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## Bringing an end to diabetes stigma and discrimination: an international consensus statement on evidence and recommendations

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## Abstract

To accelerate an end to diabetes stigma and discrimination, an international multi-disciplinary expert panel (N=51 members, 18 countries) conducted rapid reviews and participated in a three-round Delphi survey process. They achieved Consensus on 25 Statements of Evidence and 24 Statements of Recommendations. The Consensus is that diabetes stigma is driven primarily by blame, perceptions of burden/sickness, (in)visibility, and fear/disgust. People with diabetes often encounter stigma (negative social judgments, stereotypes, prejudice), which can adversely affect emotional, mental, and physical health, self-care, access to optimal healthcare, and social and professional opportunities. Up to one-in-three experience discrimination (unfair and prejudicial treatment) due to diabetes, e.g., in healthcare, education and employment. Diabetes stigma and discrimination are harmful, unacceptable, unethical, and counterproductive. Collective leadership is needed to proactively challenge, and bring an end to, diabetes stigma and discrimination. Consequently, the panel achieved unanimous consensus on a pledge to end diabetes stigma and discrimination.

In press

## Introduction

People with diabetes live with a challenging condition, requiring daily self-care to stay healthy and avoid, delay, or manage short- and long-term complications. This burden can be exacerbated by stigma (negative social judgments, stereotypes and prejudices),<sup>1</sup> which takes many forms (Panel 1). It is also exacerbated by discrimination (unfair or prejudicial treatment),<sup>2</sup> which has been described as the ‘endpoint’ of the stigmatization process.<sup>3</sup> Stigmatising practices are inconsistent with respect for the dignity and lived experience of people with diabetes.<sup>4</sup> Further, evidence indicates that diabetes stigma has multifaceted impacts for the health, self-care and wellbeing of people with diabetes.<sup>5</sup> There is growing evidence that diabetes stigma may also affect public and government support and funding for diabetes research, prevention, care and treatments.

In 2010, the International Diabetes Federation (IDF) put out a call to action to: ‘stop discrimination against people with diabetes’.<sup>6</sup> They recommended: enabling people with diabetes to claim their rights and responsibilities (as later detailed in the IDF Charter,<sup>4</sup>); increasing public awareness of diabetes and reducing diabetes stigma; and supporting people with diabetes to be at the centre of the response. This was a novel, ambitious, and critical step forward. In parallel, the first systematic review of diabetes stigma demonstrated wide-ranging potential harms but a relative lack of research focused on this important issue.<sup>1</sup> Subsequently, both advocacy and research have increased substantially, including awareness raising, sharing experiences, and understanding the nature, extent and repercussions of diabetes stigma. Arguably, there has been greater and earlier recognition in research of the stigma associated with other health conditions (e.g., cancer and mental illness in the 1960s, epilepsy in the 1970s, HIV in the 1980s/1990s, obesity in the 2000s).<sup>7-9</sup> Insights from these areas suggest that research and advocacy are both crucial, but each is likely insufficient in isolation.<sup>10-13</sup>

The pivotal change required to bring an end to diabetes stigma starts with consolidation of, and international consensus on, the evidence and recommendations. Such consensus has the power to galvanise collective leadership, commitment, and actions to challenge the status quo: the embedded negative judgements, stereotypes and prejudice present in discourse and decision-making about diabetes.<sup>5</sup> To achieve this, all sectors of the community – including but not limited to people with and affected by diabetes, and those working in advocacy, research, healthcare, industry, policy and media – need to state, unequivocally, that diabetes stigma and discrimination are not only harmful and unacceptable, but also counterproductive.

Our aims were to: a) consolidate the evidence regarding diabetes stigma and discrimination; b) achieve international consensus on brief Statements of Evidence and evidence-based Recommendations; and c) call on the diabetes community (as above) to endorse an evidence-based Pledge, demonstrating collective leadership and commitment to doing what is needed to bring an end to diabetes stigma and discrimination.

## Methods

### Establishing an expert panel

An international multi-disciplinary panel was established to inform, and serve as voting members on, the consensus. Potential panel members were identified via existing networks, snowballing, and targeted searches for authors of diabetes stigma research papers, and invited by JS, EHT, MG or RS. Members were required to have lived and/or professional experience of diabetes stigma. The panel comprises 51 members, including 17 with lived experience of diabetes and 19 with at least one family member living with diabetes (Table 1). Members are from 18 countries, across all seven IDF regions, including six from low-to-middle-income countries (Table 1).

All panel members contributed to the consensus protocol, Delphi surveys, and report, and agreed to advocate for the consensus, promoting it in their country or region to invite organisations to endorse the Pledge. In addition, subgroups of self-nominated panel members contributed to rapid reviews; design/pilot of the Delphi surveys; and iterative refinement of draft Statements and the Pledge prior to each survey (Table 1).

### Generating Statements and a Pledge: Rapid reviews

Subgroups of up to four panel members (Table 1) completed twelve topic-focused rapid reviews (Supplementary Table 2) informed by the framework for understanding diabetes stigma,<sup>1,14</sup> and the Health Stigma and Discrimination Framework.<sup>8</sup> Rapid reviews streamline knowledge synthesis in a resource-efficient manner.<sup>15</sup> The panel members extracted evidence identified through a single systematic search of manuscript titles focused on diabetes stigma (Panel 2; Supplementary Table 3), supplemented with relevant literature known to them, or identified from reference lists or non-systematic searches.

All rapid reviews involved: a) consideration of evidence overall and, where available, by diabetes types, sex, age, geographical region, race, and ethnicity; quality assessment, though formal quality appraisal was not conducted; preparation of a 2-page summary and draft Statements of Evidence and Recommendations; peer review by at least two independent panel members (Table 1); and revision as needed. The 12 topic-specific rapid reviews were consolidated into the 'Summary of Evidence' (see below). To reduce redundancy, the subgroup consolidated and refined the 78 draft Statements down to 50 draft Statements, and used this to inform a draft Pledge, for inclusion in the Delphi surveys. An example of the development of a Statement is shown in Supplementary Table 4.

### Achieving Consensus: Delphi method

Delphi is a respected method for developing consensus among panel members.<sup>16</sup> The consensus method and reporting (Figure 1) follows published guidance on Conducting and REporting DElphi Studies (CREDES).<sup>17</sup>

Three survey rounds were completed. In rounds one and two, panel members rated each Statement and the Pledge on a 4-point Likert scale ('fully disagree', 'slightly disagree', 'slightly agree', 'fully agree'),<sup>18</sup> or indicated 'don't know', and were encouraged to explain responses

or suggest revisions (via free-text responses). In round one, additional Statements were also invited. In round three, the Statements and Pledge were rated 'agree' or 'disagree', with no opportunity for further refinements. In rounds two and three, to inform ratings, panel members received their own and the group's aggregated prior ratings.

Panel members received a copy of the proposed Statements and Pledge at least 24 hours prior to each survey round and were invited to each survey (hosted via Qualtrics), via personalised email. Each survey was open for seven days, and two reminders were sent. The process was managed by an independent, non-voting moderator, with no prior relationship with any panel members or experience in diabetes stigma research. The moderator prepared and distributed the online surveys, tracked participants' confidential responses, and analysed data to inform subsequent surveys and the final consensus grade. A subgroup (Table 1) reviewed the de-identified results of each survey round and refined the Statements and Pledge for the next survey, based on panel feedback regarding clarity, evidence, duplication or omissions (see example in Supplementary Table 4).

Finally, prior to the final round, the acceptability of a public endorsement of the draft Pledge was explored with the leads of >10 organisations, including representation from Australian, Canadian, Dutch, and/or US advocacy organisations, professional associations, and universities. Early feedback was integrated into the Pledge prior to panel rating in round three.

#### *Grading of Consensus Statements and the Pledge*

Informed by the international consensus statement on weight stigma,<sup>19</sup> consensus gradings were defined as: grade U: 100% agreement (unanimous); grade A: 90–99% agreement (near unanimous); grade B: 78–89% agreement; grade C: 67–77% agreement; and no consensus: <67% agreement. Valid percentage was used to calculate consensus, excluding missing and 'don't know' responses.

#### *Delphi process outcomes*

Figure 1 summarises the iterative three-round process of ratings and refinements of Statements and the Pledge. Each round had response rate of  $\geq 98\%$ . Unanimous consensus was achieved for 17 of the 25 Statements of Evidence (Table 2) and 22 of the 24 Statements of Recommendations (Table 3). Grade A consensus was achieved for 8 and 2 respectively. The final 'Pledge to End Diabetes Stigma' (Panel 3) achieved unanimous consensus.

On 31<sup>st</sup> July 2023, the Pledge was published on a dedicated, community-based website – EndDiabetesStigma.org – to enable widespread access. In its first 14 weeks, the Pledge was endorsed by >2,000 individuals and >240 organisations (Panel 4) in >95 countries, 59% of which are low- to middle-income. The Pledge has also been translated into Arabic, two forms of Chinese, Danish, French, Italian, Japanese, Spanish and Thai, with more to follow.



## Summary of evidence

Our systematic search retrieved 116 papers (Supplementary Table 3), including 96 since 2013, representing a 6-fold increase in peer-reviewed publications in the 10 years since the first systematic review of diabetes-related stigma.<sup>1</sup> The development and validation of scales to assess diabetes stigma<sup>18,20</sup> enabled critical research into its nature, prevalence and associations. Conducted primarily among adults with type 1 diabetes (T1D) or type 2 diabetes (T2D), in at least 28 countries, the research demonstrates sources, settings, experiences, correlates, and impacts. Evidence gaps remain related to those with gestational diabetes (GDM) and rarer diabetes types; children and adolescents with diabetes; the wider community without diabetes; and in many countries and/or communities, including among Indigenous, migrant, and other minority populations. Research has mostly used qualitative methods or cross-sectional quantitative surveys, including some large-scale studies (N>1,000). The evidence base remains limited for determining mechanisms, and the effectiveness of mitigating strategies. Guided by relevant frameworks,<sup>1,8,14</sup> this summary details the supporting evidence, and evidence gaps, informing the Statements of Evidence and Recommendations, and the Pledge.

## Drivers and facilitators of diabetes stigma

All health-related stigma, including diabetes stigma, is driven primarily by blame, fear, and disgust arising from negative stereotypes and misinformation.<sup>1,8,14</sup> It is facilitated typically by media messaging and public discourse, health organisations and health professionals, cultural and social norms, policy, and law.<sup>1,8,14</sup> This may be confounded by other health-related stigma, e.g., due to obesity or mental illness (see *Intersecting stigma*). It may also vary between and within communities, reflecting localised health, sociohistorical, cultural and/or religious beliefs.

### *Blame, responsibility, control, and compliance*

There is widespread misunderstanding of the aetiology, management, and consequences of all types of diabetes. The dominant discourse portrays diabetes as self-inflicted, due to gluttony, laziness and/or irresponsibility.<sup>21</sup> Thus, managing diabetes has a perceived moral dimension, focused on how a person should live,<sup>22</sup> exemplified by the meta-narrative: '*should you be eating that?*'<sup>23</sup> This phenomenon traces back several centuries, and appears to have been facilitated by biased popular interpretation of modern scientific discoveries.<sup>24</sup>

In the 1990s, landmark trials demonstrated that intensive management can prevent or delay diabetes-related complications among people with T1D and T2D.<sup>25,26</sup> In the early 2000s, similarly pivotal trials demonstrated that rigorous health behaviours or medication-taking can prevent 55-58% of cases of T2D.<sup>27,28</sup> Recently, remission of T2D has been proven to be possible with intensive weight management: in 46% of intervention group at one year; and maintained in 36% at two years, and 8% at five years.<sup>29-31</sup> This evidence has generated widespread scientific, health and media interest. Part of the legacy of these studies has been to greatly increase the perception of personal responsibility for preventing diabetes and its complications,<sup>32</sup> and bring to the fore issues of 'control' and 'compliance', particularly for glycaemia and food self-regulation.<sup>22,24,33</sup> Diabetes stigma is potentially facilitated by a hyperfocus on personal responsibility, without balanced attention to genetic, environmental,

socioeconomic, psychosocial, and behavioural barriers and facilitators – nor to the intersecting social inequities and disadvantages that may also underpin those outcomes.<sup>34</sup> Relatedly, another key driver of diabetes stigma is the belief that people with diabetes are less worthy or deserving than people with other conditions.<sup>35</sup>

### *Perceived burden and sickness*

In many countries and cultures, people with diabetes are seen as ‘physically inadequate’, ‘sick’, ‘weak’ or a ‘burden’ on family, healthcare and/or societal resources.<sup>14,21,36</sup> Diabetes is linked to fears of infertility or high-risk pregnancies.<sup>37-40</sup> Diabetes is viewed as a ‘death reminder’,<sup>21,40</sup> due to perceptions of reduced life expectancy.<sup>37</sup> People may fear, and be motivated to avoid, someone who has a genetic predisposition to ‘disease’, both for their own health and for that of their (future) family.<sup>1,36,41</sup> The very use of the diagnostic label, ‘diabetic’, may ‘spoil’ the identity of a person (in the eyes of others) and leave them vulnerable to stigma.<sup>42,43</sup>

### *Visibility, fear, and disgust*

Visibility (or invisibility) can drive diabetes stigma. In countries where diabetes is ‘invisible’ (i.e., has low prevalence), there are reports of those living with T1D being described as ‘monsters’ or ‘strange’.<sup>44-46</sup> Relatedly, in some cultures, diabetes stigma is driven by fear, e.g. due to beliefs that diabetes caused by spiritual forces (e.g., karma, ‘kismet’, curses or an ‘evil eye’),<sup>47-49</sup> or that it is contagious.<sup>21,37,50</sup> In contrast, diabetes stigma may be less prevalent in countries and age groups where T2D is part of the ‘normal’ social fabric.<sup>51,52</sup>

The physical or behavioural signs of the condition and/or its management can also elicit fear or disgust. For example, leg amputation, a potential consequence of diabetes-related complications, is considered taboo in many cultures, including some Indigenous peoples, who view the physical integrity of the body as sacred.<sup>53</sup> This can also be due to myths, misunderstandings and/or (lack of) exposure.<sup>54</sup> Hypoglycaemia can cause conspicuous behaviours or physical symptoms (e.g. lack of co-ordination, altered mood or cognition, seizure), which can be mistaken for intoxication, epilepsy or mental illness (all of which carry their own stigmas),<sup>21</sup> inducing fear or disgust.<sup>22</sup> Witnessing insulin injections or finger-pricking can elicit facial reactions, giving the impression of disgust, but potentially reflecting an ‘empathic brain response’ to perceived pain.<sup>55</sup> Alternatively, such reactions may reflect an assumption that the person is injecting illicit substances, and express addiction stigma.<sup>14,21</sup> Finally, dietary modifications and, in recent years, the visibility and audibility (via alerts) of ‘wearable tech’ – including continuous glucose monitors, insulin pumps and hybrid closed loop systems – makes an otherwise ‘invisible condition’ visible,<sup>56,57</sup> potentially provoking varying reactions, from empowerment, to curiosity, fear or disgust.

