

DIABETES VICTORIA'S SUBMISSION IN RESPONSE TO THE PARLIAMENTARY INQUIRY INTO DIABETES

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1. INTRODUCTION

In the 15 minutes you will spend reading this document, three Australians will be diagnosed with diabetes. Currently, 1.5 million Australians (5.5% of the population) are living with diabetes¹. Alarming, if the growth rates of the past decade continue, by 2050 this figure will more than double to over 3.1 million (8.3% of the projected population).

Since 1953, Diabetes Victoria has been the leading peak body dedicated to reducing the impact of all types of diabetes on individuals, families, communities and health systems across Victoria. There are almost 400,000 Victorians living with diabetes. Most people in our community know someone with diabetes.

The impact of diabetes is of great concern in our community, as all types of diabetes are serious and can cause further health complications. Heart attack and stroke are up to four times more likely in people with diabetes. Moreover, diabetes is the leading cause of blindness in adults and a leading cause of kidney failure and amputation. Despite diabetes affecting 5.5% of the Australian population, it contributes to 11% of hospitalisations² and 11% of deaths.³

Approximately 30-50 percent of all people with diabetes experience diabetes-related distress, depressive symptoms or anxiety. This is because diabetes is a challenging and relentless condition to manage. There is no holiday from diabetes, it's a 24/7 condition. Around 4 in 5 people with diabetes have experienced some form of stigma due to diabetes, and up to 1 in 3 have experienced discrimination due to diabetes.⁴

In 2019-20, the cost to the Australian healthcare system attributed to diabetes was estimated to be \$3.1 billion, representing 2.2% of direct healthcare costs.² However, these are not the only costs. Indirect costs – including decreased productivity, work absences, early retirement, premature death – are estimated to be \$14 billion annually.

Diabetes has an unequal impact on our community. Aboriginal and Torres Strait Islanders are three times more likely to develop type 2 diabetes and its complications than non-Indigenous Australians. The risk of kidney failure due to diabetes is more than 10 times greater in Aboriginal and Torres Strait Islanders compared to non-indigenous Australians⁵. Diabetes is at least twice as common among those living in regional/remote areas or living in households with the lowest incomes. Diabetes is 30 times more common among those over 80 years of age than those under 40 years⁶.

All types of diabetes are growing at an unprecedented rate. Around 320 people develop diabetes every day in Australia, making it the fastest-growing chronic condition in the country. In addition to the 1.5 million Australians living with diabetes, it is estimated that a further 2.5 million people in Australia may have pre-diabetes⁷ (i.e. metabolic risk factors for type 2 diabetes) and more than 500,000 may already be living with undiagnosed diabetes.⁸

We see a future where diabetes can do no harm. Despite the many challenges, we do see a bright future where people with diabetes live well and longer and are empowered to manage their diabetes their way, free from stigma and discrimination. We see a future where there is a cure for, or prevention of, all types of diabetes. This drives our work every day.

This inquiry is an important opportunity to achieve a brighter future, and to ensure that the Australian government's goals related to population-based prevention and management of diabetes align with the unmet needs and priorities of people living with or affected by diabetes, combining these in state and national strategies and plans. When considering how to improve diabetes care and outcomes there is no evidence more important than the voices of those with lived experience.

To inform our submission, we invited contributions from the Victorian community to illustrate what life is like for people living with or affected by all types of diabetes. The responses we received highlight the most

prevalent challenges facing our community and the issues that matter most to them. Access to quality care is at the heart of their shared stories. Barriers to care include factors such as cost, geography, language, technology, and a lack of accessible primary care, including mental health support. The importance of research and translation of research into real-world solutions is a priority for our community, as is building greater public awareness of risk factors and prevention and changing the conversation in relation to stigma and discrimination. We heard about interactions and experiences that positively impacted people's lives, including education programs and resources that empower people to self-manage their condition, as well as enabling and encouraging support networks.

Achieving a brighter future for people living with or affected by diabetes requires a massive step change in many aspects. This includes reforming the way diabetes care is provided and integrated within the healthcare system and funded by the government. It also requires massive societal change and a concerted effort towards promoting health for all from an early age and preventing diabetes complications through early screening. Timely and affordable access to management support, treatments and technologies is vital. Equally important is the need to comprehend and address the emotional and mental health impact of living with diabetes 24/7.

Diabetes Victoria welcomes the opportunity to work with all levels of Government and the community on programs and innovations to reduce the impact of diabetes on the people who live with this condition and on the Australian health system.

The stories and evidence that follow address all five of the inquiry's Terms of Reference.

For further information or to discuss this submission, please contact Glen Noonan: CEO of Diabetes Victoria at gnoonan@diabetesvic.org.au.

2. PORTRAIT OF A LIFE WITH DIABETES

The stories below are fictional. They reflect *real* experiences of people who have generously shared with us what their life with diabetes looks like.

Following each story, we imagine what ‘A Bright Future’ could look like with improved access to existing programs and services, the implementation of state and national strategies to remove barriers, integrated models of quality healthcare and more of the recommendations we present in this submission.

