(1), p.e001506.

<sup>42</sup> Shaw J, Tanamas S. Diabetes: the silent pandemic and its impact on Australia. Melbourne, Australia; 2012.

prediabetes have received a referral to a dietitian/nutritionist from their GP.<sup>43</sup> Research has found that competing priorities, limited time available for consultations and a lack of expertise in nutrition made it difficult for GPs to discuss diet at every appointment.<sup>44,45,46</sup> This is why access to expert dietetic support is so important.

### ***Need for targeted dietetic and other allied health support***

Currently, people living with prediabetes are only eligible for Chronic Disease Management plans (sometimes known as a GP Management Plan) if they have another chronic health condition. The plans provide people with Medicare rebates for five visits to allied health professionals, including dietitians.

Perversely, people living with CVD and/or type 2 diabetes qualify for these plans, but people living with prediabetes do not, even though prediabetes is a key risk factor for both CVD and type 2 diabetes. Access to these Plans would help people reduce their risk of developing type 2 diabetes. This is a major missed opportunity in type 2 diabetes prevention.

***Recommendation: Consideration should be given to expanding access to Chronic Disease Management Plans to cover people living with prediabetes to support them in accessing expert evidence-based preventive healthcare including nutrition, physical activity, stress management and sleep***

***Recommendation: Explore funded telehealth or evidence-based digital nutritional coaching and physical activity support as a low-cost addition to MBS-funded services to significantly increase access to dietetic and physical activity support***

## **Gestational diabetes**

Gestational diabetes (GDM) is the fastest growing type of diabetes in Australia. The number of women diagnosed annually has more than doubled over the past decade. In the 12 months to June 2023:

- 44,724 women were diagnosed with GDM
- 8,985 of these women had already been diagnosed with GDM in a previous pregnancy
- 41% per cent of women with GDM required insulin to manage the condition.<sup>47</sup>

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<sup>43</sup> Mulquiney KJ, Tapley A, van Driel ML, et al. Referrals to dietitians/nutritionists: A cross-sectional analysis of Australian GP registrars' clinical practice. *Nutr Diet* 2018;75(1):98–105. doi: 10.1111/1747-0080.12377.

<sup>44</sup> Crowley J, O'Connell S, Kavka A, Ball L, Nowson CA. Australian general practitioners' views regarding providing nutrition care: results of a national survey. *Public Health*. 2016 Nov;140:7-13. doi: 10.1016/j.puhe.2016.08.013. Epub 2016 Sep 28. PMID: 27692586.

<sup>45</sup> Crowley J, Ball L, McGill AT, Buetow S, Arroll B, Leveritt M, Wall C. General practitioners' views on providing nutrition care to patients with chronic disease: a focus group study. *J Prim Health Care*. 2016 Dec;8(4):357-364. doi: 10.1071/HC15048. PMID: 29530161.

<sup>46</sup> Somerville, M. et al. (2021) 'How do healthcare providers support people with Prediabetes to eat well? an in-depth, mixed-methods case study of provider practices', *Australian Journal of General Practice*, 50(7), pp. 497–504. doi:10.31128/ajgp-08-20-5597.

<sup>47</sup> National Diabetes Services Scheme. NDSS Snapshots – All Types of Diabetes [Fact Sheet]. <https://www.ndss.com.au/wp-content/uploads/ndss-data-snapshot-202306-type1-diabetes.pdf>

Diabetes Australia forecasts that over the next decade more than 500,000 Australian women will develop GDM.<sup>48</sup>

There are a number of factors driving this increase in GDM, including increased screening and detection, the age and weight of women becoming pregnant, excessive weight gain during pregnancy and Australia's changing ethnic makeup with more mothers coming from ethnic groups with a higher risk of GDM.

Women diagnosed with GDM are at a higher risk of serious complications during labour and birth that can have a lifelong impact on both mother and baby. For the mother complications can include hypertension, pre-eclampsia and requiring caesarean section. Babies born to mothers diagnosed with GDM are at increased risk of premature birth, macrosomia, stillbirth, respiratory distress, hypoglycaemia and jaundice. The risk of many of these complications is higher in Aboriginal and Torres Strait Islander women and people living in rural and remote communities. With appropriate care and support during pregnancy, many of these complications are preventable. Women who are diagnosed with GDM may also experience a range of psychological challenges including anxiety, guilt and distress. It is essential these women can access support from qualified health professionals and peer support.

GDM also increases a mother and her child's lifetime risk of developing type 2 diabetes. Children born to mothers with GDM are more likely to develop obesity and seven times more likely to develop type 2 diabetes later in life.<sup>49</sup> This means diabetes can become an intergenerational condition. Around 60 per cent of mothers diagnosed with GDM will develop type 2 diabetes within the next 10-20 years.<sup>50</sup> They are also twice as likely to experience a range of cardiovascular events postpartum than women who have not been diagnosed with GDM.<sup>51</sup> This includes coronary artery disease, myocardial infarction, heart failure and stroke.<sup>52</sup> This increase in risk occurs regardless of the development of traditional risk factors including if women have not developed type 2 diabetes.

### ***Reducing the impact of GDM with better pre-conception care***

Pre-conception is a key opportunity to support more women to achieve a healthy weight and lifestyle as part of the pregnancy planning process.

Studies have shown that moderate intensity lifestyle interventions in women at high risk during early pregnancy can reduce their risk of GDM by 41%.<sup>53</sup>

However, few women have the opportunity to engage in supported pre-conception care to obtain a healthy weight prior to pregnancy. New approaches for pre-pregnancy planning are required including:

- More encouragement for women to plan pregnancies including improving access to safe, reliable contraception;

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<sup>48</sup> Diabetes Australia. (2020) Position Statement: Gestational Diabetes in Australia.