### *Law, policy, and regulations*

Discrimination due to diabetes is unlawful under Disability Discrimination Acts in many countries (e.g., Canada, Denmark, Japan, UK, USA).<sup>58</sup> That is, diabetes is often considered a ‘protected disability’ because it substantially limits the function of the endocrine system. However, if people with diabetes do not realise that their health condition is classed as a disability, or do not identify with the words ‘disabled’ or ‘disability’, then they may not appreciate that the law protects them from discrimination. Further, requiring someone to

identify as 'disabled' to defend their rights facilitates a power imbalance, and may facilitate both diabetes stigma and ableism.

In addition to ambiguity, key facilitators of diabetes stigma are the absence, accessibility, enforcement of, or inconsistencies between, law, policy and regulations both within and between organisations, jurisdictions or countries. Such issues make it difficult for people with diabetes to know and advocate for their rights to health, e.g., to access affordable treatments, the freedom to use them wherever they need, in a clean and safe environment, and without having to conceal their condition.<sup>59</sup> They also make it difficult for people with diabetes to know and advocate for their broader rights, regarding education, employment, insurance, obtaining and keeping a driving licence or a pilot's licence.<sup>59</sup> For example, while several countries (e.g. Austria, Canada, Ireland, UK, USA) now permit adults with insulin-treated diabetes to hold a commercial pilot's licence,<sup>60,61</sup> most still prohibit this. Similarly, while most countries also ban people with insulin-treated diabetes from joining or remaining in the military following diagnosis, the Finland government announced its intention to reverse its ban in 2023, facilitating a more inclusive environment, and recognising that policies need to be evidence-based, with safety issues assessed on a case-by-case basis.<sup>62</sup>

Differential access to insulin administration and glucose monitoring devices (e.g., by diabetes type, treatment type, or age) may facilitate stereotypes, e.g., that T1D or insulin-treated diabetes is more serious than other types, that T1D only affects children, or that they are more deserving than adults with T2D. While the policies that create differential access may be based in (cost-) effectiveness evidence, they may also be influenced by lobbying, which is subject to power relationships, resources, and public perceptions of 'worthiness'.<sup>63,64</sup>

### Manifestations of diabetes stigma and discrimination

Across all socioecological layers – individual, interpersonal, community, organisational and policy – considerable evidence demonstrates that people with diabetes experience, perceive, and anticipate diabetes stigma (defined in Panel 1). Further, there are remarkable similarities in the sources and settings of diabetes stigma reported across diabetes types.<sup>1,14,45,50,52,65-68</sup>

Across multiple settings, people with diabetes report experiencing blame and judgment,<sup>14,52,69</sup> as well as attributions to their personality for behaviours caused by low or high glucose, and other misunderstandings.<sup>45</sup> Common stereotypes conveyed in public discourse include being assumed to be (currently or previously) 'lazy', 'fat', living an unhealthy 'lifestyle', 'negligent', and therefore culpable for having diabetes.<sup>14,37,52,57,70-76</sup> In addition, T1D is stereotyped as affecting only children,<sup>14</sup> therefore ignoring the needs of adults;<sup>77</sup> and as the 'bad' type, where a 'normal' life is not possible.<sup>57</sup> Such stereotypes vary across countries and cultures.<sup>77</sup> In some cultures and countries, people with T2D are stereotyped as 'poor', 'unintelligent', 'bad', and at 'end of life',<sup>21</sup> while in others, T2D is seen as a condition affecting those with wealth.<sup>48,52</sup>

In contrast, relatively little research has sought to explore the stigmatizing attitudes and practices of those enacting diabetes stigma. However, observable accounts of diabetes stigma and discrimination have long been documented.<sup>59</sup> Across the globe, there is evidence that people with diabetes are subject to unjustified restrictions (defined in regulation or not) related to education, employment, healthcare, driving and other licensing, travel, insurance, and (more rarely) adoption.<sup>14,44,52,78</sup>

### *Print and news media and popular culture*

Diabetes stigma is perpetuated frequently in the print and news media. Common themes include a hyperfocus on personal responsibility,<sup>52,65,70,79-82</sup> often accompanied by stigmatising imagery, e.g., unflattering depictions of large bodies, donuts, junk food, sugary drinks).<sup>80</sup> In addition, headlines, which are often sensationalist and/or inaccurate,<sup>14,70,80,83</sup> focus on the burden diabetes represents to healthcare,<sup>84-86</sup> and society,<sup>83</sup> due to the 'epidemic' of T2D.<sup>14,52,82</sup> Such headlines 'position diabetes as the anticipated consequence of obesity',<sup>83</sup> 'fostering dependence on biomedicine',<sup>82</sup> and 'serve to belittle the disease'.<sup>83</sup>

The stigmatising framing of diabetes in the media influences community attitudes and practices.<sup>87-90</sup> For example, a US study (N=2,490) identified that news media framing of T2D as caused by 'behavioural choices' or social determinants reduced support for related public health policies compared with 'genetic disposition' or no causal framing.<sup>80</sup> A UK survey found that, despite strong public support overall for T2D prevention programs,<sup>64</sup> T2D received the lowest support of the three conditions, and was lowest when the question wording included attribution of T2D to 'unhealthy eating and inactive lifestyles' versus the control condition, which did not mention any cause.<sup>64</sup>

In addition, there is considerable, observable evidence that television and film productions include stigmatising portrayals of people with diabetes. These include inaccurate and/or judgmental, dramatic and/or comedic parodies of diabetes symptoms, self-care and complications,<sup>91-94</sup> and a tendency to 'place diabetics under others' protection'.<sup>93</sup>

### *Public health campaigns*

Stigmatising, overly-simplistic, sarcastic and/or fear-based messaging and imagery are often disseminated at scale, e.g., by health organisations, diabetes associations or charities, and governments.<sup>70,90,95</sup> Many diabetes organisations globally have been criticised for similar messaging.<sup>90,95,96</sup> Comparatively little published research has examined diabetes campaigns in terms of their effectiveness or unintended consequences, and the theoretical underpinnings or evidence-base (if any) of such campaigns is unclear.<sup>90,96</sup> A recent Australian study found that while most participants (with and without diabetes) perceived no stigma, on average, 15% perceived eight National Diabetes Week campaign videos (originally broadcasted from 2005 to 2015) as stigmatising diabetes, and with little positive benefit.<sup>97</sup> Qualitative studies corroborate this finding, showing that people with diabetes express dissatisfaction with the scare tactics used in diabetes awareness campaigns.<sup>14,52,70</sup>

### *Healthcare, research, and funding*

While it is acknowledged that many health professionals are supportive, and skilled in reinforcing what is going well,<sup>98,99</sup> across the world, numerous studies show that people with diabetes experience implicit and explicit stigma from health professionals.<sup>1,14,18,50,52,98,100-103</sup> For example, people with diabetes report being blamed and judged to be a 'failure' for having diabetes, its complications and/or for what they do 'wrong'.<sup>1,14,18,38,50,52,65,104</sup> For expectant mothers, across all types of diabetes, this includes the increased risk that their behaviours may cause to their unborn baby.<sup>38,105</sup>

Fewer studies have been conducted among health professionals. Some corroborate these reports,<sup>106-110</sup> while others show health professionals perceive stigma to be less prevalent in diabetes than in other health conditions.<sup>111,112</sup> Diabetes stigma is also documented among medical and nursing trainees.<sup>106,108,109,113,114</sup> For example, a 2019 US survey of medical students showed that most believe that: a) T2D, in particular, is the result of 'poor lifestyle choices'; b) people who 'let themselves gain ridiculous amounts of weight' are 'disgusting'; and c) people with T2D are not as worthy of empathetic clinical care as those with T1D.<sup>113</sup> Such stigma may deter trainees from specialising in diabetes.<sup>114</sup>

Stigmatising language – e.g. showing bias, judgements, questioning credibility, and portraying the person as 'difficult' or having 'failed' – is included in clinical records and communications.<sup>115,116</sup> It is also included in ICD-11 classifications, e.g., 'BD54 diabetic foot ulcer', and their descriptions, e.g., 'occurring in 15-25% of diabetic patients... poor foot care... increases the risk'.<sup>115</sup> This has considerable potential for transmitting bias and influencing healthcare quality. Such language is also observed in academic research papers and presentations.<sup>117</sup>

There is also real-world evidence of such language and prejudicial views influencing government policy and political decisions regarding the funding of diabetes care.<sup>87-90</sup> In 2017, the American Diabetes Association criticised the US budget director's stigmatising view on diabetes: '*We have plenty of money... That doesn't mean we should take care of the person who sits at home, eats poorly and gets diabetes*'.<sup>118</sup> While the impacts of such attitudes on actual funding are unclear, public funding of diabetes research has been described as 'in crisis',<sup>119-121</sup> and there is a mismatch in diabetes research funding allocations, i.e. dollars / per population invested, relative to some other conditions.<sup>122</sup> Furthermore, funded diabetes research focuses disproportionately on the biomedical model.<sup>123</sup>

### *Education and employment*

In the context of school and university education, diabetes stigma appears to manifest largely in children, adolescents and young adults with T1D being treated differently by teachers or staff; exclusion, e.g. due to others' worries about hypoglycemia; or ridicule by other students.<sup>45,67,124,125</sup> Adults with T1D recall their school experiences vividly, including some teachers fueling their feeling of being different, e.g., by singling them out or treating them differently, in the presence of classmates, in relation to activities and food choices due to diabetes, potentially creating a sense of isolation.<sup>14</sup> Ironically, when exceptions are not made (e.g., allowed access to their treatments and support for managing diabetes), this can cause short and long-term health impacts.<sup>14,126</sup> In some parts of the world, students may not have appropriate support to manage diabetes in the school setting.<sup>127</sup> Elsewhere, students with T1D may stop attending, or be excluded entirely from, secondary and tertiary education due to discrimination.<sup>37,44,49,128</sup>

The attitudes of employers and colleagues<sup>129</sup> can facilitate diabetes stigma and discrimination – evident for those with T1D<sup>45,78</sup> and T2D.<sup>78,130</sup> This limits employment opportunities and career advancements,<sup>70,84,85,129-133</sup> particularly for those experiencing frequent hypoglycaemia, and/or also living with overweight/obesity or diabetes-related complications.<sup>84,134,135</sup> In the US, a review of N=328,738 allegations of employment

discrimination found that 3.5% (n=11,437) involved diabetes and that people with diabetes were more likely to encounter job-retention discrimination.<sup>136</sup>

### *Family, friends, and the general public*

Some people with diabetes report that their family and friends become the 'diabetes police',<sup>48</sup> but that the blaming, shaming or judging may be founded in good intentions.<sup>14,52</sup> Known as 'miscarried helping', this phenomenon is well-recognised in the context of adolescents with T1D and their parents,<sup>137</sup> and to a lesser extent among adults with T2D,<sup>138,139</sup> and GDM.<sup>50,140,141</sup> Across diabetes types, a key focus is on food consumption and diabetes self-management behaviours.<sup>14,52,67,104,142,143</sup> For adolescents with T1D, peers without diabetes are also a source of stigma, including instances where friends look away when they inject insulin or check their glucose levels.<sup>67</sup>

In some countries and cultures, where arranged or brokered marriages are the norm and/or where women's family or societal status is linked to marriage and childbearing, people with diabetes (in particular, T1D) have reported social status loss and rejection because of their condition. For example, being rejected for marriage or perceived as a less desirable spouse.<sup>37,40,43-46,50,144,145</sup> Women with GDM report experiencing familial blame for their diagnosis, being accused of having unhealthy babies and/or not disclosing their diabetes.<sup>38,50,140,141</sup> Parents of a child with T1D may hide the diagnosis from family, friends, and their community, and, in extreme cases, abandon or not invest in a child with T1D, as T1D is assumed to be life-limiting and 'like a black mark on the family'.<sup>45,49,57</sup>

Research suggests that people who do not live with diabetes may, incorrectly, perceive it as non-stigmatized, or less stigmatized, than other conditions, e.g., HIV or mental illness.<sup>1,111,112,146</sup> Yet, people with diabetes report the public as a key source of stigma.<sup>14,52</sup> In addition, the general public appears to believe that T1D is a condition affecting 'children who are lazy, unhealthy, fat, obese, lacking exercise, and having eating disorders'.<sup>147</sup> Social media analyses illustrate that public commentary links diabetes with obesity,<sup>148</sup> gluttony,<sup>149</sup> and perpetuates other common negative attitudes, rooted in problematic socio-cultural phenomena, such as ableism and anti-fat bias.<sup>111,148</sup> For example, a content analysis showed that Instagram posts with the trending hashtag, *#diabetesonaplate*, depict energy-dense foods and are characterised as gluttonous.<sup>66</sup>

### *The diabetes community*

Given that stigma-by-association with T2D is salient among people with T1D,<sup>74-76</sup> and parents of children with T1D,<sup>45</sup> it is unsurprising that there are reports that they resent people with T2D, and perceive that T2D attracts more research and societal resources than T1D.<sup>14</sup> Some people with T1D distance themselves by stressing membership of their 'T1D in-group' to create a 'moral boundary' by which to separate themselves from those with the 'lifestyle disease',<sup>35</sup> stereotyped as 'lazy' and 'fat'.<sup>14,70</sup> One study found that 19% of adults with T1D and parents of children with T1D suggested changing the name to disassociate from T2D.<sup>84</sup>

