Title

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 pro-actively 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.

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), [1] which takes many forms (Panel 1). It is also exacerbated by discrimination (unfair or prejudicial treatment), [2] which has been described as the 'endpoint' of the stigmatization process. [3] Stigmatising practices are inconsistent with respect for the dignity and lived experience of people with diabetes. [4] Further, evidence indicates that diabetes stigma has multifaceted impacts for the health, self-care and wellbeing of people with diabetes. [5] 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'. [6] They recommended: enabling people with diabetes to claim their rights and responsibilities (as later detailed in the IDF Charter, [4]); 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. [1] 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). [7-9] Insights from these areas suggest that research and advocacy are both crucial, but each is likely insufficient in isolation. [10-13]

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. [5] 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, [1,14] and the Health Stigma and Discrimination Framework. [8] Rapid reviews streamline knowledge synthesis in a resource-efficient manner. [15] 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 (Supplementary Table 3).

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 sub-group 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. [16] The consensus method and reporting (Figure 1) follows published guidance on Conducting and REporting DElphi Studies (CREDES). [17]

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'), [18] 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, [19] 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 ≥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 31st 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. [1] The development and validation of scales to assess diabetes stigma[18,20] 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, [1,8,14] 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. [1,8,14] It is facilitated typically by media messaging and public discourse, health organisations and health professionals, cultural and social norms, policy, and law. [1,8,14] 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. [21] Thus, managing diabetes has a perceived moral dimension, focused on how a person should live, [22] exemplified by the meta-narrative: *'should you be eating that?'* [23] This phenomenon traces back several centuries, and appears to have been facilitated by biased popular interpretation of modern scientific discoveries. [24]

In the 1990s, landmark trials demonstrated that intensive management can prevent or delay diabetes-related complications among people with T1D and T2D. [25,26] In the early 2000s, similarly pivotal trials demonstrated that rigorous health behaviours or medication-taking can prevent 55-58% of cases of T2D. [27,28] 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. [29-31] 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, [32] and bring to the fore issues of 'control' and 'compliance', particularly for glycaemia and food self-regulation. [22,24,33] 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. [34] Relatedly, another key driver of diabetes stigma is the belief that people with diabetes are less worthy or deserving than people with other conditions. [35]

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. [14,21,36] Diabetes is linked to fears of infertility or high-risk pregnancies. [37-40] Diabetes is viewed as a 'death reminder', [21,40] due to perceptions of reduced life expectancy. [37] 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. [1,36,41] 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. [42,43]

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'. [44-46] 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'), [47-49] or that it is contagious. [21,37,50] In contrast, diabetes stigma may be less prevalent in countries and age groups where T2D is part of the 'normal' social fabric. [51,52]

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. [53] This can also be due to myths, misunderstandings and/or (lack of) exposure. [54] 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), [21] inducing fear or disgust. [22] 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. [55] Alternatively, such reactions may reflect an assumption that the person is injecting illicit substances, and express addiction stigma. [14,21] 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, [56,57] 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). [58] 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. [59] 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. [59] 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, [60,61] 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. [62]

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'. [63,64]

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. [1,14,45,50,52,65-68] Across multiple settings, people with diabetes report experiencing blame and judgment, [14,52,69] as well as attributions to their personality for behaviours caused by low or high glucose, and other misunderstandings. [45] 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. [14,37,52,57,70-76] In addition, T1D is stereotyped as affecting only children, [14] therefore ignoring the needs of adults; [77] and as the 'bad' type, where a 'normal' life is not possible. [57] Such stereotypes vary across countries and cultures. [77] In some cultures and countries, people with T2D are stereotyped as 'poor', 'unintelligent', 'bad', and at 'end of life', [21] while in others, T2D is seen as a condition affecting those with wealth. [48,52]

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. [59] 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. [14,44,52,78]