<sup>49</sup> Lee AJ, Hiscock RJ, Wein P, Walker SP, Permezel M. Gestational diabetes mellitus: clinical predictors and long-term risk of developing type 2 diabetes: a retrospective cohort study using survival analysis. *Diab Care*. 2007;30:878-83.

<sup>50</sup> O'Sullivan JB. Establishing criteria for gestational diabetes. *Diabetes Care*. 1980;3:437-439.

<sup>51</sup> Gestational diabetes and the risk of cardiovascular disease in women: a systematic review and meta-analysis

<sup>52</sup> Marschner, S. et al. (2023) 'Cardiovascular risk management following gestational diabetes and hypertensive disorders of pregnancy: A narrative review', *Medical Journal of Australia*, 218(10), pp. 484-491. doi:10.5694/mja2.51932.

<sup>53</sup> Sadiya, A. et al. (2022) 'Lifestyle intervention in early pregnancy can prevent gestational diabetes in high-risk pregnant women in the UAE: A randomized controlled trial', *BMC Pregnancy and Childbirth*, 22(1). doi:10.1186/s12884-022-04972-w.

- Better access to pre-pregnancy assessment via a women's GP or a local pre-pregnancy service, via a hospital or other primary or tertiary care settings, including funding the expansion of these services; and
- More encouragement for women to plan pregnancies and to attend pre-pregnancy assessment with their GP or local pre-pregnancy services

These approaches and other initiatives to reduce the impact of GDM are outlined in Goal 4 of the ANDS 2021-2030.

***Recommendation: Women at risk of developing GDM should be able to access scaled up Type 2 Diabetes Prevention Programs (see type 2 diabetes submission) to help them achieve a healthy weight prior to pregnancy***

***Recommendation: Establish pre-pregnancy weight management clinics at accessible locations Australia-wide***

### ***Managing GDM during pregnancy***

Women diagnosed with GDM require specialised health care during pregnancy including access to a multidisciplinary team that includes a credentialled diabetes educator (CDE), accredited practising dietitian and/or exercise physiologist, an obstetrician, a midwife, an endocrinologist and their GP. However, evidence suggests GDM care is often inconsistent or lacking.<sup>54</sup> Funding has not kept pace with increasing numbers of women being diagnosed with the condition and a greater investment is required to provide appropriate levels of care.

Many women are unable to access dietetic support from dietitians with experience in pregnancy. This support is essential for helping limit weight gain, managing blood glucose levels, ensuring optimal nutrition and reducing the risk of pregnancy-related complications. This situation is especially pronounced in rural areas with a recent audit showing women in these areas are less likely to receive education or medical treatment and are less likely to achieve optimal glucose management.<sup>55,56,57</sup>

Additionally, GDM education and care is not currently covered by Medicare or many private health insurance policies. This means many women receiving pregnancy care in the private sector must either pay private practitioners or, if they are unable to meet these costs, try to access services through an already over-burdened public system. Mothers who can't access these services are likely to miss out on diabetes education altogether.

<sup>54</sup> Sina, M. et al. (2020) 'Antenatal models of care for women with gestational diabetes mellitus: Vignettes from an international meeting', Australian and New Zealand Journal of Obstetrics and Gynaecology, 60(5), pp. 720-728. doi:10.1111/ajo.13144.

<sup>55</sup> Cook, SJ, Phelps L, Kwan. (2017). "Pregnancy outcomes for rural women with gestational diabetes: A retrospective audit", Paper presented to the ADIPS/SOMANZ Joint Annual Scientific Meeting, Canberra, 20 - 22 October

<sup>56</sup> Luccisano, S. P., Weber, H. C., Murfet, G. O., Robertson, I. K., Prior, S. J., & Hills, A. P. (2021). An Audit of Pre-Pregnancy Maternal Obesity and Diabetes Screening in Rural Regional Tasmania and Its Impact on Pregnancy and Neonatal Outcomes. *International journal of environmental research and public health*, 18(22), 12006. <https://doi.org/10.3390/ijerph182212006>

<sup>57</sup> Kirke, A. B., Atkinson, D., Moore, S., Sterry, K., Singleton, S., Roxburgh, C., Parrish, K., Porter, C., & Marley, J. V. (2019). Diabetes screening in pregnancy failing women in rural Western Australia: An audit of oral glucose tolerance test completion rates. *The Australian journal of rural health*, 27(1), 64-69. <https://doi.org/10.1111/ajr.12465>

***Recommendation: Introduce a Gestational Diabetes Management Plan MBS item number that would allow women diagnosed with GDM to access up to five visits from allied health professionals including credentialled diabetes educators, accredited practising dietitians and exercise physiologists***

***Recommendation: Support a national continuous quality improvement process for GDM to include regular review of guidelines and models of care including telehealth and workforce development models***

***Recommendation: Support a national healthcare professional education/competency program for all healthcare professionals involved in any aspect of diabetes in pregnancy care including pre-pregnancy***

### ***Supporting women post-pregnancy***

Appropriate post-pregnancy care is essential to improving short and long-term health outcomes for mother and child. There is a clear need for programs assisting women diagnosed with GDM in reducing their risk of developing GDM in subsequent pregnancies and developing type 2 diabetes in the future.