In turn, people with T2D may believe stigma is specific to T2D, and perceive that people with T1D are judged less harshly on account of perceptions of causality and seriousness,<sup>52</sup> and that people with T1D receive more assistance, support and access to advanced management options, e.g. continuous glucose monitoring.<sup>14,52</sup>

### *Internalised diabetes stigma*

Some people with diabetes endorse and internalise diabetes stereotypes, known as self-stigmatisation or self-stigma. Adults with T2D report feelings of embarrassment, shame, self-blame and guilt for developing diabetes.<sup>52,65,150-154</sup> Women with GDM report feelings of guilt and personal responsibility, e.g., for previous miscarriages and 'failing' their unborn child, particularly if insulin is required to manage their condition.<sup>50,140,141</sup> Self-stigma may be less common among people with T1D, and adoption of a positive diabetes identity may be protective.<sup>14</sup> However, adolescents and young adults with T1D describe feeling ashamed to manage diabetes in public,<sup>142</sup> and/or endorsing negative self-images due to the reactions of others, e.g., that they are 'weak', 'inferior', a 'burden', a 'social outcast'.<sup>67,74</sup>

### *Prevalence of diabetes stigma and discrimination*

Prevalence estimates are limited largely to adults with T1D and T2D, due to the nature of validated measures of diabetes stigma (Supplementary Table 3); there being no validated measures designed for adults with other diabetes types; nor specifically for children with diabetes. Prevalence estimates are also limited by variations in the types of stigma assessed, study designs and the limited number of countries in which they have been used. Further, prevalence may be under-estimated, as people with diabetes may not readily adopt such terms to describe their experiences.<sup>52,155</sup>

Nevertheless, research suggests diabetes stigma is a pervasive, global problem. Several large, cross-sectional quantitative studies (N>800 to N=12,000) provide consistent estimates that around four in five adults with T1D or T2D have experienced some aspect of diabetes stigma.<sup>18,20,73,84,85,102,156,157</sup> Diabetes stigma is also reported by 65% to 99% of adolescents and young adults with T1D<sup>158,159</sup> and 83% of parents of children with T1D.<sup>84</sup> Two prospective studies in the US report consistent diabetes stigma prevalence rates of approximately one in three adults with T1D or T2D (assessed over a six- or nine-month period via a brief diabetes distress stigma-specific subscale).<sup>160,161</sup> Further, around 10% reporting no issues with diabetes stigma in the past month at baseline reported such experience at follow-up, and three out of four reporting stigma in the past month at baseline scored similarly at follow-up, suggesting that diabetes stigma is enduring without intervention.<sup>160,161</sup>

In the multi-national DAWN2 study (N=8,596 across 17 countries),<sup>162</sup> a single item asked adults with T1D or T2D whether they had been 'discriminated against because of diabetes': on average, 19% endorsed the item (varying from 10%-30% across countries). A strong theme in the qualitative data from DAWN2 was public misunderstanding and discrimination at work.<sup>99</sup> Elsewhere, cross-sectional research shows up to 11% of adults with T2D report workplace discrimination or differential treatment due to diabetes.<sup>134</sup> Both diabetes stigma and discrimination appear more prevalent among women,<sup>84,163</sup> those with lower socio-economic status,<sup>164</sup> and those with T1D or insulin-treated T2D versus non-insulin-treated diabetes.<sup>84,163,165-167</sup> There is also some evidence that diabetes stigma is associated with younger age, shorter diabetes duration, and higher education level.<sup>18,20,156,164,168-173</sup> The emerging evidence is mixed regarding diabetes stigma and use of diabetes technologies, e.g., insulin delivery and glucose monitoring devices.<sup>166,167,174,175</sup>

Rates of diabetes stigma endorsed or enacted by individuals without diabetes remain largely absent from the research literature, and there are limited validated measures for use among the wider population. In Singapore, a survey of the general public (N=2,895) found that around one quarter were unwilling to have someone with diabetes marry into their family, employ someone with diabetes, or travel in a taxi or bus driven by someone with diabetes.<sup>86</sup> Further, they would not be comfortable seeing someone inject insulin, and believe that people with diabetes are responsible for 'bringing this condition on themselves'.<sup>86</sup> These evidence suggests variation in public stigma by ethnicity, age, education level, and proximity to someone living with diabetes.<sup>86</sup> In a US study of medical students (N=208), 29% endorsed a single item, 'do you have any stigma against people with diabetes?', particularly in relation to those with T2D, and were significantly less likely to endorse the seriousness of T2D.<sup>113</sup> In the 17-country DAWN2 study, societal discrimination against people with diabetes was reported by 33% of health professionals<sup>176</sup> and 22% of family members.<sup>177</sup>

### *Intersecting stigmas*

Intersectional stigma describes the concept whereby people live with multiple stigmatised or prejudicially treated conditions or characteristics. However, there is limited research exploring the experience and impacts of multiple stigmas among people with diabetes.

Several examples focus on experiences of race and gender,<sup>43,84,164,178-180</sup> For example, in a qualitative study, Black and African American adolescents with T1D spoke of how the duality of diabetes and race negatively impacted their relationships with peers and their diabetes management.<sup>181</sup> Meta-analysis demonstrates that racial/ethnic differences exist in relation to diabetes management and risk of complications.<sup>182</sup> In some cultures and countries, due to prevalent social and gender norms, girls and women with diabetes may be particularly vulnerable, as they are judgment more harshly, considered 'damaged', not an ideal marriage partner, and a potential health and financial burden.<sup>37-40,43,50,178</sup>

Among women with T2D (or prediabetes) and binge eating disorder, experiences of stigma from health professionals include judgement for their body weight and lack of weight loss, and being viewed as 'non-compliant'.<sup>183</sup> Experiences of weight-related stigma are more frequently reported by people with diabetes,<sup>14,52,66,70</sup> with pejorative labelling, and associated stereotypes, such as 'lazy', common to both diabetes and obesity.<sup>52,178</sup> Further, among adults with T2D there is a moderate-to-strong association between diabetes stigma and weight stigma, including feeling judged by health professionals due to weight.<sup>180</sup>

Other studies demonstrate experiences of the 'double stigma' of having comorbid physical health conditions (e.g. diabetes and HIV), or physical and mental health conditions, which distinguish them both physically and psychologically from their 'healthy' peers.<sup>178,184,185</sup> In several African countries, people with T2D are mislabelled 'through gossip and misinformation' as having HIV/AIDS, and thought to be 'wasting resources'.<sup>172</sup> In Cameroon, people with T2D express concerns about accepting weight loss as a legitimate approach to managing T2D 'in the era of HIV/AIDS'.<sup>185</sup>



## Consequences for people with diabetes

While prospective research is lacking, mounting cross-sectional evidence demonstrates ubiquitous, negative experiences of diabetes stigma for people living with diabetes. These are corroborated by rich, qualitative accounts of the multi-dimensional impacts of diabetes stigma on health, defined as a complete state of psychological, social, and physical well-being.<sup>186</sup>

### *Psychological well-being*

Quantitative studies show that diabetes stigma is associated with depressive symptoms,<sup>18,20,100,165,171,187-192</sup> anxiety symptoms,<sup>18,20,85,165,190</sup> and lower general emotional well-being.<sup>132,190,193</sup> Typically, there are moderate-to-strong positive correlations between diabetes stigma and diabetes distress.<sup>18,20,50,73,74,84,85,100,156,164,165,169,171,188,191-197</sup> Qualitative studies support the premise that both general and diabetes-specific emotional distress is a consequence of diabetes stigma.<sup>14,50,52,74,142,198</sup>

Diabetes stigma is associated with lower general quality of life<sup>85,199</sup> or life satisfaction,<sup>199,200</sup> and greater negative impact of diabetes on quality of life.<sup>132,195,196,201</sup> Many such impacts are illustrated in the manifestations above, e.g., education, employment, marriage and relationships. Diabetes stigma is also associated with lower general self-esteem,<sup>18,20,152,164,187,202</sup> general self-efficacy,<sup>152,164,187</sup> and resilience.<sup>168</sup> These may be outcomes of diabetes stigma and/or mechanisms of the internalisation of diabetes stigma.

Internalised stigma appears to magnify the impacts of diabetes stigma. Relative to experienced or perceived stigma, diabetes self-stigma is more strongly associated with greater diabetes distress,<sup>73,165</sup> and lower self-esteem<sup>153</sup> and general self-efficacy.<sup>73</sup> The negative cognitive and emotional consequences of diabetes stigma appear to be more prevalent among women than men,<sup>84</sup> and those with T1D, or insulin-treated T2D, compared to T2D or non-insulin-treated T2D.<sup>84,165</sup>

### *Social well-being*

Qualitative studies show the effects of diabetes stigma can include social withdrawal and avoidance of social contact, resulting in isolation or limited social, professional or other opportunities.<sup>56,74,84,124,153,198,203</sup> Those experiencing diabetes stigma are more likely to report worse interpersonal relationships with family, friends, and health professionals, less social support, and stronger feelings of isolation and loneliness,<sup>50,84,85,128,141,143,164,171,172,201,204,205</sup> and that unsupportive friendships have come to an end.<sup>52</sup> In family settings, women (with T1D, T2D or GDM) may be particularly disadvantaged, e.g., hiding their diagnosis from a (prospective) spouse, fearing abandonment, or experiencing intimidation from her husband and his family, with emotional, social and financial implications.<sup>21,38,43,44,105,206,207</sup> In workplaces, one in three adults with T1D and almost one in four adults with T2D conceal their condition from colleagues,<sup>133,193</sup> due to anticipated stigma or discrimination.<sup>52,133,153</sup>

Finally, diabetes stigma negatively impacts relationships and support in the healthcare setting,<sup>164</sup> and impacts access to quality healthcare. There is increasing evidence that when health professionals' response to above-target glucose levels is disease-focused, dehumanizing, and judgmental, or anticipated to be so, people with T1D and T2D may avoid clinic visits, HbA1c and retinal screening, and disengage from diabetes self-care tasks, due to

the feeling that their efforts are not valued.<sup>40,73,98,104,208</sup> People with T2D also report limited access to treatments, technologies and specialist care due to stigma: ‘they say ‘no, because you're type 2’’.<sup>52</sup> Similarly, women with GDM experiencing diabetes stigma also report lower engagement in healthcare (including avoidance of screening during and after pregnancy), not wanting more children, and not prioritising their own health after pregnancy.<sup>38,140,141</sup>

### *Physical well-being and self-care*

Among people with T1D and T2D, positive associations have been demonstrated between diabetes stigma and glycaemic metrics<sup>128,130,151,152,158,159,163,165,188,189,191,196,209,210</sup> While these associations are mostly small, and typically involve self-reported HbA1c, the findings are corroborated by some laboratory assessments showing up to three-fold higher odds of above-target HbA1c.<sup>158,159,163</sup> Diabetes stigma is also associated with more frequent severe hypoglycaemia,<sup>128,163,169</sup> diabetes-related ketoacidosis,<sup>163</sup> retinopathy,<sup>163</sup> hospitalisations,<sup>130</sup> and higher body mass index.<sup>169</sup> Although qualitative data support the premise that such outcomes are a consequence, rather than a determinant, of diabetes stigma, and some prospective research exists,<sup>196</sup> more is needed, and some studies find no association with HbA1c.<sup>193</sup>

Non-disclosure of diabetes, a common behavioural consequence of diabetes stigma,<sup>14,50,52,153,172,198</sup> may lead people with diabetes to compromise their self-care in public or social situations. For example, delaying or omitting glucose monitoring, and medications, particularly insulin,<sup>1,14,74,128,140,142,211-213</sup> accepting certain foods due to fear of disclosure, or binge eating as a coping strategy when faced with diabetes stigma.<sup>50,128,140,157</sup> In general, those who feel stigmatized due to their diabetes are less likely to undertake necessary self-care behaviours,<sup>73,130,140,151,152,164,165,172,188,191,194,199,200,209,213</sup> as they lack the ‘social opportunity’ to do so without retribution.<sup>214</sup> They are also less likely to have self-efficacy or activation for managing their condition,<sup>165,190,195,202,215</sup> or attend the programs that may help them to develop it.<sup>216,217</sup> Among people with T1D, diabetes stigma is associated with fear of hypoglycaemia,<sup>192</sup> hypoglycaemia avoidant behaviours,<sup>171</sup> and insulin omission.<sup>191</sup> Among adults with T2D and adolescents with T1D, diabetes stigma and self-stigma are associated with negative insulin appraisals, which are associated with greater omission of oral medications and insulin.<sup>128,169,211,218</sup> Diabetes stigma may contribute to the acceptability of diabetes technology.<sup>175,219</sup>

### *Interventions to reduce diabetes stigma and its impacts*

To date, very little empirical research has focused on strategies to reduce diabetes stigma and its impacts. However, efforts to mitigate diabetes stigma may draw on research from other health-related stigmas. For example, for *The Lancet* Commission on ending stigma and discrimination in mental health<sup>220</sup> reports that direct or indirect social contact was the most effective approach across context and cultures. Examples of other hallmarks of stigma reduction programs identified include: involving people with lived experience in all aspects of intervention development; early consideration of program scalability and sustainability; targeting policy change and funding; integration into existing services (such as clinical training); use of champions to advocate for organisational change; and evidence-based program development. Such themes are common across the diabetes stigma interventions practiced to date.

Importantly, interventions to reduce diabetes stigma and its effects need to be informed and/or led by people with or affected by diabetes and/or facilitated, for example, by diabetes organisations,<sup>221</sup> observing the mantra: #NothingAboutUsWithoutUs.