Each story is supported with quotes directly from people who contributed to our Inquiry community consultation. We work to amplify their voices every day.

I AM AT RISK OF DEVELOPING TYPE 2 DIABETES

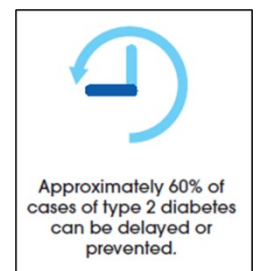
My name is Mick, I’m a proud Aboriginal man and live on country in a small town in Northern Victoria. My mum, my dad and my younger brother all have type 2 diabetes and I’m at high risk of developing it too. The doctor called it pre-diabetes. My parents don’t talk about their diabetes – I think they’ve experienced a lot of judgement and shame.

I’m trying to watch what I eat now and eating less processed foods, but finding fresh food options can be difficult where I live, so I often end up eating take-away food – it’s a lot cheaper too. I’ve struggled to get into a good routine and getting back outside since COVID, I found the lockdowns de-motivating. I’ve tried to start walking or riding around town instead of driving but my friends live way out of town so it can be hard. I’m 45 years old and some habits are hard to shift, but I think these small changes might be making a difference. It’s not easy to stay consistent, but I figure it’s worth it to stay on this side of diabetes.

I don’t go to the doctor unless I’m sick. When I do try to make an appointment, there is a long wait time because there is only one part-time doctor in this area who I feel comfortable with. I often decide it’s not worth the wait, especially as it’s so expensive. Last time I visited the doctor he told me I was at high risk of diabetes, but he didn’t provide me with much information, only suggested I clean up my diet.

DID YOU KNOW. Aboriginal and Torres Strait Islander Australians are three times more likely to develop type 2 diabetes than non-Indigenous Australians and are 4.3 times more likely to be hospitalised with type 2 diabetes.

Rate of hospitalisations for diabetes is higher for Aboriginal and Torres Strait Islander Australians living in remote than in non-remote areas².



A Bright Future

Mick hears about something called the *Life!* program – a prevention program for those at risk of type 2 diabetes and cardiovascular disease. He starts the free, 12-month group course and finds that he begins making some sustainable changes. Mick feels great and his overall health continues to improve. He speaks with a *Life!* facilitator, who provides advice on how to interpret the confusing labels on food in the supermarket. The *Life!* program’s physical activity session motivates Mick to schedule regular physical activity in his week, so he doesn’t rely on the occasional walk to keep his body moving. His motivation dips a few months after starting the program, but the other people he meets during the program support him to get back on track. Peer support has been important for Mick to stay focused on his goals.

Mick has re-connected with his local Aboriginal Community Controlled Health Organisation, which provides holistic care and regular affordable access to a General Practitioner and Aboriginal Nurse. These health professionals have completed the 'Diabetes Yarning' training and can help explain the social and cultural context of diabetes and the behavioural, socio-cultural and biomedical factors that contribute to the development of type 2 diabetes. This culturally specific information also helped Mick understand why it may have been so difficult for his parents to speak about their diabetes journey and gave him the confidence to share what he'd learned and support his broader family with managing their diabetes.

Since 2007, 80,000 Victorians have commenced the *Life!* program

Life! is the largest evidence-based prevention program of its kind in Australia. *Life!* is a free program designed to support adults to reduce their risk of developing type 2 diabetes, heart disease and stroke, by developing and integrating healthy habits into their lives, including healthy eating, physical activity and effective stress management. Facilitated by health professionals, the program is delivered as a group course or telephone health coaching service. The *Life!* program is funded by the Victorian Government.

"The best parts about the Life! program for me, were learning about healthy choices such as food intake, learning what to eat and when is the best time to eat, how to read food labels, easy exercises, and how to make gradual changes."

"During the program I also learnt that perseverance is very important. For example, I now push myself to exercise even when I am tired or there are minor changes in the weather."

"Before I found the Life! program I found minimal reliable information... The Life! program has best supported me in managing my prevention journey."

We Are Listening. Every Voice Matters:

"My daughter has the probability of developing type 2 diabetes. Medically she has fallen through the cracks of our health system."

"I was simply told I was at risk of type 2 diabetes and then left to flounder."

"The rise in type 2 diabetes indicates that as a society we aren't putting enough time/resources into the prevention space."

"I am very fortunate to have access to medical specialists. Many don't! Especially when endocrinologists and psychologists cost around \$250 a visit (Medicare rebate now negligible!)."

多举办预防2型糖尿病学习班，并已患糖尿病有新的治疗及药物进行宣传，使我们能了解新方法，延缓并发症发生。

("Hold more training classes on the prevention of type 2 diabetes, and publicise new treatments and drugs for diabetes, so that we can understand new methods and delay the occurrence of complications.")

"This is a serious issue and a prevention program can help, however there needs to be access in an ongoing capacity."