The National Gestational Diabetes Register (NGDR) is a register of all women in Australia who have been diagnosed with GDM. It was established in 2011 and is administered by Diabetes Australia as part of the NDSS as an opt-out model. All registrants are sent annual reminders to have type 2 diabetes checks for five years after their GDM diagnosis. There are opportunities to strengthen this essential piece of health infrastructure to help support Australian mothers reduce their risk of developing type 2 diabetes and cardiovascular disease.

For instance, there is a clear need for programs that help women diagnosed with GDM to reduce their ongoing risk of developing type 2 diabetes. These interventions could be embedded within an optimised and strengthened NGDR.

***Recommendation: Optimise and strengthen the NGDR including building strong connections with scaled up Type 2 Diabetes Prevention Programs to ensure all mothers diagnosed with GDM can access programs later in life***

### ***Women with pre-existing diabetes during pregnancy***

Women with pre-existing diabetes in pregnancy (type 1 diabetes, type 2 diabetes and “other types of diabetes”) are at a much higher risk of serious pregnancy and birth complications than

women who do not have diabetes in pregnancy.<sup>58,59</sup> This includes rates of major congenital malformations of about 16% (compared to about 2% in the broader population), a four times higher risk of pre-eclampsia and a four times higher risk of stillbirth. Even without complications these are highly complex pregnancies that require intensive support before, during and after pregnancy.

There are also serious long-term risks including the fact that children born to mothers with pre-existing diabetes are at a higher risk of developing type 2 diabetes and obesity later in life. This means diabetes can become an intergenerational condition. High-quality healthcare and support can reduce the risk to mother and baby.

Pre-pregnancy planning and care is essential for all women living with diabetes looking to become pregnant and there is significant evidence for this care reducing adverse outcomes.<sup>60</sup> While there is some anecdotal evidence that these conversations occur between some women with type 1 diabetes and their endocrinologists, the conversations are even less frequent in primary care, where most women with type 2 diabetes access healthcare. It is essential all women living with pre-existing diabetes are involved in planning pregnancies with their healthcare teams.

The best outcomes for women with pre-existing diabetes during pregnancy occur in hospitals with obstetrics expertise in supporting this specific group. Unfortunately, it is difficult for all women with pre-existing diabetes during pregnancy to access this highly specialised care.

Another area where can be included is by expanding access to fully subsidised CGM to women living with type 2 diabetes and “other types of diabetes” who current do not have access to this technological support. This technology places a key role in helping women maintain tightly managed blood glucose levels which reduces the risk of pregnancy complications.

There is also a need for a comprehensive register to track pregnancy outcomes among women with pre-existing diabetes, including their level of diabetes-specific pre-pregnancy planning. This would help identify services providing optimum care as well as identifying areas which require additional support.

***Recommendation: Provide accessible pre-pregnancy programs to women with pre-existing diabetes. GPs should be encouraged to review contraception and pregnancy plans as part of routine care for women living with pre-existing diabetes who are considering pregnancy***

***Recommendation: Establish a Pre-existing Diabetes in Pregnancy Register to track pregnancy outcomes among women with diabetes***

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<sup>58</sup> Macintosh MCM, Fleming KM, Bailey JA et al. 2006. Perinatal mortality and congenital anomalies in babies of women with type 1 or type 2 diabetes in England, Wales, and Northern Ireland: population based study. *British Medical Journal* 333(7560):177–182.

<sup>59</sup> Negrato CA, Mattar R and Gomes MB 2012. Adverse pregnancy outcomes in women with diabetes. *Diabetology and Metabolic Syndrome* 4:41. Available at <https://doi.org/10.1186/1758-5996-4-41>

<sup>60</sup> Wahabi, H.A. et al. (2020) ‘Systematic Review and meta-analysis of the effectiveness of pre-pregnancy care for women with diabetes for improving maternal and perinatal outcomes’, *PLOS ONE*, 15(8). doi:10.1371/journal.pone.0237571.



***Recommendation: Extend subsidised access to Continuous Glucose Monitoring to all pregnant women with diabetes using insulin***

## Other Types of Diabetes

There are a number of other, less common and less well-known types of diabetes that are generally grouped together under “Other types of diabetes”. This includes maturity onset diabetes of the young (MODY), latent autoimmune diabetes in adults (LADA), Type 3c diabetes (which occurs when another disease, such as pancreatitis damages the pancreas) or cystic fibrosis-related diabetes.

There are 12,187 Australians living with “other types of diabetes”.<sup>61</sup> This has increased around 110% over the past 10 years from 5,795.<sup>62</sup>

In many cases, people living with “other types of diabetes” have similar management requirements, including multiple daily injections of insulin, to people living with type 1 diabetes and should be supported to access the same essential technologies and medicines. The need to support people in this cohort to access life-saving and life-changing technology is outlined in our submission *Improving access to diabetes-related technology and medicines*.

## Priority Groups

While diabetes impacts people of all ages and backgrounds there are certain demographic groups where the prevalence of diabetes or the risks of complications are much higher. Additionally, there are certain ages and stages of life and of diabetes management when a person’s health needs and support required are more significant. These groups include older Australians, people from culturally and linguistically diverse communities, Australians living in rural and remote areas, people living with mental health challenges, people living with a disability and children and young people.

Aboriginal and Torres Strait Islander Australians are also a priority group. Because of the scale of the impact diabetes has on this population, the issues are expanded upon in Diabetes Australia’s submission *Reducing the impact of diabetes on Aboriginal and Torres Strait Islander Australians*.

Goal 6 of the ANDS 2021-2030 outlines a number of key actions that would help reduce the impact of diabetes amongst priority groups.