### *Changing the narrative*

Endorsement of this consensus represents a public commitment to bringing an end to diabetes stigma. For some organisations, this will require a narrative shift in their communications about (people with) diabetes. This includes the prevailing social narrative focused on blame, responsibility, control and compliance, which needs to be replaced with a balanced focus on genetic, biological, sociocultural, environmental, and behavioural factors, as well as the social inequities influencing health.<sup>222</sup> Over a decade ago, Diabetes Australia's position statement on communicating with and about people with diabetes recognised the power of language,<sup>223</sup> and inspired an international diabetes #LanguageMatters movement, with at least 14 similar national statements since.<sup>224-227</sup> The recommendations in these and other resources (e.g. via languagemattersdiabetes.com and dStigmatize.org) are designed to support changing the narrative. Some journal publishers, conferences, and funding bodies now require adoption of such language.

While few of these resources have undergone specific evaluation, studies have examined the extent to which the narrative has shifted over several years. For example, a recent study identified that 60% of diabetes scholarly articles published since 2011 used person-first language (in addition to or in the absence of condition-first language), with a 3% annual increase.<sup>117</sup> With regard to the media, two studies have evaluated changes in language used in Australian newspaper coverage of diabetes.<sup>228,229</sup> One study observed a significant reduction in the use of problematic language between 2010 and 2014,<sup>229</sup> while both identified continued use of labelling (commonly referring to 'diabetics') and lack of specificity regarding diabetes type.<sup>228,229</sup> Nonetheless, these findings suggest incremental uptake of the #LanguageMatters movement in scholarly and media reporting on diabetes. Further research is needed to examine the adoption of recommended language and to optimise implementation in other settings, e.g., by diabetes and health organisations, among health professionals, and on social media. For example, one group has developed and demonstrated the acceptability of a brief video to train health professionals to decrease the use of stigmatising language in healthcare encounters,<sup>230</sup> which warrants further evaluation.

Positive portrayals of people with visible signs of diabetes, and its potential complications, are also important to counter stereotypes and promote inclusivity.<sup>231</sup> Yet, stereotyping imagery continue to be used in the print and news media, popular culture, as well as in public health campaigns, and health information sheets,<sup>90</sup> the latter often aiming to scare/shock people into acting to prevent or manage diabetes. In addition to #LanguageMatters, there is a call to consider more carefully the imagery associated with diabetes. A study of diabetes Facebook posts found that positive imagery was the strongest predictor of liking a post and of sharing it.<sup>232</sup> Such images included healthy foods, activity and achieving goals. Drawing inspiration from weight-stigma reduction strategies,<sup>233</sup> development and implementation of diabetes-specific image banks may support use of respectful imagery.

### *Policy, advocacy, and funding*

Health and diabetes organisations play a key role in communicating and protecting the rights of people with diabetes, quality healthcare, information and education about diabetes, and to social justice, including fair treatment.<sup>4</sup> Diabetes organisations have a strong history of advocacy and providing support for people experiencing diabetes discrimination. The IDF focused on calling out diabetes stigma and discrimination in its global diabetes plan and advocacy toolkit.<sup>6,234</sup> Since 2013, the IDF's KiDS project has addressed 'diabetes-related stigma by fostering a safe and supportive school environment for children with diabetes'.<sup>235</sup> In addition, many provide legal advocacy,<sup>236-238</sup> training to prevent discrimination in workplaces and/or schools,<sup>238</sup> and advocate for equitable and sustained access to diabetes treatments and technologies.<sup>234,239-241</sup>

Increasingly, diabetes organisations across the globe are making public commitments to address diabetes stigma and discrimination. In their multi-year strategic plans, highlighting the pivotal need to challenge diabetes stigma, Diabetes Canada has committed to 'change the conversation';<sup>242</sup> and Diabetes UK has prioritised preventing discrimination due to diabetes,<sup>243</sup> and recognised that more research into diabetes stigma is pivotal to improving the mental well-being of people with diabetes,<sup>244</sup> and dedicated funding to support this.<sup>242</sup> In 2022, the diaTribe Foundation launched the [dStigmatize.org](https://www.dstigmatize.org) website.

In recent years, Diabetes New Zealand, Diabetes Australia, and Diabetes UK have used their national campaigns to raise awareness of diabetes stigma,<sup>245-247</sup> and many more organisations address diabetes myths and misconceptions about diabetes. Whilst such campaigns respond directly to the call to action against diabetes stigma, and have been widely viewed, no formal evaluations have been published. Thus, it is unclear whether they had reach or impact. It is also unclear whether such campaigns are based on theory or evidence for how to bring about such change.<sup>5,90</sup>

Given the complexities of health, and the numerous conditions affected by stigma and discrimination, then taking an intersectional approach to stigma may assist with identifying and tailoring solutions to address diabetes stigma, drawing on effective stigma reduction initiatives in other conditions, while accounting for the diverse characteristics, experiences, and needs of people with diabetes. Further, it has been argued that to bring an end to health stigma broadly, research must evolve beyond specific interventions, such that an intersectional approach, with cross-disciplinary advocacy and action is required.<sup>248</sup>

### *Healthcare*

Improving attitudes (and practices) among health professionals is an important strategy to mitigate diabetes stigma, since they occupy positions of power/influence and have frequent contact.<sup>249</sup> However, to date, little research has examined strategies to combat enacted diabetes stigma in healthcare settings.<sup>250</sup> There is some evidence for contact-based approaches in diabetes,<sup>108,113</sup> corroborated by studies in obesity or mental health conditions,<sup>220,249,251-254</sup> whereby positive exposure and interaction with individuals who have experienced stigma can reduce bias and stigma through increased empathy and understanding. Further, compared to non-specialists, diabetes specialists are more likely to be aware of diabetes stigma among people with T2D, potentially indicating greater

understanding and empathy with increased contact with people.<sup>146</sup> There is a critical need to provide training for healthcare professionals in stigma-free communication and consultations. Education in empathic, person-centred care, including use of preferred diabetes language, may mitigate stigmatization in diabetes care settings.<sup>206,227,255</sup> However, limited research has explored the role of such education in minimizing diabetes stigma.

There remains a fundamental barrier to ending diabetes stigma in healthcare. While the medical model prevails across health systems, psychosocial and environmental determinants of health and well-being are minimised. Many health professionals intervene to treat 'diabetes', rather than care holistically for the person with diabetes. The power imbalance inherent in the medical model places the 'patient' in a passive role as the recipient of care given by the 'provider' and reduces diabetes management to the behaviour of the person ('compliance') without acknowledging the complex biopsychosocial, and socio-ecological factors that affect their capability and opportunities for behaviour change and optimal health. Professional bodies can play a critical role in the provision of stigma-free practice guidance and training. Arguably, the recent ADA/EASD consensus reports on managing T1D<sup>256</sup> and T2D<sup>257</sup> represent the greatest progress to date in acknowledging these complexities. For example, both include relatively detailed recommendations regarding psychosocial care, which will require a paradigm shift (in many countries) in the provision of clinical care and a reimagining of health systems and settings. Thus, there remains far more progress to make.

### *Supporting people living with diabetes*

It is critical that we take up the call to reduce enacted stigma at all levels, but such multi-level societal change will take time. While diabetes stigma persists, it is important that people living with diabetes can recognise, challenge and cope with diabetes stigma, maintain their self-esteem and avoid self-stigma. It has been asserted that 'addressing self-stigma might be equally as essential as measuring HbA1c'.<sup>210</sup> However, research on 'what works' is lacking.

There is a need to examine the (protective) mechanisms of diabetes stigma, with prospective follow-up, and to develop and test the effectiveness of novel interventions to reduce the internalisation of diabetes stigma, based on such mechanisms, which include: endorsing genetic causal beliefs;<sup>200</sup> enhanced resilience;<sup>168</sup> self-esteem;<sup>152,153,165,202,203,258</sup> self-confidence or self-efficacy;<sup>103,151,152,202,258</sup> accepting and integrating diabetes as a part of ones' own identity;<sup>153,258</sup> performing effective self-care activities to achieve the optimal diabetes management;<sup>152,153,196,202,203,209,258</sup> and social support.<sup>165,258,259</sup>

As a starting point, intervention might include acknowledgement of diabetes stigma and its impacts within existing programs and resources, e.g., diabetes education, psycho-education, peer and social support. Further, researchers might consider examining the impacts of existing programs/interventions on internalised diabetes stigma using comprehensive assessment tools (Supplementary Table 3). The use, and potential optimization, of existing interventions/programs may be a more timely and cost-effective approach to supporting those affected by diabetes stigma than the development of novel stigma-specific interventions. For example, family members and peers have been identified elsewhere as an under-utilised resource for ongoing support,<sup>260</sup> and their inclusion in diabetes self-management education may facilitate increased empathy and improved understanding of how they best support their loved ones. Studies have shown a reduction in 'negative social perceptions' (T1-DDS subscale) following 12 weeks of continuous glucose monitoring in

children and adolescents with T1D,<sup>175</sup> and in the T1-REDEEM trial among adults with T1D and elevated HbA1c.<sup>261</sup> This is promising evidence, given neither study specifically focused on reducing diabetes stigma.

Strategies for disclosure may inform useful interventions to enable people with diabetes to seek and receive support.<sup>262</sup> In Iran, a qualitative study investigated culturally appropriate strategies to inform development of a multi-level intervention for adults with T1D experiencing diabetes stigma.<sup>206</sup> Several strategies were identified: condition acceptance, enhancing self-esteem and self-confidence, effective diabetes self-management, and having a peer support network. However, the intervention has not been evaluated systematically. In Japan, researchers and adults with T2D experiencing self-stigma designed a 10-week psycho-educational intervention (e.g., brief videos incorporating lived experience narratives, accompanied by homework). The intervention appeared acceptable and likely beneficial in a small feasibility study,<sup>263</sup> and warrants further evaluation in a larger study.

## Discussion

For this Consensus, a multi-disciplinary panel applied their lived and professional expertise to the goal of making explicit the nature and extent of diabetes stigma and discrimination, key drivers and facilitators, consequences, and the available evidence for interventions, as well as making evidence-based recommendations for what is needed to bring an end to diabetes stigma, discrimination, and their harmful effects. Furthermore, near unanimous consensus was achieved on this Evidence and Recommendations (Tables 2 and 3), and unanimous consensus was achieved on a Pledge to end diabetes stigma and discrimination (Panel 3).

Despite evidence of widespread diabetes stigma and discrimination, with manifestations reported consistently across cultures, demographic contexts, and diabetes types in which it has been examined, there are evidence gaps. Thus, we call for future research to: focus on the experiences of diabetes stigma across all life stages and among minority and marginalised communities; conduct validated assessments of stigmatising attitudes and practices in the wider community; to use prospective designs to confirm theorised causal relationships between diabetes stigma and various potential consequences: psychological, social, behavioural, clinical and policy/societal, and; to review the recommendations proposed in relation to emerging evidence. Such research may benefit from international collaboration to achieve a co-ordinated and comprehensive approach to understanding all aspects of diabetes stigma across settings, ethnicities, cultures, and countries. Furthermore, there is urgent need to develop and/or evaluate interventions designed to reduce diabetes stigma, using appropriate study designs, which preferably include randomised designs with larger sample sizes, longer follow-up periods and validated outcome measures.<sup>249,254</sup>

The media, health industry, organisations, and professionals, researchers, and research institutions all play a role in practicing or reinforcing diabetes stigma. For example, through use of simplistic, fear-based imagery and messaging, which potentially exacerbate stereotypes of individual responsibility and blame, which are then perpetuated by the general public, friends and family.<sup>90,264</sup> To end diabetes stigma, we need to recognise that understanding of diabetes is socially constructed.<sup>265</sup> We need to challenge the prevailing social narrative focused on personal responsibility, and replace it with a balanced focus on

genetic, biological, sociocultural, environmental, behavioural factors and the social inequities influencing health, which is consistent with recent calls for systems-based approaches to addressing non communicable disease.<sup>266</sup> Furthermore, communications about diabetes (and people with diabetes) need to use accurate, respectful and empathetic words, messaging and imagery.<sup>5,267</sup> This requires both individual-level change as well as a systems-level commitment to stop perpetuating or facilitating diabetes stigma. Finally, efforts to reduce diabetes stigma must avoid perpetuating stigma elsewhere (e.g. among people with other types of diabetes, conditions, experiences, or identities), and consider the impacts of intersecting stigma on individuals and communities.

If we do not commit to bringing an end to diabetes stigma and discrimination, we might expect further exacerbation of potential harms, including for the individual's emotional, mental and physical health, self-care, access to optimal healthcare, and for their quality of life, including social and professional opportunities. Such harms are magnified when individuals with diabetes internalise stigma,<sup>114</sup> leaving them susceptible to the damaging effects of isolation.<sup>268,269</sup> Diabetes stigma also affects healthcare workforce capacity, as well as public and government support and funding for diabetes research, prevention, clinical care and novel treatments – support that is already described as 'in crisis'. There is urgent need to strengthen and achieve greater consistency in laws/policies to ensure discrimination due to diabetes is unlawful across the globe.

### Strengths and limitations

The broad strengths are that this consensus was informed by a diverse expert panel, published peer-reviewed evidence, and a rigorous, independently conducted Delphi survey process. International panellists included people with lived and/or family experience, clinical and/or research experience in diabetes stigma. Thus, from beginning to end, there was meaningful engagement and collaboration across communities affected directly by diabetes. Although the expert panel comprised 51 members from 18 countries, most are from high-income countries. We acknowledge the inherent potential for selection bias in the international consensus, including the relative lack of representation of experts from low-to-middle-income countries, with rarer types of diabetes, or from Indigenous, migrant, and other minority populations. The relevance of the evidence and recommendations need to be examined within local contexts. The acceptability of a public endorsement of the draft Pledge was not explored exhaustively prior to finalisation. However, the pledge has since been taken by organisations and individuals in more than 95 countries, 59% of which are low-to-middle income countries, suggesting the Pledge is relevant and being embraced across the world.