"In order to reduce the government health expenditure dollar in this area, prevention is always better than cure. Funding for preventative measures is critical to reduce the risk at a personal level and to reduce the costs and burdens on the whole community."

"I have a great GP but getting an appointment to see him is really hard..."

"When I was given a "pre-diabetic" result for a blood test I had over 15 years ago, I did not really know or understand what that meant. Perhaps, if I had known what that meant or how I could have worked towards changing that outcome."

I AM A YOUNG ADULT LIVING WITH TYPE 1 DIABETES

My name is Eliot and I live with type 1 diabetes. I'm 19 years old.

Sometimes, living with diabetes feels like too much. I've moved out of home to go to university and I'm working part-time, so I've got a lot on. I'm taking on my own diabetes management these days. My parents used to do a lot of my day-to-day stuff with me. Mum still worries, but I just tell her everything's fine, even though I often forget to do things like dose myself before bed without her reminding me. My friends are all going out a lot, but I need to think about my diabetes when I do, as the food and drinks can spike my blood sugar if I'm not careful. I hate that I'm constantly thinking about these things and making calculations while everyone else gets to live a normal life. I know I have people in my life who care about me, but they don't understand how relentless and exhausting this condition is. I often feel isolated, and my mental health isn't great.

When I was 12, I went to a diabetes camp and it was amazing – I met other people like me, and I felt “normal” for the first time. I'm still friends with a few of those people, but there is no camp for people my age and I don't really know what else I can do to get extra support or connect to people in the same position as me. The one peer support group in my area is made up of older people and it's hard for me to relate to them.

I've started paying for my own diabetes gear now that I'm working, but it's a lot! I've had a continuous glucose monitor (CGM) since they were subsidised back in 2017, so I'm lucky like that, but other supplies aren't cheap. Going to the doctor is confusing and expensive too – I used to see a different doctor and endocrinologist when I was a kid, but since I moved out of the paediatric system, I have found it confusing. They have long wait lists and between work, uni and trying to have a social life, I don't see them as often as I should. Also, I'm reluctant to make appointments as they're expensive, and it can be hard for me to manage on my wage.

Sometimes I try to ignore my diabetes. I don't tell people if I don't have to because it makes them uncomfortable – lots of people don't understand what type 1 diabetes is. Even at university I have trouble bringing my CGM reader into the exam room at times – it's so embarrassing and makes me feel like I'm doing something wrong. One year, at a friend's birthday party, his mum wouldn't let me have any cake. If I had a dollar for every time I've been told, “you can't eat that, you've got diabetes” – well, I'd have enough for my diabetes supplies for a while!

DID YOU KNOW. Most teenagers with type 1 diabetes have never met another person with type 1 diabetes. Yet, evidence shows that meeting others experiencing similar challenges is an important component of acceptance, adjustment, and self-management of diabetes.

Transition to adult care is a significant issue for young people. In fact, in the 2012 Diabetes Australia Youth Transition Survey, it was revealed that almost half (49%) of the 17 to 24-year-olds and 71% of the 14 to 17-year-olds had never discussed transition to an adult service with their healthcare professional³.

I AM THE PARENT OF A YOUNG ADULT LIVING WITH TYPE 1 DIABETES

I'm Eliot's mum and I still worry a lot. Eliot's a good kid, and I know they're making good decisions, but type 1 diabetes is a relentless, 24/7 condition – it's hard to be in a position where you're not helpful anymore. It's been a real process learning how to let go in this “young adult” phase.

Eliot was diagnosed at the age of two. I didn't go back to work so I could always be ready to help where I could. Eliot didn't go to childcare because I couldn't find a centre to provide for the needs of a kid with type 1 diabetes. Our kinder educators were great, but they weren't trained either, so I was always there to check their glucose and give insulin throughout the day. I used to go into Eliot's room several times each

night to watch them sleep, and to check their blood glucose levels. I went to all the school sports carnivals and special events, always with my diabetes kit and jellybeans in tow.

I remember when Eliot went to diabetes camp, in Year 6, which had been a tough year for a bunch of different reasons. I remember how much they loved it and made so many special friends – some are still friends to this day – and when Eliot left camp they walked just a little lighter. I'll never forget that moment. I don't like to make it about us, but being a support person for someone living with diabetes is also a role worth acknowledging I think, and those two nights they were away at camp were just what we needed to reset at home. It wasn't like a sleepover with friends. They were safe, with health professionals trained in diabetes care, so we could switch "off". That was a real luxury for us. Eliot will never have that, but the CGM has made a huge difference.

A Bright Future:

In 2024, Eliot learns about the Future Leaders Program at Diabetes Victoria. The program brings young people together to develop their leadership skills, learn more about the physical elements of diabetes management, and how to support their own mental health, but mainly to provide a safe space to share their experiences with similar people.

"The program taught me not to be as self-conscious when talking about my diabetes or giving insulin in public. It really helped me to watch a room full of people give themselves insulin before eating without feeling ashamed."