### ***Older Australians***

More than 1 million Australians, or 67.5% of people living with diabetes, are aged 60 and over including more than 250,000 people who are aged over 80.<sup>63</sup> Additionally, the proportion of Australians who are aged 65 and over is expected to rise from 15% in 2017 to 23% in 2050.<sup>64</sup>

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<sup>61</sup> National Diabetes Services Scheme. NDSS Snapshots – All Types of Diabetes [Fact Sheet]. <https://www.ndss.com.au/wp-content/uploads/ndss-data-snapshot-202306-type2-diabetes.pdf>

<sup>62</sup> Ibid.

<sup>63</sup> Ibid.

<sup>64</sup> Australian Government. Australia to 2050: future challenges, the 2010 intergenerational report. 2010 Australian Government Canberra.



Over the next four decades the number of Australians aged 85 years and over will double.<sup>65</sup> This will drive a significant increase in the number of people living with diabetes in aged care.

### ***Aged care***

At least one in five people and one in four First Nations people currently living in residential aged care live with diabetes.<sup>66</sup> Many require specific diabetes management support and care that can differ between people living with type 1 and type 2 diabetes including special dietary requirements, assistance with glucose monitoring and help administering insulin. In many cases these needs are currently unmet. This can lead to very poor quality of life, unnecessary complications, avoidable hospitalisations, and premature death.

There is often a lack of awareness among aged care staff about the contribution of diabetes to other problems such as unexplained falls and urinary tract infections. This results in potentially avoidable transfers to hospital.

Additionally, Standard 3, Personal care and clinical care of the Aged Care Quality Standards, requires that all people in residential aged care can access safe and effective, best practice clinical care that is tailored to their needs and optimises their health and wellbeing, Sadly, when it comes to diabetes this Standard is rarely met.

A new national Diabetes In Aged Care training program for all aged care workers would improve the capability of aged care workers and service providers. A tiered training program, with training appropriately aligned to the level of care and support staff provide to people living with diabetes, is the most cost-effective way to upskill Australia's aged care workforce.

***Recommendation: Deliver a new National Diabetes in Aged Care training program for aged care staff to ensure all people living with diabetes receive essential diabetes-specific healthcare***

### ***Culturally and linguistically diverse communities***

Australians from some culturally and linguistically diverse backgrounds are at higher risk of developing type 2 diabetes than people from Caucasian backgrounds. This includes people from:

- Pacific Islands (i.e., prevalence in people born in Tonga - 17%, Samoa - 15%, Fiji - 14%)
- Middle East (i.e., Egypt - 14%, Iraq - 8%)
- South Asia (i.e., Sri Lanka - 11%, Myanmar - 8%)
- Africa (i.e., amalgamated southern and eastern Africa - 9%).<sup>67</sup>

We must ensure strategies are culturally appropriate and accessible and that education and management approaches are tailored to people's cultural preferences.

This includes ensuring resources for people living with diabetes are available in a variety of languages and that the diabetes workforce has the training and the language skills required to meet the needs of these communities.

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<sup>65</sup> Ibid.

<sup>66</sup> Australian Institute of Health and Welfare 2021. Aged care for Indigenous Australians. Viewed 30 November 2021, <https://www.aihw.gov.au/reports/australias-welfare/aged-care-for-indigenous-australians>

<sup>67</sup> AIHW. (2023) Chronic health conditions among culturally and linguistically diverse Australians, 2021.

***Recommendation: Raise awareness of the need to embed health literacy principles into all diabetes-related resources***

***Recommendation: Ensure diabetes resources and education are available in culturally appropriate formats in key languages***

***Recommendation: Upskill health professionals in Teach-Back principles to help ensure they understand if their health advice and diabetes education is understood by their patients***

### ***People living with disability and diabetes***

A little over 10% of Australians living with a disability are also living with diabetes.<sup>68</sup> Care could be improved by ensuring disability support workers are appropriately trained to support people living with diabetes, particularly people who are unable to self-administer insulin or appropriately monitor their diabetes themselves.

***Recommendation: Improve training for disability support workers supporting people living with disability and diabetes***

### ***Australians living in rural and remote areas***

People living in rural and remote areas are more likely to live with diabetes and more likely to develop diabetes-related complications. For instance, hospitalisation rates for diabetes are almost three times higher for people living in remote Australia compared to people living in major cities<sup>69</sup> and mortality rates are about twice as high.

Diabetes Australia's National Community Consultation Survey found that 40% of people in regional areas reported difficulties in accessing appointments with their GP or other health professionals.<sup>70</sup> This leads to poorer access to medicines and diabetes management.<sup>71</sup>

***Recommendation: Improve case conferencing arrangements to ensure all rural and remote general practices have access to diabetes care and management by an endocrinologist and/or CDEs in private practice or tertiary diabetes centres. This can improve patient care and provide opportunities to upskill.***

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<sup>68</sup> Brown M, Taggart L, Karatzias T et al. 2017. Improving diabetes care for people with intellectual disabilities: a qualitative study exploring the perceptions and experiences of professionals in diabetes and intellectual disability services. *Journal of Intellectual Disability Research* 61(5):435-449. Available at <https://doi.org/10.1111/jir.12369>

<sup>69</sup> Diabetes Facts [National Diabetes Statistics Report | Diabetes | CDC](#)

<sup>70</sup> Diabetes Australia. 2023. Top line report: Diabetes National Community Consultation. Where To: Victoria.