We took a systematic approach to identifying, understanding and communicating the available evidence in the form of brief Statements of Evidence and Recommendations and the Pledge. We conducted a systematic search, but not a systematic review. Neither the search terms nor the databases searched were exhaustive, and papers were only returned if the search terms appeared in the title (i.e., a focus of the paper) and were published in English. Rapid reviewers were encouraged to add relevant papers identified by other means. Evidence synthesis was necessarily succinct; thus, detail may have been omitted that could have been informative. In addition, the evidence base is further limited by the lack of published stigma research focused on rarer types of diabetes, other sub-populations, or conducted in low-to-middle-income countries. Although the rapid reviews were undertaken

by expert panel members, and peer reviewed by other panel members, the evidence was not formally appraised or weighted for quality.

### Next steps

The Pledge has already been endorsed by >2,000 individuals and >240 organisations globally in >95 countries. It has also been translated into several languages. We extend an open invitation to individuals and organisations across the world to endorse and, most importantly, implement the Pledge. To do this, meaningful community engagement with people with diabetes is necessitated to identify localised stigmatising practices (as it may not be apparent to those perpetuating them) plan, develop and implement research, initiatives, and policies to address diabetes stigma. We hope that the Pledge and the Statements of Recommendations will provide the necessary impetus for collective leadership, commitment, and action across sectors. We hope it has the potential to inspire: a) diabetes and healthcare organisations to include goals/action plans for reducing stigma and discrimination in their multi-year strategic plans, e.g. following the examples of organisations such as Diabetes Canada and Diabetes UK.<sup>242,243</sup> b) policy makers to take localised actions, which may have global impact, such as strengthening legal protections and accelerating broader rights regarding education, employment,<sup>62</sup> insurance; and c) greater emphasis on the importance of compassionate healthcare. We hope it may reduce barriers to public funding of diabetes prevention, care, and research. We anticipate that diabetes stigma enacted by the general population and in the general media will be more challenging to dismantle but we hope it may erode over time as people (with and without diabetes) increase their confidence to call out diabetes stigma and discrimination wherever it exists.

### Conclusions

Our multi-disciplinary panel with lived and professional experience of diabetes stigma and discrimination has generated and achieved consensus on 25 Statements of Evidence and 24 Recommendations, and a Pledge, which has been endorsed in >95 countries across the world. While we acknowledge that prospective research is needed, our consensus is that there is convincing evidence that diabetes stigma and discrimination are ubiquitous, insidious, pervasive, harmful, and counterproductive. Bringing an end to diabetes stigma and discrimination is both necessary and urgent. It will require multi-faceted, long-term solutions, involving international collaboration, and collective leadership from all sectors of the community (including people with and affected by diabetes, and those working in advocacy, research, healthcare, media, industry, and policy). It will require all of us to challenge our own biases, and to recognise how we may be contributing to, or facilitating, diabetes stigma and discrimination (which includes both action and inaction). Together, we can change the social norm from stigma to support.



## Contributors

This consensus was conceived by JSp, and operationalised with contributions from EHT, MG and RS. JSp, EHT, MG and RS identified and invited panel members. EHT and JSp prepared the consensus methods (which were reviewed by the panel) and conducted the systematic search and abstract screening. A subgroup of panel members (Table 1) conducted rapid reviews and prepared and/or peer-reviewed draft evidence summaries, and draft Statements of Evidence and Recommendations. JSp, EHT, MG, RS and TCS refined the draft Statements of Evidence and Recommendations and drafted a Pledge prior to the first survey and informed by panel feedback following survey rounds one and two. The three surveys were designed by EHT and JSp with input from panel members. Panel members reviewed, rated, and provided feedback on the draft Statements of Evidence and Recommendations, and the Pledge, via three Delphi surveys. EHT double-checked anonymised survey data to ensure accuracy of analyses and reporting. JSp and EHT prepared the first draft of the consensus manuscript, and led subsequent revisions, based on panel review and feedback. All named authors have formally endorsed the Statements of Evidence and Recommendations and taken the Pledge. All named authors meet the International Committee of Medical Journal Editors (ICMJE) criteria for authorship for this article, take responsibility for the integrity of the work, and have given their approval for publication.

## Declaration of interests

JSp and EHT are employed by Deakin University, and JSp is also employed by Diabetes Victoria. In the past 3 years, JSp and EHT have received competitive research grants from the Diabetes Australia Research Program, the Medical Research Future Fund Targeted Translational Research Accelerator, and the National Health and Medical Research Council of Australia. JSp and EHT have received an investigator-initiated research grant from Sanofi Diabetes and an unrestricted educational grant from Diabetes Australia. JSp has also received a competitive research grant from the Ian Potter Foundation, a research contract from the Australian Government Department of Health, and a consulting fee from Diabetes Canada. JSp received honoraria to present at educational meetings from Novo Nordisk and Sanofi Diabetes, honoraria for participating in Advisory Boards from Insulet and Sanofi Diabetes, and support for attending meetings (including travel) from the Novo Nordisk Foundation. EHT received honoraria for presentation at educational meetings from Roche Diabetes Care. All payments have been made directly to their research centre (ACBRD). The ACBRD owns the copyright of the type 1 and type 2 Diabetes Stigma Assessment Scales. JSp is the Chair, JSt the Vice-chair, and EHT website re-development lead, of the international PsychoSocial Aspects of Diabetes (PSAD) Study Group (unpaid roles). MG has received project funding from One Drop, Eli Lilly, Boehringer Ingelheim and Eli Lilly Alliance, Abbott, and Genentech, and honorarium from Sanofi and Diabetes Sisters (all paid to the diaTribe Foundation). IWT has shares in Novo Nordisk a/s. ASe has received competitive research grants from the Juvenile Diabetes Research Foundation and Auckland Medical Research Foundation (all paid to the University of Auckland), and conference attendance support (as an invited speaker) from the International Society for Pediatric and Adolescent Diabetes. BA was invited to present at RAPID conferences hosted by PSAD and Steno. MdG has received competitive research grants from the American Diabetes Association and National Institute of Health (National Institute on Aging), and received consulting fees from Mediflix Inc, and Kenner Family Foundation. SH has received consulting fees from Novo Nordisk, Lilly Diabetes Care,

Medtronic Diabetes Care, and Dexcom Germany; payments of honoraria from Novo Nordisk, Ascensia Diabetes Care; payment for expert testimony from VitalAire; support for attending meetings from Ascensia, Diabetes Center Berne, Diabeloop, Dexcom, Lilly, Medtronic, Novo Nordisk, Sanofi, Tandem, embecta, dotcool, and; receipt of medical equipment from Abbott Diabetes Care, Dexcom, Ypsomed. SH is Head of Communications, #dedoc° / Dedoc Labs GmbH. RIGH has received research support from Novo Nordisk; speaker honoraria from EASD, Eli Lilly, Encore, Liberum, Novo Nordisk, and ROVI, and; conference attendance funding from Novo Nordisk and Eli Lilly. KK is supported by the National Institute for Health Research (NIHR) Applied Research Collaboration East Midlands (ARC EM) and the NIHR Leicester Biomedical Research Centre (BRC). KK has received research funding from AstraZeneca, Boehringer Ingelheim, Lilly, MSD, Novartis, Novo Nordisk, Roche, Oramed Pharmaceuticals and Applied Therapeutics and Sanofi; consultancy fees from AstraZeneca, Boehringer Ingelheim, Lilly, MSD, Novo Nordisk, Roche, Sanofi and Servier, and payments of honoraria from AstraZeneca, Boehringer Ingelheim, Lilly, Novartis, Novo Nordisk, Roche and Sanofi. RLP has received research funding from the National Institute of Health (paid to institution), and presentation honorarium from the Diabetes Leadership Council. RLP is Chair of Policy Track for The Obesity Society Annual Meeting Program Committee (unpaid role). RMP has received research funding and consultancy fees from Eli Lilly & Company. MSe has received funding support to attend the International Diabetes Federation and the International Society for Pediatric and Adolescent Diabetes. MV has received investigator-initiated research funding from Abbott, Bausch and Novo Nordisk; consulting feeds from Abbott, Abbvie, Boehringer Ingelheim, Novo Nordisk; payments and travel support from Abbott, Abbvie, Boehringer Ingelheim, Novo Nordisk, Lilly, Merck, Pfizer; pending patent with AmpHealth for a digital health intervention; and in Diabetes Canada Mission Committee member (unpaid role).

The following members of the expert panel declare no conflicts of interest: RS, SB, AK, VP, SD, SJG, KLJ, SL, IW, KMB, BC, JKD, JAH, ECM, GN, SOD, PW, HA, LCK, CSA, ED, MdW, PD, WJ, KKN, TL, CL, BMN, DN, SP, ASa, CS, JSe, MSu, HTM, VV and TCS.

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## **Declaration of generative AI and AI-assisted technologies in the writing process**

During the preparation of this work, the subgroup of authors responsible for refining Statements of Evidence and Recommendations and the Pledge used ChatGPT to improve the clarity or brevity of some Statements and the Pledge. After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content. Further, the Statements and Pledge were then subject to Panel ratings and feedback via the Delphi process. The authors take full responsibility for the content of the publication.

Impresso

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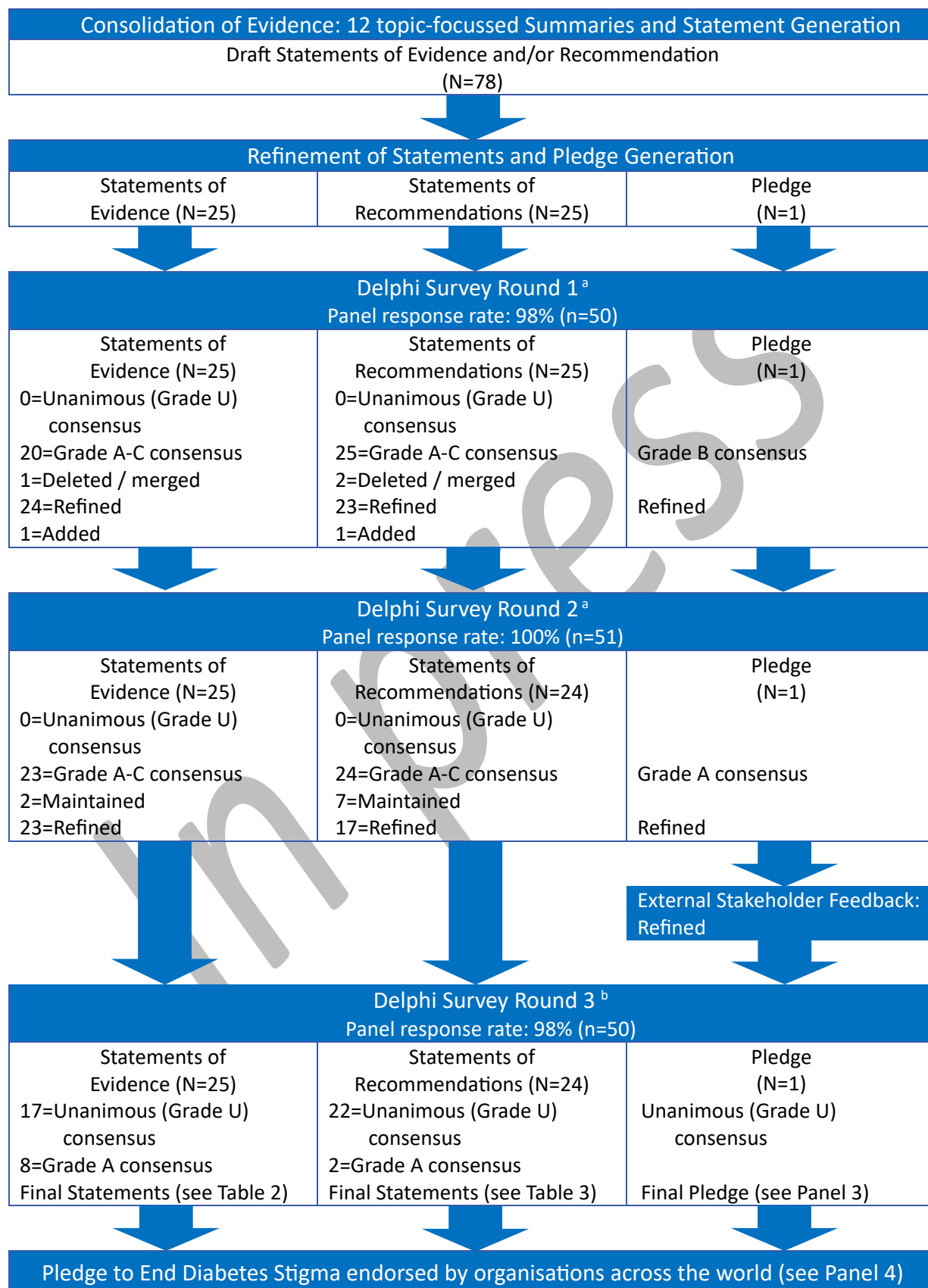


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**Figure 1. Flowchart of steps towards an international consensus on diabetes stigma**



<sup>a</sup> Round 1 and 2 consensus grading based on valid “fully agree” responses

<sup>b</sup> Round 3 consensus grading based on valid “agree” responses

## Panel 1. Definitions of diabetes stigma and discrimination

**Diabetes stigma** refers to negative social judgments, stereotypes, and prejudices about diabetes, or about a person/group due to their diabetes, occurring typically in the context of a power imbalance. There are several types:

- **Experienced (or enacted) stigma** refers to tangible examples of diabetes stigma.
- **Perceived (or felt) stigma** refers to belief in, or awareness of, the existence of diabetes stigma.
- **Anticipated stigma** refers to the expectation or fear of experiencing diabetes stigma.
- **Internalised stigma (or self-stigma)** refers to a cognitive bias in which diabetes stigma is absorbed and endorsed, leading to self-blame or shame.
- **Intersectional stigma** refers to diabetes stigma converging with other stigmatised conditions (e.g. obesity, schizophrenia) or characteristics (e.g. race, ethnicity).

### **Diabetes discrimination:**

- **At an individual level** refers to the unfair or prejudicial treatment of a person due to their diabetes, occurring typically in the context of a power imbalance.
- **At a structural level** refers to the societal or cultural norms, and/or institutional or organisational practices, that constrain a person's rights to social justice, fair and equitable treatment, due to their diabetes, occurring typically in the context of a power imbalance.

