

Diabetes stigma community commitment statement

Why it needs to stop

Introduction

PDC Health Hub is proud to unveil its comprehensive Community Commitment Statement on diabetes-related stigma, a critical document that highlights the profound impact of stigma experienced by thousands of individuals living with diabetes across Australia and beyond. This statement underscores a critical reality: diabetes stigma is not merely an isolated social challenge but a pervasive, systemic issue deeply embedded in societal structures, language, media, policy, and even healthcare delivery.

According to research, more than threequarters of adults living with either type 1 or type 2 diabetes have perceived or experienced diabetes stigma¹. It affects individuals living with all types of diabetes, including Type 1, Type 2, Gestational Diabetes, and other less common forms such as MODY and LADA, leading to significant detrimental effects on health outcomes, mental well-being, and imposing substantial costs on our healthcare systems.

The strategic framing of this issue as a systemic public health and health equity concern is paramount. By adding to the positioning of diabetes stigma at this elevated level, this signals to organisational stakeholders and policymakers that this is a high-level policy matter with far-reaching implications, requiring ongoing serious consideration and investment rather than just compassionate acknowledgement.

PDC Health Hub is steadfast in its commitment to a multifaceted, inclusive approach aimed at challenging and ultimately eliminating this pervasive stigma to those living with all types of diabetes.

Our vision is a future where all individuals living with diabetes are empowered, not judged, and where care is grounded in equity, empathy, and evidence.

This commitment culminates in an **urgent** call to action, inviting other organisations, policymakers, and the wider community to join PDC Health Hub in continuing to recognise diabetes stigma as a fundamental health equity issue and to implement concrete, collaborative strategies to foster a more understanding and supportive environment for all.

This commitment is informed by the voices of our community and extensive research including the *International Consensus to End Diabetes Stigma and Discrimination*, published in The Lancet Diabetes & Endocrinology (January 2024), etc. We acknowledge and support the collective, international efforts led by researchers, health professionals, and people with lived experience to address diabetes stigma at a systemic level. PDC Health Hub has proudly taken the <u>End Diabetes Stigma</u> <u>Pledge</u> and is committed to implementing its principles locally.



Understanding diabetes stigma and its far-reaching impact

Defining diabetes stigma and its manifestations across all diabetes types

Diabetes stigma refers to the negative social judgement, discrimination, and internalised shame that individuals may experience simply as a result of living with diabetes. Diabetes stigma experiences vary across the lifespan, and what is considered stigma to some might not be to others. Importantly, diabetes stigma is not confined to isolated incidents; it is pervasive and deeply embedded within various societal layers, including systems, language, media, policy, and even the delivery of healthcare. Its manifestations can vary from overt acts of blame and exclusion to more subtle forms of stereotyping or unsolicited comments. These stigmatising experiences occur in diverse settings, from schools and workplaces to broader cultural communities. healthcare environments, media representations, and even within families.

A critical aspect of understanding diabetes stigma is recognising its universal reach across all forms of the condition. People living with Type 1, Type 2, Gestational Diabetes, and other less well-known forms consistently experience this stigma. While the specific form, intensity, and nature of the stigma may differ depending on the diabetes type, its impact remains consistently harmful. Importantly, this stigma can be further compounded for Aboriginal and Torres Strait Islander peoples and individuals from culturally and linguistically diverse backgrounds, who may face additional layers of discrimination, misunderstanding, or cultural barriers in accessing care and support. Addressing diabetes stigma requires a culturally sensitive and inclusive approach that acknowledges and respects the diverse experiences of all people living with diabetes.



For individuals living with Type 2 Diabetes, stigma often presents through inaccurate narratives that disproportionately place sole responsibility on personal choices or weight. This oversimplified view fails to acknowledge the complex interplay of genetic, environmental, and social factors that contribute to the development of Type 2 Diabetes. It is these assumptions that foster a profound sense of blame, shame, and judgement, which can actively discourage individuals from seeking necessary medical help or engaging in open conversations about their health.²

Conversely, individuals living with Type 1 Diabetes often experience stigma in distinct ways. They might face misunderstandings, be wrongly accused of "causing" their condition, or encounter differential treatment in professional, academic, or social settings due to their reliance on insulin, the need for blood glucose monitoring, or the presence of wearable technology.