<sup>71</sup> Morton et al. The association of socioeconomic disadvantage and remoteness with receipt of type 2 diabetes medications in Australia: a nationwide registry study. *Diabetologia* 2020; 64(2): 349–360. doi:10.1007/s00125-020-05304-3

***Recommendation: Ensure all Australians have access to telehealth through improved internet access to ensure people have equitable access to CDEs and endocrinologists***

***Recommendation: Increase investment in remote and regional health and diabetes workforce to attract new staff and bolster staff retention in these areas***

## Diabetes and Primary Care

Co-ordinated, high quality multidisciplinary primary care is best practice diabetes care. According to the ANDS 2021 – 2030 this is achieved when “health care professionals work seamlessly and in partnership across primary health, allied health, community and specialist care services with direct consumer (the person with diabetes), carer and family involvement ... it requires a transformation in the way care is delivered in order to make it more consumer focused, team based and proactive.”

A person’s multidisciplinary diabetes care team may consist of:

- the person’s GP, for general health and diabetes management;
- a credentialed diabetes educator (CDE), who should be at the centre of every person’s diabetes care team to provide expert diabetes education and care and to support the GP in ensuring the person’s diabetes is optimally managed;
- an endocrinologist/diabetologist depending on the type or complexity of the person’s diabetes;
- a dietitian; and
- a number of other allied health professionals depending on the person’s needs, which can include pharmacist (for those using diabetes medication/s), podiatrist, optometrist, exercise physiologist, psychologist and other allied health professionals as needed.

The complexity of diabetes necessitates a team-based approach to reducing a person’s risk of serious, and sometimes life-threatening, complications.

The key relationship and referral pathway in the multi-disciplinary team is between the GP, as the central primary care provider and coordinator of care, and CDEs and endocrinologists.

While GPs are the central primary care providers, Australia’s GP workforce is insufficient to the scale of Australia’s growing population of people and chronic disease epidemic. Nor should they be expected to have the expert knowledge needed to manage some of the most complex conditions in isolation.

### ***Credentialed diabetes educators***

A CDE is a qualified health professional who has completed a post graduate qualification specialising in diabetes. A CDE is required to meet a range of professional standards as part of their annual accreditation process. They can play a key role in alleviating the burden on GPs and equipping people living with diabetes with the skills needed to effectively self-manage the

condition. This has been shown to help reduce the risk of diabetes-related complications and, in turn, the economic impact on health systems.<sup>72</sup>

There are approximately 2000 CDEs in Australia; however, only 27% are providing full-time diabetes services. Many people in regional and remote areas report difficulties accessing CDEs, with most based in metropolitan areas. This suggests that there is significantly more workforce capacity available; however, the lack of financial incentives, barriers to telehealth, and absence of clear referral pathways mean it is chronically underutilised.

### ***Endocrinologists/diabetologists***

An endocrinologist is a specialist in the treatment of conditions involving the endocrine system. Many endocrinologists specialise in diabetes and can be referred to as diabetologists.

Endocrinologists/diabetologists provide care to people living with diabetes when they require complex care and there is disease progression with difficult to manage blood glucose levels and diabetes-related complications. A recent ADS and ADEA survey found that very few endocrinologists/ diabetologists provide full-time diabetes services (4%). The majority of endocrinologists/ diabetologists provide diabetes services for 11 to 20 hours per week. The lack of access to endocrinologists/diabetologists is particularly acute in regional and remote areas, despite these areas having a higher prevalence of diabetes.

### ***Impact of diabetes on general practice***

People living with diabetes aged 45 and over in metropolitan areas visit a GP around 4.63 times per year, in regional areas around 4.03 and in remote and very remote areas around 4.32.<sup>73</sup> This is significantly more frequent than people without diabetes or diabetes risk factors who visit a GP 2.88 times (metropolitan), 2.43 times (regional) and 2.43 times (remote and very remote).

Another study from 2012-13 found that more than 15% of frequent users of GPs (12 to 19 visits per year) were found to be living with diabetes.<sup>74</sup> Concerningly, the same review found that frequent users were much more likely to see different GPs, with the highest users averaging 4.8 different GPs in a year. This has significant implications for continuity of care which is essential for effective diabetes management.

### ***Access to care***

Diabetes self-management is complex and can require people to make more than 180 diabetes-related decisions per day. Consequently, diabetes education is critical and should start as soon as possible.

Every person with diabetes should be referred by their GP to a CDE at diagnosis to ensure they fully understand the condition and can self-manage it. They should also be referred for follow up CDE visits at regular intervals and key life moments/diabetes transition points, where additional

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<sup>72</sup> Whitehouse, C.R. et al. (2021) 'Economic impact and health care utilization outcomes of diabetes self-management education and support interventions for persons with diabetes: A systematic review and recommendations for Future Research', *The Science of Diabetes Self-Management and Care*, 47(6), pp. 457–481. doi:10.1177/26350106211047565.

<sup>73</sup> Mazumdar S, Bagheri N, Chong S, McRae IS, Jalaludin B, Giroso F. Diabetes and the use of primary care provider services in rural, remote and metropolitan Australia. *Rural and Remote Health* 2021; 21: 5844. <https://doi.org/10.22605/RRH5844>

<sup>74</sup> National Health Performance Authority 2015, *Healthy Communities: Frequent GP attenders and their use of health services in 2012–13*.

education and support may be required such as pregnancy planning or the commencement of insulin or technology.

Analysis of recent MBS data has revealed that the majority of people living with diabetes are not accessing MBS-subsidised CDE diabetes education and care via GP Management Plans. For example, in 2022-23 MBS provided 3.5 million rebates for podiatry services, but only 87,000 rebates for CDE visits, or about one visit for every 17 people living with diabetes.

This may be because a person's GP has not completed an Annual Cycle of Care Plan and/or because the GP has not provided a referral to a CDE through a GP Management Plan.