## Panel 2. Search strategy, selection criteria and rapid reviews

A systematic search was designed (by JSp and EHT) and conducted of the Scopus and PubMed scientific literature databases (31 Jan 2023; by JSp), using the following terms (with no set limits):

- Scopus: "(TITLE(diabet\*) AND TITLE(stigma OR bias OR prejudice OR discriminat\*))"
- PubMed: "diabet\*[Title] AND (stigma[Title] OR bias[Title] OR prejudice[Title] OR discriminat\*[Title])"

Search strings were limited to TITLE to maintain focus on diabetes stigma. Search returns were uploaded to Covidence for duplication removal. Applying inclusion/exclusion criteria (Supplementary Table 1), JSp and EHT screened titles/abstracts independently, followed by full-texts where needed, and discussed and resolved discrepancies.

Scopus and PubMed returned 465 and 395 titles respectively, resulting in a combined 504 titles after duplicates were removed. Of these, 344 were excluded based on title/abstract screening and 43 following full-text review. In total, 116 relevant articles were shared with panel members to inform 12 topic-specific rapid reviews (Supplementary Table 2).

When developing the evidence summaries of the 12 topic-focused rapid reviews, panel members had autonomy to add references not delivered via the systematic search, based on searches of reference lists or known literature (Supplementary Table 3). Following peer-review and revisions, the summaries were synthesised further (see *Summary of Evidence*).

### Panel 3. Pledge to end diabetes stigma

I / We PLEDGE to contribute pro-actively to bring an end to diabetes stigma and discrimination by:

- respecting people with all types of diabetes.
- recognising diabetes stigma exists and has harmful impacts.
- acknowledging and challenging my/our own prejudices about (people with) diabetes.
- using accurate, respectful, inclusive, non-judgmental, and strengths-based language, messaging, and imagery when communicating with or about people with diabetes.
- avoiding and challenging fear-based messaging and imagery.
- condemning discrimination due to diabetes and advocating for equal treatment and support for people with diabetes.
- encouraging initiatives, policies, and laws that promote equity for all people with diabetes.

By taking this pledge, I am / we are committed, from here on, to creating a more compassionate and respectful world for people with diabetes, free from diabetes stigma and discrimination, and the harms they inflict.

Impress

## Panel 4. Organisations that have taken the Pledge, at 6 November 2023

Organisation, Country
@diabetestiponadaeimpossivel, Brazil
#dedoc, Germany
#diabeteschat, UK
AB Health and Fitness, Australia
Abbott Australia, Australia
Action4Diabetes, Malaysia
Africa Diabetes Alliance, Uganda
Agent de santé, Mali
Alfred Alliance in Diabetes, Australia
Amd880830d69, Mexico
American Diabetes Association, USA
Amp Health, Canada
Arrive Psychology, Australia
Ascensia Diabetes Care, Switzerland
Asociación Creciendo con Diabetes, Guatemala
Asociación Diabetes Madrid, Spain
Asociacion Mexicana De Diabetes En Chihuahua Capitulo Chihuahua, Mexico
Asociacion Mexicana De Diabetes En Guanajuato Capitulo Valle De Santiago, Mexico
Asociacion Mexicana De Diabetes En San Luis Potosi,A.C. , Mexico
Association des diabétiques du Finistère (AFD29), France
Association Luxembourgeoise du Diabète, Luxembourg
Association of Diabetes Care and Education Specialists (ADCES), USA
Australasian Diabetes in Pregnancy Society, Australia
Australasian Type 1 Diabetes Immunotherapy Collaborative (ATIC), Australia
Australia and New Zealand Society for Paediatric Endocrinology and Diabetes, Australia
Australian Centre for Accelerating Diabetes Innovations (ACADI), Australia
Australian Diabetes Clinical Quality Registry, Australia
Australian Diabetes Educators Association (ADEA), Australia
Australian Diabetes Society, Australia
Bairnsdale & District Diabetes Support Group, Australia
Be Fit Food, Australia
Behavioral Diabetes Institute (BDI), USA
Behavioral Neuropsychology Llc, USA
Bermuda Diabetes Association, Bermuda
Beyond Type 1, USA
BHR Limited, UK
Calamred Health, Zimbabwe
Cambridge Diabetes Education Programme (CDEP), UK
CDE Academy, South Africa
Center for Integration Science in Global Health Equity/ NCDI Poverty Network, USA
Central Coast Local Health District Paediatric Diabetes Team, Australia
Centro Integral Para Personas con Diabetes Mellitus Tipo 1 A.C, Mexico
Charles Perkins Centre - Type 1 Diabetes Node, Australia
Charles Perkins Centre, The University of Sydney, Australia
Chen Min Ling medical clinic, Taiwan
Children with Diabetes, USA



<b>Organisation, Country</b>
Close Concerns, USA
Columbus Street Partners, UK
Con Diabetes Si Se Puede I.A.P., Mexico
Cube, Australia
Danish Diabetes Association, Denmark
Danish National Institute of Public Health, Denmark
DataColada, Australia
DCB Global Center for Technology Innovation in Diabetes, Switzerland
Deakin University, Australia
Deep Digital Phenotyping Research Unit, Luxembourg Institute of Health, Luxembourg
Dexcom Inc., USA
Diab'aide, France
DiaBeating The Odds, USA
Diabete Italia, Italy
Diabeter, Netherlands
Diabeter Centrum Amsterdam, Netherlands
Diabetes - What To Know, USA
Diabetes Advocacy, Canada
Diabetes and Health Solutions, Australia
Diabetes and Limbs Salvage Foundation (DLSF), Nigeria
Diabetes Australia, Australia
Diabetes Collaborative Clinical Trial Network, Ireland
Diabetes Complete Care, Australia
Diabetes Connections, USA
Diabetes Daily Grind, USA
Diabetes Edinburgh, UK
Diabetes Education Services, USA
Diabetes India Youth in Action, India
Diabetes Initiative Indonesia, Indonesia
Diabetes Inteligente, Argentina
Diabetes Psychology Network UK, UK
Diabetes SA, Australia
Diabetes Sisters, USA
Diabetes South Africa, South Africa
Diabetes Specialists, Australia
Diabetes Technology Research Group (DTRG), Australia
Diabetes UK, UK
Diabetes Venture Fund, Serpentine Ventures, Switzerland
Diabetes Victoria, Australia
Diabetic Accessories SA, South Africa
Diabetics Doing Things LLC, USA
Diabulimia Helpline, USA
Dia-Log, UK
DIAM, French Guiana
DiapointME, UAE
Diathrive Health, USA
diaVerge Diabetes Education & Coaching, USA
Diavivir aprendiendo a vivir con diabetes ac, Mexico

<b>Organisation, Country</b>
DigiBete, UK
Diversity in diabetes, USA
Diyabet Gelismeleri, Turkey
DNC Egypt, Egypt
Dnyaneshwari Foundation, India
dQ&A, USA
Dr. Traci's House, Inc., USA
DSN Forum UK, UK
DUET diabetes Limited, UK
EdHealth Australia, Australia
Embecta Corp., USA
European Association for the Study of Diabetes (EASD), Germany
Exivision Infotech Private Limited, India
Expert by experience and HCP, UK
Faculty of Pharmacy, Jordan University of Science and Technology, Jordan
Fayisa (community-based organization), Kenya
Federación Mexicana de Diabetes, A.C., Mexico
FENAREDIAM, France
FFD, Franch
FlashGM Study, Australia
Food & Life Personalised Nutrition, Australia
Friends of Mewar, India
Functional Rehab, Australia
Fundación Argentina Diabetes, Argentina
Gloucestershire CCG (ICB), UK
Glucomundo, Spain
Glucose Toujours, France
Glycemic Index Foundation, Australia
Grupo Beta de niños con diabetes tipo 1 IAP, Mexico
Guerreros Azules, Venezuela
Hanna Diabetes Exper, Switzerland
Health Finance Institute, USA
HealthScape LifeSciences LLC, USA
Hope in the Mess Telephone Counselling Service, Australia
In-Range Animation, USA
INS -DPSofala, Mozambique
Institute for Health Transformation, Australia
Instituto de Saúde Mental e Diabetes / Mental Health Institute, Brazil
Insulet, USA
Insulin For Life Global, Australia
International Alliance for Diabetes Action (IADA), USA
International Diabetes Experts Consortium, India
International Diabetes Federation Europe (IDF Europe), Belgium
Japan Diabetes Society, Japan
JCS/T2D A Diabetes Joruney, USA
JDRF (International), USA
JDRF Australia, Australia
Kathmandu institute of Child Health, Nepal

<b>Organisation, Country</b>
KnowDiabetes, Australia
Leicester Diabetes Centre, UK
Life for a Child, Australia
LifeScan, USA
Living Evidence for Diabetes Consortium, Australia
Lord of War, Inc., USA
Mahidol Public Health Association, Burkina Faso
Médecin référent diabète, Antigua And Barbuda
Medical Monofilament Mfg, USA
Meethi Zindagi, Pakistan
ME Health Clinic, Australia
Menopause Mithers, UK
Men's Agenda for National Development Sierra Leone, Sierra Leone
MIBH-Diabetes Services, Australia
Michigan Medicine, USA
Midwest Diabetes Advocacy Group, Ireland
Mount Sheridan Medical Practice, Australia
My Type Of Family, UK
Narienshi, Comoros
National Association of Diabetes Centres (NADC), Australia
NCDI Poverty Network, Rwanda
Network Movement for Youth and Children's Welfare (NMYCW), Sierra Leone
New Zealand Society for the Study of Diabetes (NZSSD), New Zealand
Newcastle University, UK
NHS South East London ICB, UK
Nldoc, UK
Non-Communicable Diseases Alliance Kenya, Kenya
North East Essex Diabetes Service (NEEDS), UK
Northern Frontier Medical Association, Kenya
ONG Santé Diabète, France
ONG Santé Diabète, Mali
PDC Health Hub by Perth Diabetes Care, Australia
PDC Type 1 Diabetes Collective, Australia
People's Diabetes Foundation, Belize
Pop Policy, Australia
Portale Diabete, Italy
Positive on Glucose, Lebanon
Primary Care Diabetes Europe (PCDE), Spain
Primary Care Diabetes Society of Australia (PCDSA), Australia
PSI Division of Health Psychology, Ireland
Psychological Society of Ireland, Ireland
PsychoSocial Aspects of Diabetes (PSAD) Study Group (international), UK
Queensland Diabetes and Endocrine Centre, australia
Ray Kelly Fitness Pty Ltd, Australia
Rays of Hope Support Initiative (ROHSI), Nigeria
Reconciliation And Development Association (RADA), Cameroon
Rentokil-Initial, Australia
Republikadiabetes.com, Spain

<b>Organisation, Country</b>
Research Society For Study Of Diabetes In India, India
Rio Tinto Children's Diabetes Centre; a JDRF Global Centre of Excellence, Australia
Roche Diabetes Care South Africa, South Africa
Royal Melbourne Hospital Dept Diabetes & Endocrinology, Australia
SA Diabetes Advocacy, South Africa
Sante Kildare, Canada
Satsar Hospital Batala, India
SFD, France
sisu Health Group, Australia
Sitara, Comoros
Smiths Outdoors, Australia
Société Luxembourgeoise de Diabétologie SLD, Luxembourg
Southern New Mexico Diabetes Outreach, USA
Specialist Diabetes Services, Australia
Spring Valley Care Services, UK
St Hemmingways (community-based organization), Kenya
Sweet Life Diabetes Community, South Africa
Sydney Endocrinology, Australia
T1D Exchange, USA
Taiwan Medical Clinics Association, Taiwan
The Australian Centre for Behavioural Research in Diabetes (ACBRD), Australia
The BETTER project, Canada
The Diabetes Football Community C.I.C, UK
The Diabetic GP Clinic, Australia
The diaTribe Foundation, USA
The ENDIA Study, Australia
The Hollies Care Centre, UK
The Leona M. and Harry B. Helmsley Charitable Trust, USA
The Obesity Collective, Australia
The PATH Lab, Ireland
The People's Diabetes Foundation, USA
Thrivable, USA
Thriveabetes, Ireland
Tidepool, USA
Torbay and South Devon NHS Foundation Trust, UK
Trollway Diabetes Inc., USA
Type One Outdoors, USA
Type1Screen, Australia
UConn Rudd Center for Food Policy & Health, USA
Uganda NCD Alliance, Uganda
Union des Amis Socio Culturels d'Action en Developpement (UNASCAD), Haiti
University of Pretoria Diabetes Research Centre, South Africa
Villari's Self Defense & Wellness Center, USA
vzw hippo and friends, Belgium
WALE, Mali
West African Institute of Public Health, Nigeria
Western Health (Victoria), Australia
Whitehaven Residential Care Home, UK

<b>Organisation, Country</b>
Xeris Pharmaceuticals, Inc, USA
You, Me & T1D, Australia
Zimbabwe Diabetes Organisation, Zimbabwe

Organisations are listed in alphabetical order. An up-to-date list is available via: [EndDiabetesStigma.org](https://EndDiabetesStigma.org). Organisation names appear as documented on the website by an authorised representation of the given organisation.