The nuanced understanding of how stigma manifests differently for Type 1 versus Type 2 Diabetes, while affirming its universal harm, exposes a sophisticated comprehension that effective anti-stigma interventions must be specifically tailored to address these varying contexts and narratives. **Importantly, it is imperative that we do not add to the stigma that already exists when delivering such campaigns.** A tailored approach is essential for maximising the impact of communication strategies, and lived experience of those living with all types of diabetes is key. No one knows what living with diabetes is like better, or can explain the impact of stigma more clearly.

"I'm a type one, but people don't understand that there are different types. Many people believe that if you have diabetes, you are overweight and lazy. Even the images you see in advertisements depict many overweight people. Maybe highlight sports people in these images







Implications for individuals and public health systems

Diabetes stigma extends far beyond individual emotional distress; it is fundamentally a structural and systemic issue with profound implications for public health. At the individual level, prolonged exposure to stigma can lead to isolation, disengagement from essential healthcare services, delayed diagnosis, and ultimately, poorer long-term health outcomes. It creates unnecessary suffering and contributes to a cycle of avoidance that exacerbates health challenges.^{23,6}

From a broader public health and systemic perspective, the consequences are far-reaching and financially significant:

Delays in diagnosis	Delays in diagnosis are common, driven by fear of judgement or the assumption of blame associated with a diabetes diagnosis. ^{2,3,6}
Reduced engagement with healthcare	Reduced engagement with healthcare becomes prevalent as people actively avoid check-ups, educational programs or early intervention strategies due to pervasive stigma. ^{2,3}
Poorer mental health outcomes	Poorer mental health outcomes, including diabetes distress, depression, anxiety and burnout are consistently observed among people living with diabetes. 4.5.6
Inequities in access	Inequities in access to vital resources, technology, education and culturally approporiate support are perpetuated by systemic stigma. ⁷
Higher long-term costs	Higher long-term costs are incurred by the health care system due to preventable complications that arise from delayed or inadequate care, a direct consequence of stigma. ^{8,9}

The causal pathway from stigma to negative health and economic outcomes is clear. Stigma, as a root cause, contributes to psychological distress, which then manifests as behavioural changes, such as avoiding necessary medical care. 2,3,4,5,6 These behaviours directly result in poorer clinical outcomes, leading to preventable complications that impose a significant financial burden on the healthcare system.^{8,9} For organisational stakeholders, particularly those managing budgets or public resources, this economic argument transforms the issue from a purely compassionate plea into a pragmatic, cost-effective public health investment. PDC Health Hub believes that improving diabetes outcomes and reducing the economic burden of the disease are impossible without addressing stigma as a core barrier to care.

Furthermore, language plays a powerful and often overlooked role in either perpetuating or dismantling stigma. The words used in public discourse shape perceptions, influence self-perception, and dictate how individuals are treated within healthcare settings and society at large.¹⁰

The use of stigmatising language, such as "non-compliant," "failing," "the bad diabetes," or "lifestyle disease", reinforces outdated views that wrongly attribute blame to individuals for their condition.¹⁰

Similarly, media representations that rely on fear, guilt, or oversimplified messages further embed these harmful stereotypes into the public consciousness.

CATEGORY	IMPACT
Individual impact	Isolation, disengagement from healthcare, delayed diagnosis, poorer health outcomes, poorer mental health (diabetes distress, depression, burnout). ^{2,3,4,5,6} Research from Diabetes UK found that over 50% of people living with diabetes miss healthcare appointments at least sometimes due to stigma. ⁷
Public health system impact	Systemic delays in diagnosis, reduced systemic healthcare engagement, inequities in access (technology, education, culturally appropriate support), higher long-term costs (due to preventable complications). ^{8,9,10}

80%

More than 80 per cent of people with diabetes report feeling blamed or shamed by people because they live with the condition.¹²

"Diabetes stigma has impacted every element of my life for most of my life. If this were any other disease that was constantly trying to kill you every moment of every day of your life, people would show some compassion. Instead of trying to make you feel like it were your own fault." - Katie, lives with T1D



PDC Health Hub's commitment and vision

PDC Health Hub is unwavering in its commitment to reducing and ultimately eliminating diabetes stigma through a multifaceted and inclusive approach. We operate and deliver our services on the fundamental belief that every person living with diabetes deserves to live free from judgement and to have unhindered access to the support and care necessary to thrive. We are here to support the diabetes community, we will always keep showing up for them.