There is a considerable amount of important and cost-effective diabetes-related care that lacks MBS item numbers. As a result of this, the only means of accessing this care is via people paying for it out of their own pocket. More than two-thirds of people living with diabetes are aged 60 or over and many are managing multiple co-morbidities, which limits their capacity to pay, leading many people to forgo care.

***Recommendation: Access to CDE healthcare could be expanded by requiring private health insurance to cover structured diabetes education delivered by a CDE for every person living with diabetes or pre-diabetes***

## Reforming Primary Healthcare

The Australian Government is currently reforming Australia's healthcare system to ensure it is aligned with the needs of our current population and the current burden of chronic disease. Many of the key reform initiatives were outlined in the Strengthening Medicare Taskforce Report released earlier this year with some being allocated funding in the 2023-24 Federal Budget. Reforms which can substantially help people living with all types of diabetes are voluntary patient enrolment (VPE), blended payments (rather than the existing fee-for-service model) and ensuring health professionals are working to their full scope of practice.

### ***My Medicare***

My Medicare, the VPE initiative announced in the 2023-24 Federal Budget, has the potential to improve continuity of care and drive investment in preventive care which improves health outcomes and reduces a person's risk of diabetes-related complications. Studies have found that VPE is associated with improvements in rates of a number of Annual Cycle of Care checks including HbA1c, cholesterol and heart health.<sup>75</sup>

### ***Blended Payments***

Australia's current fee-for-service primary health care model was designed to support people with acute health issues, not ongoing chronic disease management. As well as the need for longer consultations for people with complex health needs and multiple co-morbidities, there is a requirement for funding models that reimburse other essential chronic care as well as incentivising preventative care.

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<sup>75</sup> Bamimore, M.A. et al. (2021) 'Quality of diabetes care in blended fee-for-service and blended capitation payment systems', Canadian Journal of Diabetes, 45(3). doi:10.1016/j.jcjd.2020.09.002.

For instance, ongoing monitoring of blood glucose data, provided via diabetes technology and completed outside of appointments, supports early detection of emerging health issues and can guide interventions to reduce the impact of a range of diabetes-complications. This work can be batched and done for multiple patients at making it highly cost-effective but currently there is no reimbursement available.

Diabetes Australia supports a blended model that combines both block payments for practices as well as fee-for-service reimbursement. The block funding should incentivise annual cycle of care checks, early interventions to prevent diabetes-related complications and other key preventive health measures.

Royal Australian College of General Practitioners President Dr Nicole Higgins has highlighted the Danish health system “which is 70% fee for service and 30% block funding, where the GP leads a multidisciplinary care team ... [as] the happiest and healthiest healthcare system.”<sup>76</sup>

### ***Integrated Health Checks***

A new Integrated Health Check collecting baseline health data from enrolled patients, who are registered with My Medicare, would serve a number of purposes including driving My Medicare enrolment and providing baseline health data for individuals and practice populations.

The health check could include core indicators such as HbA1c, blood pressure, weight and cholesterol. Improvements against these indicators, on a practice population level, could form the base of blended payments.

Additionally, this data could also help inform emerging population health AI-driven screening programs that have the capacity to check a range of patients.

### ***Unleashing the Potential of our Health Workforce Review***

Health Minister Mark Butler recently announced the Unleashing the Potential of our Health Workforce to examine ways of ensuring Australia’s health professionals are working to their full scope of practice.

Scope of practice refers to the activities a health professional is permitted to perform within their profession. Those activities are based on legislation and regulations (Federal and State), as well as education, training and experience.

Diabetes Australia, the Australian Diabetes Society and the Australian Diabetes Educators Association fully support this Review and look forward to contributing to reforms that will assist Australia’s CDE workforce work to their scope of practice which will help make a career as a CDE more financially viable, reduce pressure on general practice and make it easier for people to access high quality CDE care.

***Recommendation: Align My Medicare with blended payments to incentivise and support GPs and other primary care providers to enhance preventive care for people living with diabetes***

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<sup>76</sup> Attwool, Jolyon. “Government flags shift in fee-for-service model” newsGP <https://www1.racgp.org.au/newsgp/professional/government-flags-shift-in-fee-for-service-model#:~:text='One%20of%20the%20best%20models,'>

***Recommendation: Fund a new Integrated Health Check to enable general practices to establish baseline health markers for patients living with and at risk of diabetes as well as supporting the introduction of blended payments and the launch of My Medicare***

***Recommendation: The National Scope of Practice Review should work towards recognising CDEs as a single, national profession with its own scope of practice rather than individual practitioners being identified by, and have their scope limited to, their underlying health profession. CDEs receive appropriate education and training in diabetes education, management and care and should be able to work to their full scope of practice, but are often limited by legislation and regulations to the scope of practice of their underlying profession***

### ***Improving access to credentialled diabetes educators***

There are significant opportunities for Australia to improve the quality of care provided to people living with diabetes by better utilising CDEs. For instance, by reforming MBS item numbers to support longer consultations.

Currently the majority of CDE diabetes care is provided through Item 10951 which covers a 20-minute appointment. While this may be useful for acute care, it is not suited to providing the majority of care and diabetes education, particularly at key transition points essential to supporting diabetes self-management.

A 2020 ADEA-ADS Workforce Survey found that the average CDE appointment ranged in length from 27 minutes for a follow up appointment for a person living with prediabetes to 69 minutes for a person recently diagnosed with type 1 diabetes. Across the 10 categories of appointment surveyed, only three categories had an average appointment time of less than 30 minutes (all were follow-up appointments) while five categories had an average of 45 minutes or more per appointment.