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, [52,65,70,79-82] often accompanied by stigmatising imagery, e.g., unflattering depictions of large bodies, donuts, junk food, sugary drinks). [80] In addition, headlines, which are often sensationalist and/or inaccurate, [14,70,80,83] focus on the burden diabetes represents to healthcare, [84-86] and society, [83] due to the 'epidemic' of T2D. [14,52,82] Such headlines 'position diabetes as the anticipated consequence of obesity', [83] 'fostering dependence on biomedicine', [82] and 'serve to belittle the disease'. [83]

The stigmatising framing of diabetes in the media influences community attitudes and practices. [87-90] 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. [80] A UK survey found that, despite strong public support overall for T2D prevention programs, [64] 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. [64]

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, [91-94] and a tendency to 'place diabetics under others' protection'. [93]

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. [70,90,95] Many diabetes organisations globally have been criticised for similar messaging. [90,95,96] 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. [90,96] 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. [97] Qualitative studies corroborate this finding, showing that people with diabetes express dissatisfaction with the scare tactics used in diabetes awareness campaigns. [14,52,70]

Healthcare, research, and funding

While it is acknowledged that many health professionals are supportive, and skilled in reinforcing what is going well, [98,99] across the world, numerous studies show that people with diabetes experience implicit and explicit stigma from health professionals. [1,14,18,50,52,98,100-103] 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'. [1,14,18,38,50,52,65,104] For expectant mothers, across all types of diabetes, this includes the increased risk that their behaviours may cause to their unborn baby. [38,105]

Fewer studies have been conducted among health professionals. Some corroborate these reports, [106-110] while others show health professionals perceive stigma to be less prevalent in diabetes than in other health conditions. [111,112] Diabetes stigma is also documented among medical and nursing trainees. [106,108,109,113,114] 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. [113] Such stigma may deter trainees from specialising in diabetes. [114]

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. [115,116] 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'. [115] This has considerable potential for transmitting bias and influencing healthcare quality. Such language is also observed in academic research papers and presentations. [117]

There is also real-world evidence of such language and prejudicial views influencing government policy and political decisions regarding the funding of diabetes care. [87-90] 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'*. [118] While the impacts of such attitudes on actual funding are unclear, public funding of diabetes research has been described as 'in crisis', [119-121] and there is a mismatch in diabetes research funding allocations, i.e. dollars / per population invested, relative to some other conditions. [122] Furthermore, funded diabetes research focuses disproportionally on the biomedical model. [123]

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. [45,67,124,125] 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. [14] 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. [14,126] In some parts of the world, students may not have appropriate support to manage diabetes in the school setting. [127] Elsewhere, students with T1D may stop attending, or be excluded entirely from, secondary and tertiary education due to discrimination. [37,44,49,128]

The attitudes of employers and colleagues[129] can facilitate diabetes stigma and discrimination – evident for those with T1D[45,78] and T2D. [78,130] This limits employment opportunities and career advancements, [70,84,85,129-133] particularly for those experiencing frequent hypoglycaemia, and/or also living with overweight/obesity or diabetes-related complications. [84,134,135] 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. [136]

Family, friends, and the general public

Some people with diabetes report that their family and friends become the 'diabetes police', [48] but that the blaming, shaming or judging may be founded in good intentions. [14,52] Known as 'miscarried helping', this phenomenon is well-recognised in the context of adolescents with T1D and their parents, [137] and to a lesser extent among adults with T2D, [138,139] and GDM. [50,140,141] Across diabetes types, a key focus is on food consumption and diabetes self-management behaviours. [14,52,67,104,142,143] 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. [67]

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. [37,40,43-46,50,144,145] Women with GDM report experiencing familial blame for their diagnosis, being accused of having unhealthy babies and/or not disclosing their diabetes. [38,50,140,141] 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'. [45,49,57]

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. [1,111,112,146] Yet, people with diabetes report the public as a key source of stigma. [14,52] 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'. [147] Social media analyses illustrates that public commentary links diabetes with obesity, [148] gluttony, [149] and perpetuates other common negative attitudes, rooted in problematic socio-cultural phenomena, such ableism and anti-fat bias. [111,148] For example, a content analysis showed that Instagram posts with the trending hashtag, #*diabetesonaplate*, depict energy-dense foods and are characterised as gluttonous. [66]