This commitment is translated into a series of core principles and actionable strategies:

Education and Training

Language

Advocating for health equity

Collaboration

<u>_ived</u> experience











PDC Health Hub actively challenges stigma through comprehensive education, proactive advocacy, and, crucially, the amplification of lived experiences. This involves not just disseminating information but actively shaping narratives to counteract harmful stereotypes. PDC Health Hub is dedicated to creating safe and welcoming environments across all its clinics, events, and digital spaces, ensuring that individuals feel respected, understood, and supported without fear of judgement.

A cornerstone of PDC Health Hub's strategy is the active use and promotion of inclusive, person-first language in all forms of communication - clinical, written, verbal, and online. This commitment aligns with and supports the International *Language Matters* movement, recognising that language holds immense power in shaping public perception and individual self-worth. Furthermore, PDC Health Hub advocates tirelessly for health equity, committing to avoid assumptions about an individual's health, choices, or diabetes type, and striving for equitable access to care for all, regardless of their specific diabetes diagnosis.

PDC Health Hub deeply values collaboration with individuals who have lived experience with diabetes. These individuals are actively partnered within the co-design of education initiatives, communication strategies, program development, and advocacy efforts. This collaborative model ensures that solutions are authentic, relevant, and truly responsive to the needs of the diabetes community while also considering cultural diversity. To address stigma within the healthcare sector itself, PDC Health Hub provides targeted training, professional development, and resources to health professionals, equipping them to deliver non-judgmental and compassionate care.

Finally, PDC Health Hub recognises that systemic change requires broad collaboration. PDC Health Hub actively works with – and invites - other organisations, media outlets, community groups, and government bodies to fundamentally change the public conversation about diabetes in Australia.

PDC Health Hub's commitment to person-first language and the amplification of lived experience is not merely a policy statement; it is a sophisticated understanding of communication as a powerful tool for systemic change. They have invested from the outset to ensure the voices of people living with diabetes are heard. This approach moves beyond simple information dissemination to actively shaping narratives and empowering individuals to have a voice. By emphasising person-first language, PDC Health Hub acknowledges the profound power of words to either perpetuate or dismantle stigma. It is our dedication to partnering with individuals with lived experience that recognises that authentic and effective solutions must be co-created with those who directly experience the problem.

PDC Health Hub is not just an advocate, but a credible and experienced leader in ensuring the lived experience voice is **heard.**



What needs to change?

We are calling on government stakeholders and all diabetes related organisations and stakeholders to:

- 1. Embed stigma-reduction strategies into national and state diabetes action plans.
- 2. Fund public education campaigns that reflect the complexity of diabetes and shift community attitudes away from blame.
- 3. Support inclusive, person-first language in all government communications and policy.
- 4. Prioritise mental health support and peer connection opportunities for people living with diabetes.
- 5. Ensure equitable access to diabetes education, technology and culturally safe care across all types of diabetes.
- 6. Engage people with lived experience in co-designing health policy, programs and reearch initiatives.
- 7. Promote training for healthcare professionals on stigma, communication and compassionate care delivery.
- 8. Include diabetes stigma as a priority in national chronic disease and mental health frameworks.

A recent survey by PDC Health Hub to 15,000 clients showed an alarming trend relating to stigma:

People stopped talking about their diabetes, seeking help, they felt ashamed and shared that it has impacted their mental health.