### ***What's missing?***

One area where people living with diabetes require greater support is accessing allied health support. This theme has echoed throughout the submissions made to the Parliamentary Inquiry, informal consultation as part of Australia's Biggest Conversation about Diabetes run by Diabetes Australia through National Diabetes Week and our consultation survey.

The major support people feel they are missing out on is expert dietetic support. As outlined above, there is an urgent need for increased access for people living with prediabetes, but this extends to people living with all types of diabetes who will require ongoing nutritional support throughout life. The level of support required may vary but it is essential that people receive individualised and tailored advice.



***Recommendation: A new MBS item number for longer CDE appointments that can be utilised for key moments including initial appointments for diabetes education and care and key transition points such as the initiation of insulin and commencement of continuous glucose monitoring. These are all complex consultations requiring time to supply adequate education and respond to questions***

***Recommendation: Extend the existing 20-minute consultation to 30 minutes for follow-up appointments to better reflect an average CDE follow-up appointment***

***Recommendation: Implement a Newly Diagnosed Diabetes Education Plan that entitles a person to up to four visits with a Credentialed Diabetes Educator***

***Recommendation: Increase Chronic Disease Management Plan visits from 5 to 10***

***Recommendation: Expand access to My Health Record to include members of a person's multidisciplinary diabetes care team to support more efficient and effective diabetes care, reduce duplication and remove barriers to access and coordination***

## Complications

Diabetes-related complications, including blindness, heart conditions, chronic kidney disease, limb amputation, dementia and stroke are one of the most debilitating and costly impacts of diabetes. The prevalence and impact of many of these complications has been highlighted above.

These complications significantly impact on people's quality of life and place a major cost burden on our health system. Research has found that the direct costs of supporting a person living with diabetes more than doubles to \$9,600 compared to \$3,500 for a person without complications once complications develop.<sup>77</sup>

Most diabetes-related complications can be prevented or delayed if detected early when treatments are most effective. This is why preventing diabetes-related complications is a major opportunity in the response to the diabetes epidemic.

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<sup>77</sup> Lee C, Colagiuri R, Magliano D et al. 2013. The cost of diabetes in adults in Australia. *Diabetes Research and Clinical Practice* 99:385–390.



## **Existing complications preventions program**

In recent years Australia has made good progress in preventing diabetes-related complications by funding two programs: Keepsight and FootForward.

*KeepSight* is a diabetes-related eye check reminder program. Funded by the Federal Government as a public-private partnership with Specsavers, people enrolled with the program receive reminders when they are due for a diabetes eye check. It is modelled on the National Health Service Diabetic Eye Screening Programme in the UK which has reduced diabetes-related blindness so significantly that diabetic retinopathy is no longer the leading cause of blindness in working age Britons.<sup>78</sup> One in five Australians (325K) living with diabetes in Australia are currently registered with KeepSight, 20% of these people are considered at high risk and likely to see the greatest benefit from the program. Enrolments continue to increase year-on-year for this highly successful program.

*FootForward for diabetes* is an information and education program funded by the NDSS and delivered by Diabetes Australia and the Australian Diabetes Society. It is a coordinated and integrated program which promotes early self-identification of foot problems and early access to health professionals and high-risk foot services to reduce the incidence of people with diabetes presenting with serious foot complications.

## **Diabetes-related kidney disease**

Diabetes-related kidney disease is one of the most widespread and, potentially most debilitating and costly, diabetes complications. An estimated 330,000 Australians living with diabetes have chronic kidney disease.<sup>79</sup> Around 10,000 people in this cohort will experience kidney failure and require dialysis or a kidney transplant.<sup>80</sup> This is about 37% of the total number of people experiencing kidney failure.<sup>81</sup> It is estimated diabetes-related kidney disease costs the Australian economy around \$2.68B a year.<sup>82</sup> Kidney failure accounts for around \$1.9B of this cost.<sup>83</sup> This has a huge impact on hospital capacity as people living with diabetes requiring dialysis account for around 5% of all hospitalisations.<sup>84</sup>

***Recommendation: Implement a National Diabetes Kidney Disease Screening Program that ensures all Australians living with diabetes get kidney checks within recommended timeframes.***

## **Heart disease**

Heart complications, including heart attacks, congestive artery disease, stroke and heart failure, are the most common diabetes-related complications and also a leading cause of death in

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<sup>78</sup> Scanlon, Peter.H. (2021) 'The contribution of the English NHS Diabetic Eye Screening Programme to reductions in diabetes-related blindness, comparisons within Europe, and future challenges', *Acta Diabetologica*, 58(4), pp. 521–530. doi:10.1007/s00592-021-01687-w.

<sup>79</sup> Kwok, R, MacIsaac, R, and Ekinci, E. (2023) *Change the Future: Saving Lives By Better Detecting Diabetes-related kidney disease*. Diabetes Australia, Australia.

<sup>80</sup> Ibid.

<sup>81</sup> Ibid.

<sup>82</sup> Ibid.

<sup>83</sup> Ibid.

<sup>84</sup> Ibid.

people living with diabetes.<sup>85</sup> However, heart complications can be prevented or delayed in many people if they are detected early when treatments are most effective.

There are emerging diagnostic checks that can accurately and efficiently predict an elevated risk of various heart conditions.

***Recommendation: Ensure all Australians living with diabetes and at elevated risk of heart complications can access the most effective and accurate diagnostic tools as soon as practicable.***

## **Mental health**

Almost half of Australians living with diabetes experience a mental and/or emotional health challenge every year.<sup>86</sup> While diabetes mental health challenges are widespread, they are rarely discussed as part of routine diabetes care and are sometimes referred to as a silent diabetes complication.