The diabetes community

Given that stigma-by-association with T2D is salient among people with T1D, [74-76] and parents of children with T1D, [45] 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. [14] 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', [35] stereotyped as 'lazy' and 'fat'. [14,70] One study found that 19% of adults

with T1D and parents of children with T1D suggested changing the name to disassociate from T2D. [84]

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, [52] and that people with T1D receive more assistance, support and access to advanced management options, e.g. continuous glucose monitoring. [14,52]

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. [52,65,150-154] 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. [50,140,141] Self-stigma may be less common among people with T1D, and adoption of a positive diabetes identify may be protective. [14] However, adolescents and young adults with T1D describe feeling ashamed to manage diabetes in public, [142] and/or endorsing negative self-images due to the reactions of others, e.g., that they are 'weak', 'inferior', a 'burden', a 'social outcast'. [67,74]

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. [52,155]

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. [18,20,73,84,85,102,156,157] Diabetes stigma is also reported by 65% to 99% of adolescents and young adults with T1D[158,159] and 83% of parents of children with T1D. [84] 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). [160,161] 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. [160,161]

In the multi-national DAWN2 study (N=8,596 across 17 countries), [162] 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. [99] Elsewhere, cross-sectional research shows up to 11% of adults with T2D report workplace discrimination or differential treatment due to diabetes. [134] Both diabetes stigma

and discrimination appear more prevalent among women, [84,163] those with lower socio-economic status, [164] and those with T1D or insulin-treated T2D versus non-insulin-treated diabetes. [84,163,165-167] There is also some evidence that diabetes stigma is associated with younger age, shorter diabetes duration, and higher education level. [18,20,156,164,168-173] The emerging evidence is mixed regarding diabetes stigma and use of diabetes technologies, e.g., insulin delivery and glucose monitoring devices. [166,167,174,175]

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. [86] Further, they would not be comfortable seeing someone inject insulin, and believe that people with diabetes are responsible for 'bringing this condition on themselves'. [86] These evidence suggests variation in public stigma by ethnicity, age, education level, and proximity to someone living with diabetes. [86] 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. [113] In the 17-country DAWN2 study, societal discrimination against people with diabetes was reported by 33% of health professionals[176] and 22% of family members. [177]

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, [43,84,164,178-180] 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. [181] Meta-analysis demonstrates that racial/ethnic differences exist in relation to diabetes management and risk of complications. [182] 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. [37-40,43,50,178]

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'. [183] Experiences of weight-related stigma are more frequently reported by people with diabetes, [14,52,66,70] with pejorative labelling, and associated stereotypes, such as 'lazy', common to both diabetes and obesity. [52,178] 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. [180]

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. [178,184,185] In several African countries, people with T2D are mislabelled 'through gossip and

misinformation' as having HIV/AIDS, and thought to be 'wasting resources'. [172] In Cameroon, people with T2D express concerns about accepting weight loss as a legitimate approach to managing T2D 'in the era of HIV/AIDS'. [185]

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. [186]

Psychological well-being

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

Diabetes stigma is associated with lower general quality of life[85,199] or life satisfaction, [199,200] and greater negative impact of diabetes on quality of life. [132,195,196,201] 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, [18,20,152,164,187,202] general self-efficacy, [152,164,187] and resilience. [168] 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, [73,165] and lower self-esteem[153] and general self-efficacy. [73] The negative cognitive and emotional consequences of diabetes stigma appear to be more prevalent among women than men, [84] and those with T1D, or insulin-treated T2D, compared to T2D or non-insulin-treated T2D. [84,165]

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. [56,74,84,124,153,198,203] 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, [50,84,85,128,141,143,164,171,172,201,204,205] and that unsupportive friendships have come to an end. [52] 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. [21,38,43,44,105,206,207] In workplaces, one in three adults with T1D and almost one in

four adults with T2D conceal their condition from colleagues, [133,193] due to anticipated stigma or discrimination. [52,133,153]