At the Future Leaders camp and throughout the program, Eliot connects with other young people with similar experiences and challenges; they develop leadership skills and receive mentorship. The Leaders program also gives Eliot access to learn and share with diabetes professionals like dietitians and nurse educators. The Future Leaders group stay in touch, meaning Eliot is part of a peer support group and feels connected to people that get it.

Following the completion of the program, Eliot starts to meet with a psychologist to discuss diabetes burnout and other daily pressures of life as a young adult living with a chronic condition. Eliot's connection with others going through the same challenges have shown them that mental health support should be another part of routine diabetes care.

Later, Eliot is encouraged to attend a comprehensive self-management program called OzDAFNE where they can learn how to adjust their insulin to suit the timing, type and amount of food they want to eat. Developing these skills gives Eliot more freedom and choice to do the things they want.

Eliot's mum feels a little more settled these days, she sees the support Eliot is seeking and receiving and knows they have the tools to manage their diabetes in a way that supports their emotional and physical health. Eliot and their parents are happy to hear about a state and national plan following the Parliamentary Inquiry into Diabetes, which will improve their access to world-class diabetes management devices, supplies, healthcare and the resources Eliot needs to live well.

We Are Listening. Every Voice Matters:

"I did not attend diabetes camps when I was a child. They were available but I was too shy to attend. From everything I have heard in the past 30 years, I wish that I had attended as so many children and families seem to have had life-changing experiences."

"Increase access to mental health support for individuals living with type one diabetes... Increase education on the impact of poor mental health on diabetes management in diabetes educators, nurses, endocrinologists."

"It's life changing, it's tiring, confusing, complex and forever. Kids aren't able to process what it means to be permanent. It impacts families and stress related illnesses. It's scary, my child's life is in my hands and it's up to me to understand..."

“Prior to OzDAFNE I was doing a lot of ‘guesstimating’ – some educated and other parts not. After completing the OzDAFNE course I will be able to remove a lot of the guess work and take a more informed approach to my overall diabetes management which will lead to better control and more freedom.”

“I’m very grateful for the CGM subsidy by the government. Thank you. It changed my diabetes management and my life.”

“I could not retire when I wanted to because I had to pay for health insurance and CGM - I still have to pay a lot of money for insurance to keep access to an insulin pump.”

“This condition is permanent, it is relentless, and communication and stigma about Type 1 needs to change. That this condition is not about ‘control’ or good or bad - it is a daily challenge to maintain a healthy lifestyle...”

I AM A CHINESE IMMIGRANT. I’VE JUST BEEN DIAGNOSED WITH TYPE 2 DIABETES

My name is Lin and I’m 45 years old. I moved from China to Australia 5 years ago, so it’s still very hard for me to understand English. I speak Mandarin at home. A couple of months ago, I went to the doctor as I had a sore on my foot that was not healing, and I was having trouble walking. After looking at me closely and doing a few tests - my doctor told me I have type 2 diabetes.

The sore became infected, and I needed to spend a few nights in hospital. The doctors and nurses were friendly and tried to give me information to help, but I had trouble understanding them. Sometimes the way they explained things to me contradicted what another doctor told me earlier, but maybe I was confused because no one could speak to me in Mandarin.

I’m worried I’m not doing what I’m supposed to do for this condition, but I don’t know anything about type 2 diabetes. All the brochures and other information I was given is written in English, and I have no idea what it says. All I have gathered is that I need to reduce my weight, but I’m not overweight. I am so scared. Did I do something wrong?

One doctor said I need to eat less rice, but I don’t know what I am supposed to eat instead. I also don’t have a traditional Chinese shop close to home, so I often have to shop at the Australian Grocery store where I don’t understand the labels on the food. I must be buying the wrong things.

I really don’t want to tell my family this news as I am afraid of what they will think of me, and I don’t want my community to think that I am unhealthy. I am worried that I will be exiled from my community if I can’t continue to eat at our cultural celebrations, which are so important to us.

I recently lost my job after my boss found out I have diabetes. They saw me taking my medication, so I had to tell them. They told me it was best if I found a less physical job as they were worried my condition would impact the hours I can work. I don’t know if I’ll find another job if I tell people – maybe it’s better if I keep my diabetes a secret? Having diabetes seems very expensive, I already know that my local pharmacy doesn’t have some of the medications that my doctor said I needed, so I have no idea what I am supposed to do now? I am overwhelmed by what this will all mean for me.

My doctor told me I should book another appointment with her soon, and I should also find a diabetes educator, a podiatrist and a dietitian but I am only able to see these specialists 5 times a year or must pay extra fees. Why is there a limit of only 5 appointments? I need more help, especially now. I can’t get back in to see my doctor for another eight weeks, but I’ll have to tell my family about this condition soon. I wish that my doctor spoke Mandarin, it would make things so much easier.