Mental and emotional health challenges can have a negative impact on diabetes management and make it more difficult for people living with diabetes to manage the condition which can lead to more variable glucose levels, increased risk of complications and hospital admissions. Conversely, appropriate mental health support has been shown to improve diabetes management, reduce the risk of diabetes-related complications and, consequently, lower the cost of healthcare.

Access to specialised diabetes mental health care can be difficult to secure with about 400,000 Australians living with diabetes reporting difficulties in accessing care. Barriers to access include the cost including the limited number of subsidised visits available under a mental health care plan, limited availability of trained healthcare professionals and a lack of mental healthcare professionals with specific training and expertise in diabetes-related mental healthcare.

***Recommendation: Ensure all Australians living with diabetes who experience diabetes-related mental health challenges can access support from mental health care professionals with appropriate diabetes-specific training.***

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<sup>85</sup> Baker Heart & Diabetes Institute, The dark heart of type 2 diabetes. 2018, Baker IDI: Melbourne.

<sup>86</sup> Diabetes Australia. 2020 Survey on the Mental and Emotional Impact of living with diabetes, Surveyed by: Orima Research. 6 July 2020.

# RECOMMENDATIONS

1. Develop a new implementation plan for the National Diabetes Strategy with clear timelines, funding and deliverables
2. Optimise the National Diabetes Services Scheme database to enable it to better provide recall and reminder notices to people living with diabetes to increase rates of preventive diabetes health checks
3. Fund education campaigns that raise awareness and understanding of all types of diabetes rather than propagating myths and falsehoods
4. Adopt the Diabetes Australia Language Position Statement as the agreed community standard when writing and speaking about diabetes
5. Ensure the reduction of diabetes-related stigma is a core consideration in the development of any new government policy or initiative
6. Australia urgently needs a national awareness campaign to increase community and health professional knowledge of the 4Ts to support earlier detection and minimise costly and dangerous hospitalisations
7. Expand access to Chronic Disease Management Plans to cover people living with prediabetes to support them to access expert evidence-based healthy lifestyle healthcare including nutrition, physical activity, stress management and sleep
8. Explore funded telehealth or evidence-based digital nutritional coaching as a low-cost method of significantly increasing access to dietetic support
9. Women at risk of developing Gestational Diabetes Mellitus should be able to access scaled up Type 2 Diabetes Prevention Programs (see type 2 diabetes submission) to help them achieve a healthy weight prior to pregnancy
10. Establish pre-pregnancy weight management clinics in selected maternity centres across the country
11. Introduce a Gestational Diabetes Management Plan item number that would allow women diagnosed with GDM to access up to five visits from allied health professionals including credentialled diabetes educators and accredited practising dietitians to help them manage the condition
12. Optimise and strengthen the National Gestational Diabetes Register including building strong connections with scaled up Type 2 Diabetes Prevention Programs to ensure all mothers diagnosed with GDM can access programs later in life
13. Deliver a new National Diabetes in Aged Care training program for aged care staff to ensure all people living with diabetes receive the necessary diabetes-specific healthcare
14. Raise awareness of the need to embed health literacy principles into all diabetes-related resources
15. Ensure diabetes resources and education is available in culturally appropriate formats in key languages
16. Upskill health professionals in Teach-Back principles to help ensure patients understand health advice and diabetes education
17. Provide accessible pre-pregnancy programs to women with pre-existing diabetes

18. Establish a Pre-existing Diabetes in Pregnancy Register to track pregnancy outcomes among women with diabetes
19. Extend subsidised access to Continuous Glucose Monitoring to all pregnant women with diabetes using insulin
20. Increase investment in telehealth and other digital health services to try and ensure more equitable access to appropriate, specialised care
21. Fund case-conferencing initiatives to support urban hospitals in upskilling rural and remote health providers
22. Align My Medicare with blended payments to incentivise and support GPs and other primary care providers to enhance preventive care for people living with diabetes
23. Fund a new Integrated Health Check to enable general practices to establish baseline health markers for patients living with and at risk of diabetes as well as supporting the introduction of blended payments and the launch of My Medicare
24. The National Scope of Practice Review should work towards recognising CDEs as a single, national profession with its own scope of practice rather than individual practitioners being identified by, and have their scope limited to, their underlying health profession. CDEs receive appropriate education and training in diabetes education, management and care and should be able to work to their full scope of practice but are often limited by legislation and regulations to the scope of practice of their underlying profession
25. A new Medicare Benefits Scheme item number for longer CDE appointments that can be utilised for key moments including initial appointments for diabetes education and care and key transition points such as the initiation of insulin and commencement of continuous glucose monitoring. These are all complex consultations requiring time to supply adequate education and respond to questions
26. Extend the existing 20-minute consultation to 30 minutes for follow-up appointments to better reflect an average CDE follow-up appointment
27. Implement a Newly Diagnosed Diabetes Education Plan that entitles a person to up to four visits with a Credentialed Diabetes Educator
28. Increase Chronic Disease Management Plan visits from 5 to 10
29. Implement a National Diabetes Kidney Disease Screening Program that ensures all Australians living with diabetes get kidney checks within recommended timeframes
30. Ensure all Australians living with diabetes and at elevated risk of heart complications can access the most effective and accurate diagnostic tools as soon as practicable
31. Ensure all Australians living with diabetes who experience diabetes-related mental health challenges can access support from mental health care professionals with appropriate diabetes-specific training