Finally, diabetes stigma negatively impacts relationships and support in the healthcare setting, [164] 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. [40,73,98,104,208] People with T2D also report limited access to treatments, technologies and specialist care due to stigma: 'they say 'no, because you're type 2''. [52] 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. [38,140,141]

Physical well-being and self-care

Among people with T1D and T2D, positive associations have been demonstrated between diabetes stigma and glycaemic metrics[128,130,151,152,158,159,163,165,188,189,191,196,209,210] 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. [158,159,163] Diabetes stigma is also associated with more frequent severe hypoglycaemia, [128,163,169] diabetes-related ketoacidosis, [163] retinopathy, [163] hospitalisations, [130] and higher body mass index. [169] Although qualitative data support the premise that such outcomes are a consequence, rather than a determinant, of diabetes stigma, and some prospective research exists, [196] more is needed, and some studies find no association with HbA1c. [193]

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

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[220] 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, [221] 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. [222] Over a decade ago, Diabetes Australia's position statement on communicating with and about people with diabetes recognised the power of language, [223] and inspired an international diabetes #LanguageMatters movement, with at least 14 similar national statements since. [224-227] 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. [117] With regard to the media, two studies have evaluated changes in language used in Australian newspaper coverage of diabetes. [228,229] One study observed a significant reduction in the use of problematic language between 2010 and 2014, [229] while both identified continued use of labelling (commonly referring to 'diabetics') and lack of specificity regarding diabetes type. [228,229] 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, [230] 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. [231] 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, [90] 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. [232] Such images included healthy foods, activity and achieving goals. Drawing inspiration from weight-stigma reduction strategies, [233] 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. [4] 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. [6,234] Since 2013, the IDF's KiDS project has addressed 'diabetes-related stigma by fostering a safe and supportive school environment for children with diabetes'. [235] In addition, many provide legal advocacy, [236-238] training to prevent discrimination in workplaces and/or schools, [238] and advocate for equitable and sustained access to diabetes treatments and technologies. [234,239-241]

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'; [242] and Diabetes UK has prioritised preventing discrimination due to diabetes, [243] and recognised that more research into diabetes stigma is pivotal to improving the mental well-being of people with diabetes, [244] and dedicated funding to support this. [242] In 2022, the diaTribe Foundation launched the 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, [245-247], 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. [5,90]

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. [248]

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. [249] However, to date, little research has examined strategies to combat enacted diabetes stigma in healthcare settings. [250] There is some evidence for contact-based approaches in diabetes, [108,113] corroborated by studies in obesity or mental health conditions, [220,249,251-254] 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. [146] 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. [206,227,255] 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 [256] and T2D[257] 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'. [210] 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; [200] enhanced resilience; [168] self-esteem; [152,153,165,202,203,258] self-confidence or self-efficacy; [103,151,152,202,258] accepting and integrating diabetes as a part of ones' own identity; [153,258] performing effective self-care activities to achieve the optimal diabetes management; [152,153,196,202,203,209,258] and social support. [165,258,259]

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, [260] 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, [175] and in the T1-REDEEM trial among adults with T1D and elevated HbA1c. [261] 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. [262] In Iran, a qualitative study investigated culturally appropriate strategies to inform development of a multi-level intervention for adults with T1D experiencing diabetes stigma. [206] 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, [263] 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. [249,254]

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. [90,264] To end diabetes stigma, we need to recognise that understanding of diabetes is socially constructed. [265] 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. [266] Furthermore, communications about diabetes (and people with diabetes) need to use accurate, respectful and empathetic words, messaging and imagery. [5,267] 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, [114] leaving them susceptible to the damaging effects of isolation. [268,269] 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. [242,243] b) policy makers to take localised actions, which may have global impact, such as strengthening legal protections and accelerating broader rights regarding education, employment, [62] 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

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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.

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