**DID YOU KNOW. 11% of total hospitalisations (1.3 million)
were associated with diabetes in 2020-2021**



A Bright Future:

After finally telling her daughter about her diagnosis, Lin's daughter helps explain a little more about diabetes, and tells Lin that she can make a call to ask professionals for support. Lin calls the Diabetes Victoria Multilingual Helpline and, with the help of an interpreter, an experienced diabetes educator helps to alleviate some of her stress. Lin is provided with resources in Chinese, including videos, pictorial guides and fact sheets. She is also told about an upcoming NDSS-funded *Living Well with Diabetes* event, which is delivered in Mandarin by Chinese Health Professionals and is an opportunity for Lin to meet other Chinese-speaking people living with diabetes. After this event, Lin learns about a peer support group full of Chinese people, which she gratefully connects with.

Lin makes an appointment at the Diabetes Victoria Clinic and an interpreter joins the one-on-one session. During this appointment, a diabetes educator helps Lin develop a personalised diabetes management plan to suit her lifestyle. This includes suggestions around how she can make changes to her existing diet – like reducing the rice and increasing the amount of vegetables at mealtimes. Lin is also connected with a doctor who has been trained in managing type 2 diabetes and speaks Mandarin, this has been crucial for ensuring that Lin is provided with information and referrals that will work for her.

Lin is told about the Diabetes Victoria Advocacy team who help to redress the workplace discrimination Lin encountered by lodging a formal complaint to the Victorian Equal Opportunity and Human Rights Commission against Lin's former employer. The advocacy team also link Lin with Centrelink for income assistance. Lin feels relieved and supported.

Although Lin still has concerns about how she can afford all the treatment she needs, particularly in relation to her ongoing complications with her feet, when the outcomes of the Parliamentary Inquiry into Diabetes are implemented, Lin will have better access to the medicines and technology she needs, such as a Continuous Glucose Monitor.

“The doctor doesn't have the time to tell you everything. This session is a good way of finding out answers to questions you have forgotten to ask the doctor...” – Living Well event participant

“It is always very useful for newly diagnosed people to connect with other diabetics and see the services available firsthand. For others like me it serves as a reboot to put you back on track.” – Living Well event participant

We Are Listening. Every Voice Matters:

“Prior to being diagnosed as being pre-diabetic, I had no knowledge of the ramifications or consequences of diabetes.”

“It is a debilitating disease and living with it the past few years has undoubtedly changed the trajectory of my life. Doctors are struggling to control my blood sugars due to a sluggish liver. My mental health has been affected and sometimes I struggle.”

我的血糖一直偏高，由于个人原因还没有吃治疗糖尿病的药物，感觉试纸很贵，不是经常测试。（“My blood sugar has always been on the high side. Due to personal reasons, I haven't taken the medicine for diabetes. I feel that the test strips are very expensive, so I don't test them often.”）

"... there have been times when my chemist just doesn't have the prescriptions or test strips in stock when I have tried."

"Subsidise additional sessions for allied health care. Five per year is not nearly enough."

"The people who from a refugee background will be confusing with food when they arrive here, which food will be the best to choose for their health, some people, due to the language barrier, they don't want to access the health service."

"The stigma behind diabetes, especially type 2 is horrible - people think you are just lazy and fat. Better public education on these diseases."

"I just came here two weeks ago from Russia and it is very difficult for me to find any information or support because I don't have Medicare..."

"People with type 2 diabetes, should have all medications listed on the PBS."

"I think we need more support in work force. As I have faced discrimination by a owner. But I have found workplaces who do not know what diabetes is."

"I once heard on ABC radio that 'type 2 diabetes was the one you deserve because you did it to yourself.'"

"I have lived with Diabetes for 38 years. It has never been harder or more expensive to access GPs, Specialists, ongoing Mental Health Support, consumables. It is just way too expensive. Why can't I get a healthcare card?"

I HAVE GESTATIONAL DIABETES AND I LIVE IN RURAL VICTORIA

With all the things to consider in my first pregnancy, I didn't anticipate that diabetes would be one. My name is Rachel and I'm 35 years old. I was diagnosed with gestational diabetes at 26 weeks pregnant. I didn't have any of the identified risk factors, so I didn't get the test earlier.

My hormones were already going wild at this point, so the guilt hit me hard when I was diagnosed. After trying to get pregnant for so long and doing everything to prepare my body for this, I thought I'd done something to hurt my baby. I didn't even understand what Gestational Diabetes Mellitus (GDM) was - I've never heard anyone talk about it.

I live three hours from the city, so specialist care is hard to find. I was already travelling an hour each way for scans and checkups, so when I was told to contact a dietitian and a diabetes educator, the waiting lists were so long that I ended up just Googling a lot and finding a few forums online for my questions. While the forums helped reduce my feelings of isolation, I didn't get a lot of answers and I worried the entire time until his birth.

It wasn't easy to get supplies either. I registered for the National Gestational Diabetes Register, which is part of the National Diabetes Services Scheme, so there were some subsidies like test strips. I made sure I stocked up whenever I travelled because our local pharmacy didn't often have everything I needed.

I kept hearing about "sub-optimal control", but I was able to avoid medication and mostly manage with diet and lots of testing. I felt like I didn't have much control at all! I was already a stranger in this new pregnant body. I tried, but I had to learn a lot very quickly.