UAE: United Arab Emirates; UK: United Kingdom; USA: United States of America

In press

**Table 1. Composition of expert panel**

Name (alphabetical by surname)	Diabetes Experience			Country	Ethnicity (self-identified)
	Lived	Family	Professional		
Hamzah Al Zubaidi <sup>c</sup>	..	..	Research	UAE	Arab / Middle Eastern
Katie Babbott <sup>b</sup>	..	Yes	Research	New Zealand	NZ European
Arifin Bustanul	..	..	Research	Indonesia	Banggai Laut, Central Sulawesi / Indonesian
Liz Cambron-Kopco <sup>c</sup>	T2D	Yes	Advocacy	USA	Hispanic / Latino
Bryan Cleal <sup>b</sup>	..	..	Research	Denmark	Danish
Emma Davidsen <sup>c, e</sup>	..	..	Research	Denmark	Danish / Caucasian
Mary de Groot <sup>c</sup>	..	Yes	Clinical / Research	USA	White / Irish /Dutch
Maartje de Wit <sup>c</sup>	..	Yes	Research	Netherlands	Dutch / European / White
Phyllisa Deroze <sup>c</sup>	T2D	..	Research	USA	Black American
Sonya Deschênes <sup>b, e</sup>	..	..	Research	Ireland	Canadian / White
Jane K Dickinson <sup>b</sup>	T1D	Yes	Clinical / Research	USA	White American
Matthew Garza <sup>b, d, e</sup>	..	Yes	Advocacy	USA	White / Hispanic / Latino
Susan J Guzman <sup>b, c</sup>	..	..	Clinical / Research	USA	White / Caucasian
Stephanie Haack	T1D	..	Advocacy	Germany	German / Caucasian
Jennifer A Halliday <sup>b</sup>	..	..	Research	Australia	Australian
Elizabeth Holmes-Truscott <sup>a, c, d, e</sup>	GDM	Yes	Research	Australia	Australian
Richard I G Holt <sup>c</sup>	..	..	Clinical / Research	UK	White British
Walther Jensen	T2D	..	Experience Expert	Denmark	White
Kevin Joiner <sup>b</sup>	..	..	Research	USA	non-Hispanic White
Asuka Kato <sup>b</sup>	..	..	Research	Japan	Japanese
Kamlesh Khunti <sup>e</sup>	..	Yes	Clinical / Research	UK	British Indian
Karoline Kragelund Nielsen <sup>c</sup>	..	Yes	Research	Denmark	European / Scandinavian
Tejal Lathia	..	Yes	Clinical / Research	India	Hindu / Jain / Indian
Christopher J Lee	T2D	Yes	Advocacy	Australia	Aboriginal
Shengxin Liu <sup>b</sup>	..	..	Research	Sweden	Chinese / East Asian
Bridget McNulty	T1D	..	Advocacy	South Africa	White
Eimear C Morrissey <sup>b</sup>	..	..	Research	Ireland	White Irish
Diana Naranjo	GDM	Yes	Research	USA	Ecuadorian American
Giesje Nefs <sup>b</sup>	..	..	Clinical / Research	Netherlands	Dutch
Shane O'Donnell <sup>b</sup>	T1D	..	Research	Ireland	Irish
Rebecca L Pearl <sup>c</sup>	..	..	Research	USA	White
Victor Pedrero <sup>b</sup>	..	..	Research	Chile	Hispanic / Latino
Suman Prinjha <sup>c</sup>	..	Yes	Research	UK	British Indian / South Asian
Rebecca M Puhl <sup>c</sup>	..	Yes	Research	USA	White
Anita Sabidi	T1D	..	Advocacy	Indonesia	Betawi tribe / Southeast Asian

Name (alphabetical by surname)	Diabetes Experience			Country	Ethnicity (self-identified)
	Lived	Family	Professional		
Corrina Santa Ana (Cornejo)	T2D	Yes	..	USA	Hispanic / Latino
Renza Scibilia <sup>d</sup>	T1D	..	Advocacy	Australia	Australian
Chitra Selvan	..	..	Clinical / Research	India	South Asian
Anna Serlachius <sup>b</sup>	..	..	Research	New Zealand	Finnish / NZ European
Jazz Sethi	T1D	..	Advocacy	India	Indian
Mohammad Seyam <sup>c</sup>	T1D	..	Clinical	Palestine	Arab
Timothy C Skinner <sup>d</sup>	..	Yes	Clinical / Research	Australia	English
Jane Speight <sup>a,c,d,e</sup>	..	Yes	Research	Australia	White British
Jackie Sturt	..	..	Research	UK	White British
Mythily Subramaniam	..	Yes	Research	Singapore	Indian
Helle Terkildsen Maindal <sup>c</sup>	..	..	Research	Denmark	Danish / Caucasian
Virginia Valentine <sup>c</sup>	GDM, T2D	Yes	Clinical	USA	Anglo European American-White
Michael Vallis <sup>c</sup>	..	..	Clinical / Research	Canada	Caucasian
Sabina Wagner <sup>b</sup>	..	..	Research	Denmark	Danish
Ingrid Willaing <sup>b</sup>	..	..	Research	Denmark	Danish
Per Winterdijk <sup>b</sup>	T1D	..	Clinical / Research	Netherlands	Dutch / White

GDM: gestational diabetes; T1D: type 1 diabetes; T2D: type 2 diabetes.

NZ: New Zealand; UAE: United Arab Emirates; UK: United Kingdom; USA: United States of America

All panel members voted in the Delphi surveys, and contributed to the consensus protocol and this manuscript as co-authors.

<sup>a</sup> Panel member prepared consensus protocol, conducted systematic search and prepared a first full draft of the manuscript and subsequent revisions; <sup>b</sup> Panel member prepared first draft of evidence summaries and Statements; <sup>c</sup> Panel member peer-reviewed first draft of evidence summaries and Statements; <sup>d</sup> Panel member consolidated and refined Statements and Pledge for each survey round; <sup>e</sup> Panel member reviewed/piloted Delphi survey design.

**Table 2. Consensus on diabetes stigma: Statements of Evidence**

Statement	Consensus grade
<b>Drivers and facilitators</b>	
There is an inaccurate, and overly simplistic, societal view that people with diabetes are to blame for their condition and its complications – this societal view is a key driver of diabetes stigma.	U
Stereotypes about people with diabetes include assumptions that they are: sick or weak; lazy or lacking motivation, willpower, self-control, or capability; or to blame for their condition and/or health outcomes.	U
Diabetes stigma can be driven by a lack of knowledge, fear and/or disgust about the condition, its causes, management and/or its complications.	U
Diabetes stigma is facilitated by the use of oversimplified, sensationalist and/or fear-based messaging and imagery about diabetes and its complications in the media, health campaigns and in healthcare.	U
Diabetes stigma is perpetuated by the use of words that are inaccurate, harmful, and judgmental in the context of diabetes, e.g., <i>'lazy'</i> , <i>'non-compliant'</i> , <i>'uncontrolled'</i> , <i>'poor control'</i> , <i>'failing'</i> .	A
Many people without diabetes do not perceive diabetes to be stigmatized.	A
<b>Manifestations – experiences</b>	
While diabetes stigma has emerged as a focus of research in the past decade, it has been a lived experience for people with diabetes for much longer.	U
Large, cross-sectional studies suggest up to four in five adults with diabetes (type 1 or type 2) experience diabetes stigma; and, on average, one in five has experienced discrimination due to diabetes. The prevalence varies by country and culture, but diabetes stigma is present everywhere that it has been investigated.	U
Diabetes stigma has been researched primarily among adults with type 1 or type 2 diabetes, using qualitative methods and cross-sectional surveys. Comparability of diabetes stigma prevalence and experience across studies is limited, in part due to differences between studies in design, methods, samples, measures, and settings.	U
<b>Manifestations – sources</b>	
People with diabetes may experience diabetes stigma from numerous sources (e.g., health professionals, health organisations, general public, family, friends, colleagues); and in multiple settings (e.g., healthcare, popular culture, media, social media, schools, workplaces, and other community settings).	U
Some health professionals contribute to diabetes stigma, e.g., by blaming, judging and/or mistrusting people with diabetes.	A
Some people with diabetes are stigmatized by other people with, or affected by, diabetes.	U
Diabetes stigma may be perpetrated unknowingly e.g., through implicit bias, and sometimes with good intentions, without realisation of the harm that it causes.	A
<b>Correlates, outcomes, and impacts</b>	
People with diabetes who experience or internalise stigma due to their condition are more likely to report depressive symptoms, anxiety symptoms, diabetes distress, and lower self-esteem.	U
People with diabetes who anticipate, experience, or internalise diabetes stigma are more likely to hide their condition and self-management activities from others, e.g., delaying or skipping essential medication taking and glucose monitoring in public, with implications for their health.	U



Statement	Consensus grade
People with diabetes who experience diabetes stigma in healthcare settings are more likely to: have higher HbA1c and/or severe hypoglycaemia; experience lower quality healthcare consultations; disengage from healthcare; and experience delayed access to treatments, technologies, and specialist care.	U
When people with diabetes internalise diabetes stigma as self-stigma (e.g., shame and self-blame), the negative impacts of diabetes stigma are magnified.	A
Some people with diabetes experience unfair treatment and/or discrimination due to diabetes in relation to marriage, childbirth, healthcare, education, employment, insurance, and licensing (e.g., to drive a vehicle).	A
The experience of diabetes stigma is associated with certain demographics (female, younger, with lower socioeconomic status, and higher education); and clinical characteristics (recent diagnosis, intensive insulin therapy, overweight, diabetes-related complications).	U
Internalising diabetes stigma as self-stigma, e.g. shame and self-blame) is associated with lower self-esteem, and less social support, resilience, and empowerment.	A
<b>Law, policy, regulations, and funding</b>	
Discrimination due to diabetes is not addressed universally in laws, policies, and regulations; and complexity in these can make it difficult for people with diabetes to know and advocate for their rights.	U
Diabetes stigma may negatively impact public and financial support for diabetes prevention, care, treatments, programmes, and research.	U
<b>Interventions</b>	
There is a lack of research focused on what works to reduce diabetes stigma, self-stigma, and their impacts.	U
<b>Intersecting stigma</b>	
There is limited research on the intersection of diabetes stigma with other forms of stigma and discrimination, e.g., age, body size, disability, gender, other health conditions, race, sexuality, socio-economic status.	U
There is very little research about the experiences of diabetes stigma and its impact among disadvantaged, minority, and diverse populations (e.g., Indigenous people, refugee and asylum seekers, migrants).	A

U: Unanimous consensus (100%); A: Grade A consensus (90-99%) – all eight Grade A ratings were 98%

**Table 3. Consensus on diabetes stigma: Statements of Recommendations**

Statement	Consensus grade
<b>General</b>	
Bringing an end to diabetes stigma requires multi-faceted, long-term solutions; it involves international collaboration, and collective leadership from all sectors of the community (including people with diabetes, advocacy organisations, researchers, health professionals, media, industry and policy makers).	U
There is opportunity to learn from other areas of health (e.g., HIV, mental health, and obesity), where addressing stigma has been recognised as crucial.	U
Planning, developing, and implementing research, initiatives, and policies to address diabetes stigma requires meaningful engagement with people with diabetes and their families.	U
<b>Research – general</b>	
A comprehensive approach is needed to understand all aspects of diabetes stigma, including causes, facilitators, mechanisms, and impacts, as well as effective strategies for ending diabetes stigma. This will require a variety of study designs, including prospective, observational, and trial designs to test interventions.	U
Given the dearth of interventions designed to reduce diabetes stigma, there is need for research to examine the effects (both positive and negative) of existing educational, behavioural, psychosocial, and clinical interventions on diabetes stigma.	A
Further research is needed to understand the drivers and extent of beliefs, attitudes, and behaviours perpetuating diabetes stigma among health professionals, and in the general population.	U
<b>Drivers and facilitators</b>	
To end diabetes stigma, the prevailing social narrative focused on personal responsibility needs to be challenged, and replaced with a balanced focus on genetic, biological, sociocultural, environmental, behavioural factors and the social inequities influencing health.	A
Given that it is unacceptable and counterproductive to stigmatise anyone for having diabetes, or its complications, we all must recognise, challenge and counter our own prejudice.	U
<b>Manifestations – experiences</b>	
International collaboration is needed to assess the experiences and extent of diabetes stigma across settings, ethnicities, cultures, and countries.	U
Further research is needed into the experience of diabetes stigma among those with gestational diabetes and rarer types of diabetes, across life stages, genders, socioeconomic status, ethnicities, languages, cultures, and countries. This includes qualitative research, longitudinal quantitative research, and the development/use of valid and reliable assessment tools	U
<b>Communication, campaigns, and media</b>	
All communications about (people with) diabetes need to be clear, accurate, respectful, non-judgmental, and non-stigmatising. When relevant, refer specifically to the type(s) of diabetes without stigmatising other types.	U
Due to the potential for harm, fear-based messaging is unethical and should not be used.	U

Statement	Consensus grade
To avoid perpetuating diabetes stigma and its harms, diabetes awareness campaigns need to be informed by theory and evidence and tested for negative consequences prior to implementation.	U
The print and news media needs to provide fair, accurate, and non-stigmatizing reporting of diabetes; and media organisations need to commit to stop facilitating diabetes stigma.	U
Further research is needed to understand and reduce diabetes stigma in the print and news media, social media, and popular culture.	U
Researchers and educators need to ensure that their communications with and about people with diabetes are stigma-free (including study information and tools, grant applications, presentation, and publication of research findings). Funding bodies, publishers, conference organisers, and employers have a role in ensuring stigma-free communications.	U
<b>Healthcare</b>	
Health professionals supporting people with diabetes need to ensure their practice is stigma-free. Training in stigma-free consultation skills needs to be implemented early in clinical training and demonstrated through continuing professional development and accreditation; and professional bodies need to include stigma-free practice in their professional standards.	U
Diabetes self-management education needs to acknowledge the existence of diabetes stigma and its impacts.	U
<b>Policy, advocacy, and funding</b>	
Discrimination due to diabetes needs to be defined clearly, prohibited by law, and reflected in organisational policies (e.g., in education and workplaces).	U
Organisations that advocate for and support people with diabetes need to pursue an end to diabetes stigma in their strategic plans, communications, and research strategies.	U
Political support and funding for diabetes prevention, care, treatments, and research should not be adversely impacted by diabetes stigma.	U
<b>Intersecting stigma</b>	
Efforts to reduce diabetes stigma must avoid perpetuating stigma elsewhere (e.g. among people with other types of diabetes, conditions, experiences, or identities), and consider the impacts of intersecting stigma on individuals and communities.	U
More research is needed to examine how diabetes stigma interacts with experiences of stigma related to other characteristics, e.g., age, gender, ethnicity, identity, other health conditions; and how to minimise negative consequences of intersecting stigmas among people with diabetes.	U
Culturally sensitive research is needed to understand diabetes stigma and its impacts among disadvantaged, minority, and diverse populations, e.g. Indigenous people, refugee and asylum seekers, migrants.	U

U: Unanimous consensus (100%); A: Grade A consensus (90-99%) – both Grade A ratings were 98%