"We need more
education, debunking
myths and
misconceptions,
normalising diabetes,
acceptance in the
community"

"I'd like to see more awareness of what it is and what the types are and an understanding of its impact on the everyday, the constant part it takes in your life e.g. burnout, how you feel when low/high"

A call to action

It is time to move beyond blame, shame, and silence. Diabetes is not a personal failure, nor a punchline. It is a serious, complex health condition that deserves compassion, respect, and understanding.

We call on healthcare providers, the media, policymakers, workplaces, and the wider community to join us in addressing diabetes stigma in their community. Together, we can build a future where people with diabetes feel empowered, not judged; supported, not shamed; and where care is grounded in equity, empathy, and evidence.

We urge you to recognise diabetes stigma as a health equity issue - and if you're in a position to do so - to lead the change through policy, funding, and public messaging.

Together, we can build a future where people living with diabetes are no longer shamed or blamed, but respected, empowered, and supported to live well.

Stigma is preventable. The time to act is now.

Collaboration and partnership

PDC Health Hub is open and willing to collaborate with **any organisation, institution or stakeholder that shares our commitment to ending diabetes stigma**.

We believe that collective action and shared values are essential to creating lasting change. If your organisation aligns with our vision and values, we welcome the opportunity to work together.



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- 2: Ashraf MN, Cheng AYY. Impact of Living with Stigma in Persons with Type 1 Diabetes: A Patient-Physician Perspective. Diabetes Ther. 2024 Feb;15(2):311-316. doi: 10.1007/s13300-023-01528-9. Epub 2024 Jan 16. PMID: 38227173; PMCID: PMC10838868.
- 3: Samuel Akyirem, Emmanuel Ekpor, Diana Namumbejja Abwoye, Janene Batten, LaRon E. Nelson, Type 2 diabetes stigma and its association with clinical, psychological, and behavioral outcomes: A systematic review and meta-analysis, Diabetes Research and Clinical Practice, Vol 202, 2023, 110774, ISSN 0168-8227, https://doi.org/10.1016/j.diabres.2023.110774.
- 4: https://www.diabetesaustralia.com.au/blog/common-signs-of-diabetes-burnout-and-diabetes-distress/
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- 10: https://www1.racgp.org.au/newsgp/clinical/diabetes-costing-health-system-more-than-9-billion
- 11: https://www.diabetesaustralia.com.au/wp-content/uploads/Language-Matters-Diabetes-Australia-Position-Statement.pdf
- 12: https://www.diabetesaustralia.com.au/mediarelease/heads-up-end-the-diabetes-blame-and-shame/

This commitment is informed by the voices of our community and extensive research including the International Consensus to End Diabetes Stigma and Discrimination, published in The Lancet Diabetes & Endocrinology (January 2024) and Diabetes UK Exploring Diabetes Stigma Report (March 2023). We acknowledge and support the collective, international efforts led by researchers, health professionals, and people with lived experience to address diabetes stigma at a systemic level thus far and we look forward to seeing this continue, and supporting this work.

Document commissioned by









Collective action against stigma.

We believe meaningful change requires united voices. That's why we proudly support the International Consensus to End Diabetes Stigma and have taken the End Diabetes Stigma Pledge. In the spirit of collaboration and collective advocacy, we encourage other organisations to also take the Pledge, and consider developing their own commitment statements tailored to their communities and experiences. By aligning our efforts with the international movement while addressing local realities, we can work together to dismantle stigma in all its forms.



Commitment supporters

RIO TINTO CHILDREN'S DIABETES CENTRE

A Breakthrough T1D Centre of Excellence











"The experience of stigma for people living with all forms of diabetes can be extremely harmful. Not only is it distressing but it can negatively impact on an individual's sense of identity and how they engage with vital aspects of diabetes management. We know that people will often delay or avoid checking their glucose levels or administering insulin when in public and may be more likely to disengage with healthcare services. They may also be more likely to avoid disclosing their diabetes to people, missing out on important emotional and practical support. It is incumbent on those of us with the capacity to give voice to this important issue, to advocate for a safer, more inclusive environment for people living with diabetes."

- Dr Keely Bebbington, Mental Health Research Lead

Rio Tinto Children's Diabetes Centre; a Breakthrough T1D Centre of Excellence at The Kids Research Institute Australia