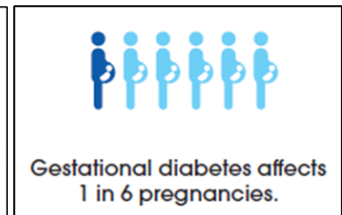
My partner and my parents were a huge support, but I didn't tell anyone else about my GDM during my pregnancy, because when I did the reactions just added to my feelings of guilt. People seemed to think I'd caused my diabetes - it was almost worse when they tried to defend me "but you're so active!". I found that these attitudes really impacted my social life, as I couldn't eat what everyone else was eating and I didn't want to be singled out.

My beautiful, happy baby boy was born three months ago and I'm starting to feel human again now – despite the lack of sleep.

After a few delays, I managed to get in for a glucose tolerance test with my GP when my baby was 9 weeks old and, just like that, my GDM was “resolved”. Someone in my mother’s group had a friend who’d had GDM and warned me that I might now be at higher risk of type 2 diabetes. I must have been told before, but this felt like a whole new blow to me.

We’d always talked about having two or three kids – but now I’m not sure...

DID YOU KNOW. Women with a history of
**Gestational Diabetes Mellitus (GDM) have up to an
8 times higher risk of developing type 2 diabetes.**



A Bright Future:

Through her existing networks, Rachel was provided with the details for the NDSS Helpline. She contacted the helpline to talk to someone about her increased risk of type 2 diabetes, and to ask for some additional resources. She spoke to a dietitian at Diabetes Victoria, who suggested she look into the *Life!* program stream tailored for women with GDM history and some other great telehealth resources, including mental health support.

On their son’s first birthday, Rachel and her partner requested donations for behavioural research in diabetes instead of gifts, so that more people dealing with diabetes stigma and feelings of guilt and shame can be better understood and supported. Rachel now openly shares her ongoing journey with diabetes in a blog and has empowered many more women facing the same challenges.

Rachel learns about changes which will improve access to supplies and support in rural Victoria. Armed with resources, knowledge and a little more confidence, Rachel and her partner are starting to plan and look forward to expanding their family before too long.

We Are Listening. Every Voice Matters:

“The only pharmacy in my rural town doesn’t stock all diabetes supplies at all times. I have to order in advance. I have had to ring around and travel out of town for 40 mins to get insulin when insulin pump failed.”

“As a migrant in this country who developed gestational diabetes during a stressful pregnancy, I was at high risk for developing type 2 diabetes but was not educated or provided with any further follow ups to prevent the onset of type 2 diabetes.”

“GPs in Regional Victoria (Mansfield) are booked out for weeks in advance.”

“Living regionally, specialist care is either a long way away or long waiting times. I choose to travel but that adds to expense of course.”

“GPs are in short supply in regional Victoria. In 2 years, no GP has been willing to take us on.”

“I had gestational diabetes (twice). It ‘disappeared’ for 25 years and returned as Type 2. I manage it as best I can through diet, exercise & medication. But I hate it.”

“Community consultation and scoping to better understand barriers to service and treatment access are essential.”

3. RECOMMENDATIONS

The issues that are important for people living with or affected by diabetes align with Diabetes Victoria's strategic priorities and the priorities identified in the National Diabetes Strategy. Critical work is needed to remove or reduce barriers to quality diabetes care. Evidence-based programs and services exist which have real benefits for self-management, physical and mental health, and are highly cost-effective to run. Proven successful programs need support and sustained long-term investment to enable greater access, ensure they remain appropriate to modern diabetes care and can be delivered flexibly to suit the needs of the people who need them.

Government collaboration with key partner organisations, including Diabetes Victoria, and people affected by or at risk of developing diabetes, will be pivotal in implementing state and national diabetes strategies and plans to improve health outcomes, improve diabetes care and reduce the impact of diabetes in Australia. To improve diabetes care pathways, we need integrated models of care with coordinated, tailored care plans to offer comprehensive and multidisciplinary diabetes management across primary, secondary and tertiary care. This holistic approach, coupled with an increased focus on prevention and funding to enable the next diabetes breakthroughs, will pave the way to a future in Australia where diabetes can do no harm.

Each of Diabetes Victoria's recommendations below respond to one or more of the Inquiry's five Terms of Reference.

ACCESS TO QUALITY CARE (TOR 2, 3, 5)

Limited access to quality and timely diabetes care can significantly impact the ability of people affected by diabetes to manage their health effectively. This can lead to complications, which can unnecessarily reduce health, quality of life and life expectancy. Throughout this submission process the community have talked to us at length about how the impact of increasing costs relating to healthcare and diabetes technology, geographical barriers to accessing various types of support (particularly specialist mental health support), lack of workforce availability (particularly in relation to primary care, specialist diabetes care and mental health), and lack of culturally appropriate support, are ongoing stressors in their everyday lives. It is important that these socio-economic factors are addressed to improve diabetes support.