**Supplementary Table 1. Inclusion / exclusion criteria for systematic search**

Inclusion criteria	Exclusion criteria
<p>Population(s): people with diabetes                      OR other populations' views about (people with) diabetes.</p> <p>Intervention(s): not necessary but, if present, focused as below.</p> <p>Comparator(s): not necessary / people with other conditions etc.</p> <p>Outcome(s): i.e., focus of investigation = diabetes stigma, prejudice, bias, discrimination – sources, prevalence, experiences, associations, impacts, interventions to reduce stigma or its effects;                      OR general stigma, e.g., general self-stigma scale completed by people with diabetes;                      OR stigmatising attitudes, biases etc by another group towards (people with) diabetes;                      OR reported / observed / experienced discrimination due to diabetes.</p> <p>Study design: any</p>	<p>Studies where the focus is on other forms of stigma / discrimination (e.g. based on age, gender, race, education, poverty) <i>in the absence of</i> a focus on diabetes-related stigma and/or the other form of stigma cannot be distinguished from diabetes-related stigma. The exception is weight-related stigma, because weight is potentially a visible characteristic of diabetes, and a driver of the blame/judgement of people with diabetes.</p>

**Supplementary Table 2. Rapid review topic areas and descriptions**

<b>Topic areas</b>	<b>Descriptions: Examples, considerations</b>
Drivers & facilitators	<p>Drivers: e.g., beliefs re personal responsibility of diagnosis and outcomes; beliefs re causes of diabetes; fear of injections; association with laziness and irresponsibility.</p> <p>Facilitators: e.g., cultural norms, religion, community vs individualistic approaches (e.g., individual responsibility for health).</p>
Assessment	Among the affected population, i.e., general and diabetes-specific measures, and among people without diabetes, i.e., population-based assessments, self-assessment of endorsed and enacted stigma etc.
Manifestations	a) Experiences in affected population: e.g., types of stigma (perceived, experienced, self-stigma); Settings & sources of stigma, e.g., media, social media, diabetes organisations, diabetes campaigns, health professionals, social media, workplace, schools.
	b) Practices in the community: e.g., evidence of beliefs, attitudes, stereotypes, bias, prejudice, rejection, discrimination etc, including settings & sources, e.g., mass media, diabetes organisations, diabetes campaigns, health professionals, social media, workplace, schools.
Prevalence	a) Affected population: stigma, discrimination.
	b) Community: e.g., general population, Health professionals.
Intersecting stigmas	Convergence with other forms of stigma: e.g., obesity, mental health, gender, race, age, educational status, socioeconomic status. The extent to which they may relate to or compound diabetes stigma.
Outcomes	a) Affected population: e.g., psychological (including mental health), social, behavioural, clinical, medical (inc. access to healthcare).
	b) Policy and structural: e.g., employment, driving and travel restrictions, education, legal rights, funding for research and clinical care / treatments.
Protective mechanisms & vulnerabilities	Among the affected population, what facilitates or reduces the impact or internalisation of stigma, e.g., self-esteem, social support?
Interventions	a) Community: to reduce stigma practices, e.g. organised by type of interventions, target population or socioecological layer.
	b) Affected population: to reduce the impact or internalisation of stigma.

**Supplementary Table 3. List of articles referenced in the *Summary of Evidence*, identified: a) via the systematic search, and b) post-search**

<b>a) 116 eligible articles identified via the systematic search</b>
American Diabetes Association. Cracking the case. A federal jury finds diabetes discrimination at the FBI. <i>Diabetes forecast</i> 2009; <b>62</b> (10): 61-3.
Abdoli S, Abazari P, Mardanian L. Exploring diabetes type 1-related stigma. <i>Iran J Nurs Midwifery Res</i> 2013; <b>18</b> (1): 65-70.
Akugizibwe M, Zalwango F, Namulundu CM, et al. "After all, we are all sick": multi-stakeholder understanding of stigma associated with integrated management of HIV, diabetes and hypertension at selected government clinics in Uganda. <i>BMC health services research</i> 2023; <b>23</b> (1): 20.
Alessi J, De Oliveira GB, Erthal IN, et al. Diabetes and obesity bias: Are we intensifying the pharmacological treatment in patients with and without obesity with equity? <i>Diabetes Care</i> 2021; <b>44</b> (12): e206-e8.
Alzubaidi H, Namara KM, Samorinha C, Saidawi W, Versace VL, Speight J. Type 2 Diabetes Stigma Assessment Scale (DSAS-2): Cultural and linguistic adaptation and psychometric assessment of the Arabic version. <i>Primary Care Diabetes</i> 2022; <b>16</b> (5): 703-8.
Arent S. The Role of Diabetes Healthcare Professionals in Diabetes Discrimination Issues at Work and School. <i>The Diabetes Educator</i> 2002; <b>28</b> (6): 1021-7.
Baker J, Scragg R, Metcalf P, Dryson E. Diabetes Mellitus and Employment: Is there Discrimination in the Workplace? <i>Diabetic Medicine</i> 1993; <b>10</b> (4): 362-5.
Basinger ED, Farris M, Delaney AL. Investigating the Experience of Diabetes Stigma in Online Forums. <i>Southern Communication Journal</i> 2020; <b>85</b> (1): 43-57.
Benedetti MM. Discrimination and diabetes. <i>Diabetes Research and Clinical Practice</i> 2014; <b>103</b> (2): 338-40.
Benioudakis ES, Kalaitzaki A, Karlafti E, Kalpou MA, Savopoulos C, Didangelos T. Dimensionality and psychometric properties of the Greek version of the Type 1 Diabetes Stigma Assessment Scale (DSAS-1-Gr). <i>Psychiatriki</i> 2022.
Berney T. Commentary: Not reimbursing islet transplantation creates discrimination against patients with type 1 diabetes. <i>CellR4 Repair Replace Regen Reprogram</i> 2019; <b>7</b> .
Beverly EA, Guseman EH, Jensen LL, Fredricks TR. Reducing the stigma of diabetes in medical education: A contact-based educational approach. <i>Clinical Diabetes</i> 2019; <b>37</b> (2): 108-15.
Blackwood L, Gavin J, Arnott E, Barnett J, Dack C, Johansen J. #DiabetesOnAPlate: the everyday deployment and contestation of diabetes stigma in an online setting. <i>Critical Public Health</i> 2022.
Bock S. Contextualization, reflexivity, and the study of diabetes-related stigma. <i>Journal of Folklore Research</i> 2012; <b>49</b> (2): 153-78.
Botchway M, Davis RE, Merchant AT, Appiah LT, Moore S. Diabetes-related stigma and its influence on social networks, social support, and HbA1c in Ghana. <i>Ethnicity and Disease</i> 2021; <b>31</b> (1): 57-66.
Brazeau AS, Nakhla M, Wright M, et al. Stigma and its association with glycemic control and hypoglycemia in adolescents and young adults with type 1 diabetes: Cross-sectional study. <i>Journal of Medical Internet Research</i> 2018; <b>20</b> (4).
Brazeau AS, Nakhla M, Wright M, et al. Stigma and Its Impact on Glucose Control Among Youth With Diabetes: Protocol for a Canada-Wide Study. <i>JMIR Res Protoc</i> 2016; <b>5</b> (4): e242.
Browne JL, Ventura A, Mosely K, Speight J. 'I call it the blame and shame disease': A qualitative study about perceptions of social stigma surrounding type 2 diabetes. <i>BMJ Open</i> 2013; <b>3</b> (11).

Browne JL, Ventura A, Mosely K, Speight J. 'I'm not a druggie, I'm just a diabetic': A qualitative study of stigma from the perspective of adults with type 1 diabetes. <i>BMJ Open</i> 2014; <b>4</b> (7).
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Brunton SA. Blame and Shame: The Stigma of Diabetes. <i>Clinical Diabetes</i> 2022; <b>40</b> (1): 9.
Budhwani H, De P, Sun R. Perceived Stigma in Health Care Settings Mediates the Relationships Between Depression, Diabetes, and Hypertension. <i>Population Health Management</i> 2022; <b>25</b> (2): 164-71.
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Cho SE, Kwon M, Kim SA. Influence of Diabetes Knowledge, Self-Stigma, and Self-Care Behavior on Quality of Life in Patients with Diabetes. <i>Healthcare (Switzerland)</i> 2022; <b>10</b> (10).
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Farrington C. Wearable technologies and stigma in diabetes: The role of medical aesthetics. <i>The Lancet Diabetes and Endocrinology</i> 2016; <b>4</b> (7): 566.
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\* Some focus on diabetes stigma but were published after the search was conducted. Most were identified via hand-searching of reference lists or were known to the panel.

In press

**Supplementary Table 4. Example of the development a Statement of Evidence**

<b>Draft Statements of Evidence (generated by rapid reviewer subgroup following peer review subgroup feedback)</b>							
<ul style="list-style-type: none"> <li>The media portrayal of diabetes is influential in public attitudes towards the condition; stereotypical representations perpetuate discrimination based on the belief that people living with diabetes are to blame for their condition, a likely primary mechanism of stigma related to T1D, T2D, and GDM.</li> <li>People with diabetes perceived popular culture, media and health campaigns to have an important role in creating and reinforcing stigma.</li> <li>Media portrayals of diabetes are influential and can be harmful; it plays an important role in shaping public attitudes and beliefs about people with diabetes.</li> <li>Media portrayals of diabetes are often scientifically inaccurate and reinforce stereotypes.</li> <li>Negative beliefs and misunderstanding about diabetes are facilitated in the wider community by inaccurate and dramatic portrayals of diabetes in mainstream and social media.</li> </ul>							
Delphi Round	Statements of Evidence (generated by subgroup)	Agreement ratings (by panel members)					Summary of feedback (from panel members)
		Fully Agree	Slightly Agree	Slightly Disagree	Fully Disagree	Don't Know	
One	Diabetes stigma is perpetuated in campaigns, mainstream and social media, and healthcare by inaccurate and fear-based messaging and imagery of diabetes and its complications.	74%	20%	6%	0%	0%	<ol style="list-style-type: none"> <li>Some fear appeals may include accurate information. Consider adding "oversimplified", "sensationalist"</li> <li>What is meant by campaign? Specify 'health campaign'</li> <li>Why specify mainstream and social media? What is meant by 'mainstream'?</li> </ol>
Two	<b>REVISED:</b> Diabetes stigma is perpetuated by the use of over-simplified, sensationalist and/or fear-based messaging and imagery about diabetes and its complications in the media, health campaigns and in healthcare.	88%	10%	2%	0%	0%	<ol style="list-style-type: none"> <li>Grammatical edits</li> <li>Broader society issues which campaigns contribute to</li> </ol>
Three	<b>REVISED:</b> Diabetes stigma is facilitated by the use of over-simplified, sensationalist and/or fear-based messaging and imagery about diabetes and its complications in the media, health campaigns and in healthcare.	100%	-	-	0%	-	N/A

**Supplementary Table 5. Assessment of diabetes stigma among people living with diabetes**

Measure and citation	Psychometric validation: Target Population / Other	Aspects of stigma assessed <sup>a</sup>	Items	Language versions (Countries)
<b>Scales designed to assess diabetes stigma</b>				
Diabetes Self-Stigma Scale (DSSS) <sup>149</sup>	Target: Adults with T2D	Comparative inability, social withdrawal, self-devaluation, and apprehensive feeling	16	Korean <sup>a</sup>
Type 1 Diabetes Stigma Assessment Scale (DSAS-1) <sup>18</sup>	Target: Adults with T1D Other: Adolescents with T1D <sup>153</sup>	Treated differently, blame and judgement, identity	19 Short form: 8 <sup>186</sup>	English (Australia; <sup>b</sup> NZ; USA); Danish; Greek (Greece); Iranian; Japanese; Korean; Turkish Short form: English (USA)
Type 2 Diabetes Stigma Assessment Scale (DSAS-2) <sup>16</sup>	Target: Adults with T2D	Treated differently, blame and judgement, self-stigma	19	English (Australia; <sup>b</sup> NZ; USA); Arabic (Saudi Arabia); Kannada (India); Spanish (USA; Colombia); Turkish
<b>Brief subscales designed to assess diabetes stigma, incorporated within measures designed to assess other / broader diabetes-specific constructs</b>				
“Stigma” subscale of Barriers to Diabetes Adherence (BDA) questionnaire <sup>168</sup>	Target: Adolescents with T1D	Perceived and internalised stigma	6	English (USA); <sup>b</sup> Arabic (Qatar)
“Negative social perceptions” subscale of the Type 1 Diabetes Distress Scale (T1-DDS) <sup>187</sup>	Target: Adults with T1D	Perceived stigma	4	English (USA); <sup>b</sup> French (Canada); German; Portuguese (Brazil); Spanish
“Shame/stigma subscale” of the Type 2 Diabetes Distress Assessment System (T2-DDAS) <sup>164</sup>	Target: Adults with T2D	Self-stigma and shame	3	English (USA); <sup>b</sup> French (Canada); Spanish
<b>Generic stigma or generic health stigma scales that have been used to assess stigma among people with diabetes</b>				
8-item Stigma Scale for Chronic Illnesses (SSCI-8)	Target: Adults with chronic illness <sup>c</sup>	Internalised and enacted stigma	8	English (USA) <sup>b</sup>
Self-Stigma Scale (SSS)	Target: Minority groups Other: Adults with T2D <sup>182</sup>	Cognitive, affective, and behavioural dimensions	39	Chinese (Hong Kong); <sup>b</sup> Japanese
Kandem Institute Stigma Scale (KISS) <sup>184</sup>	Target: Adults with chronic conditions, including diabetes	Perceived and enacted social stigma, discordant stigma, and self-stigma	24	Japanese <sup>b</sup>

T1D: type 1 diabetes; T2D: type 2 diabetes; NZ: New Zealand; USA: United States of America. <sup>a</sup> As reported by scale developers; <sup>b</sup> Language of original validation;

<sup>c</sup> SSCI-8 has been employed in T1D and T2D samples, including for validation purposes of diabetes-specific scales<sup>2,4</sup>