COST/ GEOGRAPHY/ PRIORITY GROUPS

- Strengthen Medicare support to provide equitable access to more subsidised diabetes-related healthcare services, screenings, medications, devices, other supplies and specialists (including allied health), regardless of geographic location or socioeconomic status, via the NDSS.
- Increase the provision of telehealth services for diabetes management, particularly in rural and remote areas.
- Assist young people with type 1 diabetes to meet and support others, including specifically designed peer support programs.
- Work alongside Aboriginal Community Controlled Health Organisations to co-design localised and culturally appropriate diabetes programs, resources and other supports.
- Invest in capacity building for the Aboriginal Health Workforce to improve their understanding of diabetes risk and management within the community.
- Invest targeted funding to help support individuals living with diabetes complications, ensuring affordable and accessible healthcare to those who need it most.
- Increase the focus on supporting young adults living with diabetes (aged 18-29) through: improved information and processes to assist them in accessing NDSS products and systems; increasing diabetes-related formal mental health supports and informal peer support opportunities; and co-

designed resources which ensure information is delivered and accessed in a way that is familiar to them.⁹

- Improve the care and safety of linguistically and culturally diverse groups by providing additional services/programs including:
 - Free interpreter service access for allied health professionals.
 - Access to bicultural workers for support navigating the health care system.
 - Workforce training in culturally appropriate care.
 - Increased availability of a range of in-language and culturally relevant and tailored resources and information, particularly for newly arrived and emerging migrant/refugee communities, and other groups who are in the greatest need of support.
 - Peer support designed for culturally diverse groups.

INTEGRATED QUALITY CARE PATHWAYS

- Develop and implement integrated models of care with coordinated, tailored care plans to offer comprehensive and multidisciplinary diabetes management across primary, secondary and tertiary care. This includes enabling a greater focus on prevention of the complications of diabetes through integrated quality care pathways and a reduction in hospital admissions.
- Focus on the provision of a primary care system which can address the complex needs of those living with diabetes, including increased workforce capacity through inter-professional learning and mentoring.
- Move routine, non-urgent and less complex specialist outpatient services out of hospital settings back to primary care to reduce the burden on outpatient departments.
- Invest in and implement virtual diabetes specialist support available to all Australians experiencing a diabetes-related emergency, regardless of geography.
- Invest in health promoting campaigns for people currently living with diabetes-related complications to help reduce the burden on the primary and tertiary health system.
- Enable timely and effective discharge from tertiary to community and primary care through improved referral pathways and simplified care models which enable a coordinated approach to care.

HOSPITALS

- Improve the safety and experiences of people with diabetes in hospitals by improving glucose management and triage of acute events. Develop a 'real-time diabetes dashboard' supported by a specialist diabetes team to provide timely, evidence-based best practice care for people with diabetes.
- Monitor the safety and experiences of inpatients with diabetes: Invest to initiate a state-wide audit of hospital inpatient care for people with diabetes, linked to quality improvement.
- Development of treatment approaches based on individualised care, focused on improving in-patient experience, with resources available to allow the workforce to better support people affected by diabetes.
- Capacity-building in the palliative care workforce to support people with diabetes-related complications.

TECHNOLOGY

- Expand the Continuous Glucose Monitor subsidy to include all Australians living with diabetes.
- Expand the Insulin Pump Program to include all Australians using insulin to manage their diabetes. This would mean access to fully subsidised insulin pump therapy for all children and adults using insulin, without requiring private health insurance.
- Support research into new and emerging diabetes-related technology.

- Review and improve regulatory pathways for the efficient assessment of new and emerging diabetes-related technology.
- Ensure equity of access to current and emerging diabetes-related technology.
- Empower individuals to monitor their health and make informed decisions about the safe and effective use of current and emerging technology.¹⁰
- Provide access to appropriate resources and multidisciplinary teams who are expert in the support of people who use technology to manage their glucose levels.

MENTAL HEALTH SUPPORT

- Support the mental health of Victorians living with diabetes through the provision of funding for the NDSS Helpline to employ psychologists with expertise in diabetes, and the investment in enabling organisations (like Diabetes Victoria) to provide diabetes-specific mental health and peer support for people living with diabetes, including camps for children with type 1 diabetes.
- Invest in behavioural and psycho-social research in diabetes led by the Australian Centre for Behavioural Research in Diabetes.
- Embed psychologists and allied health professionals (mental health nurses, social workers and counsellors) in diabetes specialist teams, to enable truly holistic and collaborative care through investment in a research trial to examine the impact of psychologists as part of the multidisciplinary diabetes care team and commit to fund research findings.
- Provide services for young people to connect with diabetes-related mental health support.

STRATEGIC RESEARCH INVESTMENT (TOR 1, 2, 3)

Research is an essential foundation of a strategic response to the diabetes pandemic. Considerable advances have been made in the past decade, but more work is needed to improve diabetes care and treatments, and to provide support for world-leading researchers. Strengthening investment in diabetes research is pivotal to improve quality of life for people living with diabetes and to find a cure. To have impact, research must respond to, and be guided by the diabetes community, enabling the translation of research into real-world solutions. The [Diabetes Research Matters](#) report lists the top research priorities of people living with type 1, type 2, gestational, and rarer types of diabetes, as well as their family members.

- Increase funding for research into the causes, prevention, diagnosis, treatments, management and support of all types of diabetes.
- Increase funding for research where there is established unmet need to understand and improve health and quality of life.
- Amplify the voices of people living with or at risk of diabetes and ensure that research benefits people sooner by prioritising research that involves the diabetes community in co-design and recruitment, is informed by community or is community-led.
- Ensure research informs health policy.

PRIORITISE THE PREVENTION OF DIABETES (TOR 1, 4, 5)

Prevention is key to generating long-term health and economic benefits by delivering improved health outcomes for current and future generations. Current health expenditure is primarily spent on treating diseases. Given the increase in the prevalence in chronic conditions such as type 2 diabetes, health care expenditure and the burden on health care providers will continue to rise. By increasing investment in preventative measures, longer-term health expenditure could be stalled, and the health and wellbeing of Australians will improve.

- Increase prevention investment to 5% of total annual health expenditure across federal and state budgets.

- Expand and enhance awareness campaigns for all types of diabetes, address diabetes stigma and discrimination, promote type 2 diabetes prevention, promote early detection strategies and regular health checks.
- Increase investment in evidence-based prevention policies and legislation, strategies and programs to improve the environment and living conditions that surround us, and support and empower people to live healthier lives.
- Increase investment in targeted and tailored interventions for priority populations and address the inequitable access to preventative programs and strategies.
- Fund and promote community-based programs that encourage social inclusion, healthy lifestyles, nutrition, and physical activity to help Australians make informed decisions that can reduce their risk of type 2 diabetes.

END DIABETES STIGMA (TOR 2, 3, 5)

Diabetes stigma continues to impact the lives of all people affected by diabetes. Around 4 in 5 people with diabetes have experienced some form of diabetes stigma, which can lead to being treated differently. This is discrimination. Up to 1 in 3 people with diabetes have experienced discrimination due to their diabetes.

Diabetes stigma and discrimination have many negative impacts on the health, self-care, wellbeing, professional and social lives of people with diabetes. Diabetes stigma can also have a negative impact on public and government support and funding for diabetes research, prevention, clinical care and treatments.

Supporting people affected by diabetes to feel safe and empowered to seek out and utilise the tools to aid prevention (of diabetes and its complications), early diagnosis and self-care will both encourage greater participation in, and enhance the impact of, programs and resources.

Change is needed to bring an end to diabetes stigma. It starts with a collective agreement to challenge the status quo – the embedded negative judgements, stereotypes, and prejudice that influence discussions and decision-making about diabetes.

- Support the **End Diabetes Stigma** international campaign and commit to changing the conversation through consistent use of supportive and appropriate language with and about people affected by diabetes to combat existing and embedded stigma and prejudice.^{11 12}

SUSTAINED INVESTMENT IN DIABETES PROGRAMS (TOR 5)

People living with diabetes need access to information, starting from the moment they are diagnosed. People can access information in several ways, including speaking with their local GP or health professional, however the costs and waiting times can often be prohibitive. To help manage this, community training and education programs, events, and webinars need to be available to all Australians living with diabetes. These sessions aim to empower individuals to live their life well with diabetes, with up-to-date information delivered about topics that matter most to them. Sessions are presented by experts within the field of diabetes, including health professionals and people living with diabetes. These programs provide opportunities for people to connect with others living with diabetes and are a great way for people to engage with a community of support. Proven successful programs need support and sustained long-term investment to enable greater access to those who need them.

- Support long-term investment in funded programs proven to empower and connect those affected by diabetes – including camps, peer support groups and self-management programs – throughout the various ages and stages of their life and diabetes journey.

- Support and invest in the implementation of comprehensive diabetes education programs for early childhood workers.
- Support and invest in the provision of comprehensive diabetes education programs for school teachers and disability and aged care workers.
- Promote culturally sensitive materials and resources that cater to diverse populations and languages, to improve accessibility and engagement.

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 - 4 Speight J, Holmes-Truscott E, Scibilia R, Black T (2021). [Heads Up on Diabetes & Stigma](#). Diabetes Australia, Canberra.
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 - 9 “Our voices, our lives, our choices” www.ndss.com.au/wp-content/uploads/report-youth-2020-our-voices.pdf
 - 10 “Empowering Us” [www.diabetesresearchclinicalpractice.com/article/S0168-8227\(23\)00593-4/fulltext](http://www.diabetesresearchclinicalpractice.com/article/S0168-8227(23)00593-4/fulltext)
 - 11 End Diabetes Stigma <https://enddiabetesstigma.org/>
 - 12 “Our Language Matters”: Diabetes Australia Position Statement <https://www.diabetesaustralia.com.au/position-statements/>